A Developmental Systems Guide for Child and Adolescent Behavioral Health Practitioners

Sean E. Snyder

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Preface

> *"Anything that's known to any human about what's healthy should be knowable to every human, so we can be healthy. If humans have discovered something that's helpful, everyone deserves to know it as soon as they need to. We as a field need to measure ourselves against that, how quickly can we get to that vision? We need to ask ourselves, how do we set up our institutions, the right way, to get things to people who need them."*
>
> Bruce Chorpita, PhD

Open Access to Knowledge

This book came from the idea of how to get things to people, specifically how to get the knowledge of evidence-based practices for child mental health to the people doing the work. And it is not simply sharing knowledge. It is an attempt to make that knowledge actionable. The book is set up for readers to navigate the basics—engagement, assessment, and intervention—with an emphasis on the common elements or active ingredients of those areas. The hope is that this is a book that could be ready at hand, something you will pull off your virtual bookshelf in your practice setting.

Open Access to Knowledge Creation

The book is an open access textbook, and we do not take that term lightly. With openness, we hope to be transparent about the realities that are happening in the field. With accessibility, we hope that anyone can read and reference the book. It was written in the spirit of access; many of the chapter coauthors are first-generation college students and together they represent various racial, ethnic, sexual, and gender identities. There is accessibility to being an author, and that leads to greater representation in the creation of this book's knowledge base.

Openness to New Knowledge

This book is a project, too. It was a joy to work with all of the coauthors, clinical dialogue guests, and the many scientific and clinical colleagues across the country on our virtual writing groups. (Thank you, Dr. Alayna Park, for setting those up!) Our work is never finished, and I welcome any feedback from readers to make this book better, more helpful, more open, accessible, and actionable. Everything, really, is iterative.

PART I

THEORETICAL AND PRACTICAL FOUNDATIONS

1

Chapter

Our Framework within the Developmental Systems Perspective

Sean E. Snyder, MSW; Bernie Newman, PhD, MSW

Shawna, a new four-year-old client, runs over to me, a stranger, and wraps her arms around my legs, looking up longingly. Her foster mom comes over and states calmly, “Shawna, honey, we don’t know this lady, so we don’t say hello by touching her.” I gently put a little distance between Shawna and me and put out my hand to introduce myself to her foster mom. Two years later, I attend the finalization of adoption court hearing in which Shawna sat next to her foster mom appearing securely attached. Six months after that, I hear from the foster mom that Shawna is again having nightmares about her abuse as a toddler. Shawna is pulling physically and emotionally away from her, withdrawing, and trying to attach to strangers. Despite Shawna’s frequent rejection and anger, her mom is still reaching out to her emotionally and trying to comfort Shawna when she wakes up in terror. Although I cannot guarantee anything, I reassure her that she is doing exactly the right thing, and this consistency is exactly what Shawna needs. It should pay off with Shawna’s eventual ability to form secure attachments, but what happened in the first three most formative years of her life has affected her deeply.

Introduction

The first three years of life have lifelong consequences, affecting our neurological and psychological make-up. Transitional growth is concentrated during this period, with the brain reaching 85% of its size and structure (as cited in Dulcan, 2020). The impact of changes on the developmental trajectory can be life altering. For example, when I began working with Shawna at age four, she had already gone through an intense period of neurological, social, and emotional growth in the first two years of her life, as a result of serious child maltreatment and deprivation. Her resilience (even prior to therapy) and receptiveness to consistent nurturant and appropriately responsive caregiving reflects the potential impact of intervention and environmental change. Conversely, Shawna's re-experiencing of the effects of the abuse and signs of a serious emotional disorder also reflect the nature of change, adaptation, and growth.

The Developmental Systems Approach

The developmental systems approach explicitly focuses our attention on 1) the complex interactions of the child or adolescent developmental needs, capacities, and challenges with 2) the micro, mezzo, and macro systems that create and sustain resources and barriers (Hayden & Mash, 2014). Assessment, diagnosis, and intervention that incorporate a developmental systems approach allow clinicians to work with the understanding that children and adolescents are experiencing developmental challenges, tasks, and capacities that intersect with risk and protective factors of the environment. When working with children and adolescents, it's critical to understand the development within a child's neurological and physiological systems, as well as the immediate physical and social environment and interactions among all systems relevant to the child's life. Simply put, this approach combines the work of developmental psychology and ecological systems to recognize what Hayden and Mash (2014) describe as a framework that emphasizes "the role of developmental processes, the importance of context, and the influence of multiple and interacting events and processes in shaping adaptive and maladaptive development" (p. 3). A well-established body of theory and empirical research guides us in applying this framework.

Aspects of Ecological Systems

The developmental systems approach is grounded in Bronfenbrenner's (1977) bioecological model. This classic paradigm conceptualizes the ecosystems that are part of each human's life, and this conceptualization serves as an excellent starting point for understanding the developmental systems approach. Bronfenbrenner (1977) conceptualized systems that interact with each child as the micro, mezzo, and macro systems. The micro system consists of the child as an individual system of biological and psychological subsystems which interact with the primary family, neighborhood, childcare, and school systems. Macro systems include institutional influences like the school system, government, and culture. The mezzo system is an intermediary step between the micro and the macro system, representing the transactions between the micro and macro systems. More precisely, this is where these systems intersect and affect the child, family, neighborhood, or school. The mezzo system also involves systems that the child is not directly part of, for instance the employer of the child's caregiver. It is the reciprocal product of these interactions that are critical to understand during assessment, intervention, and evaluation. For example, to what extent does the labor market provide employment opportunities or barriers to for the caregiver? In turn, how do the products of these transactions shape the caregiver's access to basic needs, adequate housing, security, and socioemotional health that is available to the child? It is the interactions between and among systems that are the focus of the ecological framework.

For the clinician, advocating for large-scale changes while helping clients and their families obtain resources is a critical part of the clinical work.

Many have pointed out that Bronfenbrenner's theory is often oversimplified to focus only on the micro, mezzo and macro systems with the child standing only in the micro system (Asiabi & O'Neil, 2015). A focus on the transactional nature of the bioecological model highlights important contributions that this model makes, including the idea that the child and all transactional systems are reciprocal partners over time. These dynamics create patterns of healthy or unhealthy behaviors and proclivities that have enormous potential for future outcomes.

Bronfenbrenner focuses on the context of the environment interacting with the individual resulting in mutual reciprocity. The child not only reacts to but shapes the environment; this changed environment further shapes the child and so on. Darling (2007) suggests that a critical part of Bronfenbrenner's model focuses on interactions between the two. This interactional focus brings the clinician's attention to the importance of the individual uniqueness of each child, the changing environment, and the transactions that occur between them. Ashiabi and O'Neil (2015) describe the bioecological model as consisting of nested systems that allow us to focus on how interactions within each system influence all systems, including the development of the child.

This can be especially useful when studying mental health disorders in children and adolescents. For example, consideration of the interactions within these systems can elucidate tendencies that may reinforce behaviors and emotions associated with depression, anxiety, and disruptive actions. These transactions may be the critical precipitators of disordered behavior, and focusing on them can strengthen assessment and intervention.

This approach combines the work of developmental psychology and ecological systems theory.

Human interaction with the environment occurs on different planes, with localized interactions in the home, neighborhood, and school environments, and globalized interactions within culture and societal expectations or social determinants (Hayden & Mash, 2014). It must also be acknowledged that larger structural forces of our society are also often impinging on the child's immediate micro system. For instance, poverty, community violence, insecure housing, and overcrowded/under-resourced schools are large scale risk factors that must be addressed systemically. Macro level interventions such as guaranteed median level family income, affordable and available housing, and equity in our public education system can create new environmental conditions that influence the available transactions for the child and their immediate environment. For the social worker (or other clinician), advocating for these large-scale changes alongside working with individual clients and their families to obtain resources is a critical part of the clinical work. If we are to address the causal factors which create the conditions of vulnerability for all children, we must work to meet individual needs in the existing inadequate system that presents multiple risk factors and then advocate for changes on a larger scale. The vulnerability posed by exposure to multiple risk factors is especially of concern for families and communities subject to health disparities caused by poverty, racism, and the lack of safe, affordable, and available housing.

Which transaction, proximal (between child and caregiver) or distal (between caregiver and labor market) has the most influence on the child's wellbeing or vulnerability to mental health disorders? The notions of proximal and distal transactions refer to the relational distance of the child to the stimulus within the bioecological model. Proximal processes can be defined as consistent, close, and complex interactions within an ongoing primary relationship such as parent-child, siblings, caregiver-child, or teacher-child. These processes are essential mechanisms for development. The combination of distal and proximal processes creates the social, emotional, and physical conditions of the environment for every child. Ashiabi and O'Neal's (2015) analysis of over 2000 children showed that the initial influence on outcomes for children comes from the child's socioeconomic status and the amount of neighborhood social capital. They further showed that childhood outcomes are then mediated by the closer proximal interactions with the amount of parental and family stress. Recognition of the larger influence of proximal processes is not to diminish the impact of large structural inequities in our society that create and sustain enormous risk factors that make some families more at risk for hardship, stress, and deprivation. Furthermore, such effects of structural inequalities can increase the odds that proximal processes will be less than ideal for each child.

These structural inequities, in turn, create stress and insecurities that trickle down to the microsystem of the child, placing her in harm's way. Rather than overstate the entire family, neighborhood, or school system as being overwhelmingly influential and deterministic, it is often the close interactions that the child has or does not have that shape her proclivities for healthy or unhealthy, disordered behaviors. That is, it is the abusive or nurturing parent, the supportive or punitive teacher, the kind or cruel sibling, or the positive or ill-intentioned neighbor who make the biggest difference in the child's developmental outcomes. This consideration directs our assessment differently, in a way that may, in the end, be more fruitful; that is, our assessment should ask, where are the intense, consistent, and close interactions of the child, and what is the tenor, tone, or message of those interactions?

When a child demonstrates the symptoms of a mental health disorder, the dysfunction is a product of interactions between the child and his environment, not a pathology inside of the child.

Adler-Tapia (2012) observes that child therapists are situated in a complicated matrix. This matrix can be conceptualized as an array of a child's everchanging neurobiologic, physiologic, and socioemotional capacities and needs, which are intertwined with societal policies, inequities, and prejudices, as well as the more immediate and direct family and community systems interactions. Our focus as we attempt to understand, assess, and intervene with children and adolescents needs a framework that takes into account all of the moving parts. We have found that a developmental systems approach is this framework.

Aspects of Developmental Psychopathology

A developmental systems framework has also been heavily influenced by the developmental psychopathology approach conceptualized by Sroufe and Rutter (1984) and Cichetti (1993). In 2005, Cichetti and Cohen edited the first of three volumes of *Developmental Psychopathology*. In these volumes, they focus on bio-psycho-social interactions that set the context for normal and abnormal development across the lifespan, a focus that aligns with a developmental systems approach. Like the ecological perspective, developmental psychopathology framework studies human behavior as transactional relationships between each individual child or adolescent and his or her environment at multiple levels.

This suggests that when a child demonstrates the symptoms of a mental health disorder, the dysfunction is a product of interactions between the child and her environment, not a pathology inside of the child. Cichetti and Cohen (2005) propose that an exclusive focus on symptoms and DSM criteria may be misleading and instead, "adaptive functioning, the nature of the surrounding environment, and the relationship between organism and environment become critical areas for assessment, perhaps even central for understanding of a given disorder" (p. 31). Pathology is marked by the variance in degree from what is considered normative behavior in the context of culture, opposed to having distinct sets of behaviors that are pathological in kind/quality (Coghill & Burke, 2012). For instance, oppositionality is a common behavior in children; it becomes pathological not because it becomes a different kind of behavior but because of its increased quantity in duration, frequency, or magnitude. Child and adolescent disorders occur in a context in which multiple factors interact over time. The person and the environment mutually shape and adapt to each other.

The major premise of developmental psychopathology is that psychopathology develops and is governed by developmental principles which play out in multiple developmental domains (Cicchetti, 2005; Sroufe & Rutter, 1984; Sroufe, 2013). Clinicians need to understand normative ranges and identify the range of normative behaviors and feelings as continua and not as hard and fast thresholds. With the ideas of transactional processes and normative ranges, a developmental systems approach to understanding mental health disorders among children and adolescents focuses our attention on three processes:

1. Developmental processes that contribute to physical, social, emotional, cognitive, and behavioral outcomes.

2. Systemic influences (highlighting risks and protective factors) on the child, including the child herself (genetic predispositions and other biological factors), parents, caregivers, neighborhood, extended family, school, peers, and society.

3. Transactions within and between the child and systems and the mutual reciprocity that affects child outcomes.

The clinician must bring their attention to the many tensions in these concepts, especially when considering psychopathology versus normality, what is considered to be *health functioning*, and what is known as *developmental continuities and discontinuities* (Hayden & Mash, 2014).

We focus our attention on developmental processes, systemic influences, and transactions between the child and systems.

Developmental Processes. As child and adolescent clinicians, we need to know children and appreciate their developmental processes that secure each developmental task. This does not mean that we need to memorize every developmental milestone at each stage, but we do need to be attuned to what children are likely to be doing within their developmental period and alert to indicators of possible developmental delay. We also need to know how this process unfolds. The developmental pathway helps us understand the process of continuities and discontinuities of development through repeated assessments and clinical judgments over time. The synthesis of these assessments and judgments can come from effective strategies of intervention, including referral for developmental or medical assessment, investigation of antecedents and consequences of both normative and developmentally out-of-step behavior or emotion and consultation to more directly assess concerns In addition, accurate diagnosis of mental health disorders among youth require knowledge of emotional and social maturity for a given age range in order to distinguish disordered behavior from normative behavior.

A developmental systems approach explains impairment in terms of an outcome of interactions between the genetic susceptibilities of the individual, her developmental needs and capacities of the moment transacting according to the goodness-of-fit with the environment (Cicchetti, 2005; Sroufe, 2013). There are mutual reciprocal changes in this ever-evolving relationship between the person and the environment. The idea of successful adaption to the environmental adversity is known as resilience, and often resilience may be related to protective factors, or those conditions that serve to buffer vulnerabilities to dysfunction and unsuccessful adaptation to environmental adversity (Hayden & Mash, 2014).

A developmental systems perspective incorporated into this approach brings our attention to concepts of equifinality and multifinality. When similar environments transact with different individuals to produce different outcomes, multifinality is observed (Cicchetti & Rogosch, 1996). For example, identical twins raised in the same environment are unique individuals with their own personalities and social emotional make-ups. With equifinality,different combinations of biological and psychological predispositions of different children combine with different environments yet produce a similar outcome (Cicchetti & Rogosch, 1996). As we work with children and families, we will encounter children with varying predisposing factors who demonstrate similar diagnostic syndromes and children with similar predisposing factors who demonstrate varying diagnostic syndromes. We need to remain open to all information and the potential of each child and adolescent we meet.

The developmental trajectory and outcome of each child throughout her lifetime is also one of vast potential. Rutter (2012) refers to earlier research which demonstrates that the same experience of risk can release multiple trajectories. For some, the individual might show a traumatic reactivity with negative consequences, while others might show what Rutter calls a “steeling” effect. Developmental trajectories can be stable or show dramatic changes over time, and there is not a singular cause for pathology. It is important to determine factors across many levels of the child’s life as part of our understanding of their developmental trajectory and the potential for positive influences to improve developmental outcomes.

Developmental trajectories can be stable or show dramatic changes over time, and there is not a singular cause for pathology.

Normative Developmental Ranges and Domains. Child pathology can be defined through recognizing its presence as an adaptational difficulty or incongruence with generally held social standards, i.e., through the social judgments of collective adults in the child’s life. There are various theories highlighted in child psychopathology literature, ranging from psychodynamic and attachment models to social learning, behavior, and cognitive models, to constitutional/neurobiological models, to interpersonal or family systems models. These theories will be surveyed in the intervention section of this book. For our purposes here, we will focus on normative developmental ranges and domains, which are a more concrete guide of child psychopathology for practitioners. Four central developmental domains have often been cited in the literature: 1) Cognitive Development; 2) Language Development; 3) Sensory-Motor Development, and 4) Social and Emotional Development (Drabick, 2009; Kendall & Comer, 2010; Pollak, 2015; Sroufe, 2013).

History of developmental issues can be informative to the presenting issue (Thapar & Riglin, 2020). In addition to these indirect effects of developmental difficulties, it is critical to know of developmental delays or challenges associated with specific disorders. Language and cognitive developmental delays as well as social skill deficits can each be associated with either criteria or specifiers for Autism Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD), Oppositional Defiant Disorder (ODD), Conduct Disorder (CD), and Intellectual Disability (ID) (Sroufe, 2013; Thapar & Riglin, 2020). Clinicians must work out whether developmental differences are attributable to a specific mental health disorder or a developmental variation for a child that exists outside of a diagnosis.

Developmental, Systemic Influences

A developmental systems perspective provides a framework to assess systemic and transactional influences in conjunction with developmental processes and normative expectations as each separately or in combination relate to developmental differences and criteria or symptoms of specific mental health disorders (Hayden & Mash, 2014). It is also through a developmental systems lens that we can not only assess and diagnose but also intervene with strategies that are designed to improve functioning both within and between systems. As we consider the factors about gene-environment and development as well as transactional processes, consider various epidemiological considerations that weave throughout, such as age differences, socioeconomic status, sex differences, rural versus urban differences, ethnicity, and culture.

Gene-Environment and Development. Present and past environmental resources and genetic and biological predisposition of the child interact to create individual outcomes for each child. Hayden and Mash (2014) assert that "most forms of child psychopathology are likely to have an oligo- or polygenic basis, involving susceptibility genes that interact with one another and with environmental influences to result in observed levels of impairment"(p. 5). Genetic influences on mental health disorders are rarely reduced to a direct impact of one specific gene. Rather, our genetic make-up results in genetic predispositions to certain disorders and these predispositions are modified by other genetic factors and our interactions with the environment. Environmental stressors, in particular, appear to have the most impact on the extent to which a genetic predisposition will result in a specific disorder (Thapar & Riglin, 2020). Social adversities are multifactorial but that we can make efforts to identify key elements that may be amenable to change as we work with the child and family (Thapar & Riglin, 2020).

Childhood development is adaptive to prevailing responses and conditions in the immediate environment (Rutter, 2012). Research on early stressors and maltreatment in particular shows what Rutter calls "experience-adaptive programming effects" in which long after the conditions of maltreatment exist, the changed neural pathways of the brain and the reactivity of the HPA axis remain. Cichetti and Cohen (2005) point out that disordered behavior could have been adaptive at one point. However, if it continues when no longer adaptive to the environment, this may create delayed or reduced achievement of social and emotional developmental tasks. The clinician can be instrumental in partnering with the child or adolescent to develop transactions that are adaptive to the current environment.

Shawna's early caregiving environment was neglectful and abusive. One of her coping strategies was to disinhibit her social communication and to reach out and attach to any adult in her presence. Although she now had a consistent caregiver and no longer needed this strategy, her response stayed the same. It is as though her brain was hardwired to respond to any adult as though there was no secure base to return to. It took repeated transactions of stable and consistent caregiving before Shawna began to reciprocate, starting to trust that her caregiver would not neglect or abuse her and she no longer needed to attach to strangers to get her needs met.

Transactions and Mutual Reciprocity. This example illustrates both the ways in which the child's social and emotional development and behaviors are shaped by the early environment and the potential for her to respond in a new adaptation to a healthier environment. But it also demonstrates that when the environment changes, it takes a great deal of time and effort to revise the body's and brain's adaptive response. However, when the caregiver is consistent, and there is a persistent new environment, eventually the child's emotional and behavioral response will adapt once again.

These transactions cannot, however, be one-sided. The caregiving environment can change, but until these changes are internalized, and the consistency of the change is strong enough, the child's responses to the previous adaptation will remain. It is with time and consistent presentation of healthy transactions that the child can be expected to show positive change. This mutual dance between child or adolescent and adult reflect the reciprocal nature of interactions that shape both the child and the environment. In turn, the environment shifts slightly upon each transaction. For example, Shawna has created an adaptive function based on a past abusive environment. Now that she is in a safe and secure environment, she no longer needs the behavior, but she must repeatedly and consistently experience these new environmental conditions before her neurological and behavioral activation system reorganizes into a more healthy and functional response.

Transactions in a healthy environment must mirror the consistency and duration of the dysfunctional environment which contributed to the maladaptive unhealthy and sometimes disordered behaviors and emotional reactivity. This is challenging for families, the child, and the clinician. Assessment of small changes and encouragement for these changes to continue and build on each other are essential. The mezzo system in which the individual child interacts with the family, school, and peers can allow the child to integrate reinforcement of healthy functional behavior and extinction of previously learned maladaptive responses. The child's adaptive responses in turn create healthier families, peers, and school environments. This is often the arduous process of developmental systems that clinicians who work with children and adolescents must orchestrate for healing and recovery to occur.

Final Thoughts and Looking Forward

As we have seen, a developmental systems approach combines aspects of the ecological model and the developmental psychopathology framework. These together have a synergism in their joint explanation of the manifestation of childhood emotional and behavioral disorders. While each can stand on its own, both parts of a developmental system assist clinicians in their quest for precision care and help them understand the particular influences and potential palliatives for an individual child. Developmental psychopathology and ecological systems inform the other. A developmental systems theory will allow a systematic approach to each of the clusters of childhood emotional behavioral disorders.

The chapters immediately following this introduction will cover assessment, formulation, and treatment planning, then move to special treatment considerations with psychopharmacology. The first section of the book includes considerations of race, racial trauma, and multicultural counseling to discuss these critical aspects of psychosocial therapy more pointedly. The second section of the book will walk through the most common diagnoses and clinical areas in child mental health, with learnings focused on engagement, assessment, and intervention. Each one of these chapters is prefaced by an interview with a clinical voice in the field, so that readers may understand how this work is done on the ground. The chapters will end with links to open-access resources to provide clinicians with assessment tools and intervention materials that are ready at-hand. The last section of the book will cover organizational factors related to doing behavioral healthcare. Thank you for taking the time to read our book; it is the effort of clinicians trying to give back to other clinicians. When clinicians collaborate, not compete, children and communities can heal.

Things Clinicians Should Know

Assessment, diagnosis, and intervention that incorporate a developmental systems approach incorporate an understanding that children and adolescents are experiencing developmental challenges, tasks, and capacities that intersect with risk and protective factors of the environment.

A developmental systems approach to understanding mental health disorders among children and adolescents focuses our attention on

- Developmental processes that contribute to physical, social, emotional, cognitive, and behavioral outcomes.
- Systemic influences on the child, including the child herself (genetic predispositions and other biological factors), parents, caregivers, neighborhood, extended family, school, peers, and society.
- Mutually reciprocal transactions within and between each child and the systems that she interacts with.

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2

Chapter

A Developmental Systems Approach to Understanding Race and Ethnicity within Child Development and Psychopathology

Brianna A. Baker, BA; Sean E. Snyder, MSW

Chrystal is a 12-year-old Afro-Latinx cisgender female in the sixth grade at a predominantly White private school. Chrystal has been referred to her school's social worker due to her withdrawal from school activities and lack of class participation. While in session, Chrystal reports feeling "stressed out," "numb," and "overwhelmed" by the recent national headlines of police brutality against Black people. She has become anxious every time she uses social media due to the fear of seeing a video of a racist incident against "people who look like her." Chrystal tells her therapist that she feels hopeless and constantly wonders about "being the next hashtag." These feelings of sadness and anxiety have prompted her to become easily distracted and ambivalent about her school performance.

Introduction and Overview

As you have learned, developmental systems theory (DST) is an integrative model of human development that includes epigenetic and social contexts as ecological influences on behavior and psychology (Ford & Lerner, 1992; Griffiths & Tabery, 2013). In concordance with this theory, this chapter will explore the entities of race and ethnicity within the context of child psychopathology, assessment, and treatment. While race and ethnicity are certainly global constructs, this chapter will focus on the United States in particular. Specifically, this chapter aims to accomplish the following:

- Introduce the concepts of race and ethnicity, as well as racial-ethnic identity.
- Explore the impact of racism on the human psyche, including race-based traumatic stress and racial trauma.
- Utilize a developmental systems approach to understanding the influences of race and ethnicity on the development of psychopathology in children through the concepts of race socialization and racial identity development.
- Discuss implications for effective clinical practice.

Race, Ethnicity, and Social Science: A Brief History

The following section will cover the definition of race and ethnicity within a historical perspective of social science and racism; this will help us frame the impact of racism on help-seeking and mental health services. From a systems perspective, macro-level influences that have been shaped over time have a trickle-down effect on individual-level behavior. These contexts have vast implications on clinician approaches to care.

Defining Race and Ethnicity

How does one know their race? Is it determined by phenotype (physical appearance and attributes) or genotype (genetic expression)? Does someone tell us our race, or are we born with this knowledge? The United States possesses a long and complicated history pertaining to race and ethnicity. How we define race in this country varies across people, regions, and institutions. Many scholars and researchers rely on definitions from the government as these institutions fund grants and programs related to race and ethnicity. As such, race and ethnicity are defined by the Office of Management and Budget (OMB) and the United States Census Bureau using sociological and biological research support. Still, the OMB is rather ambiguous and discrete when explicitly outlining its methods for codifying racial-ethnic groups. The OMB produces categorizations of race and ethnicity used by the United States Census Bureau that combine ancestry, cultural identification, and sociological or scientific perspectives.

Currently, they are five main racial groups (on the US Census Questionnaire. These groups consist of White, Black or African American, American Indian or Alaska Native, Asian, or Native Hawaiian or other Pacific Islander. These large categories are further distinguished by country or region of origin. The questionnaire, which relies on self-identification, allows respondents to select one or multiple racial categories. The definition of ethnicity remains ambiguous although it generally refers to cultural commonalities such as religion, cultural origin, and language (Baumann, 2004). Only two ethnic categories comprise the US Census Report: “Hispanic, Latino, or Spanish: or Not Hispanic, Latino, or Spanish.”

In modern-day language, the term BIPOC has been used to describe “Black, Indigenous, (and) People of Color.” This term refers to historically marginalized racial-ethnic groups collectively while honoring the individual experiences of colonialism, racism, and discrimination which affect each racial group differently.

As you can see, navigating race and ethnicity can be complex, and it has implications for macro-level issues like how we govern ourselves as well as more local issues like everyday interpersonal interactions between individuals and groups of people. This is especially true for children and adolescents. Thus, it is crucial to develop an understanding of the impacts of race and racism to best understand child psychopathology. The following sections in this chapter explore child development and psychopathology using a racial perspective to provide you with the tools and background necessary to appropriately and effectively address diverse clients. As you read, we encourage you to think about your own racial and ethnic identity and how that may influence your approach to building trusting and affirming therapeutic alliances as a mental health professional.

Social Science and Racism: A Historical Lens

The macro-level of culture and power exerts influence on individuals and communities from the top down. The United States’ earliest history is engrained in White Europeans’ desire to categorize and control, and this includes conquest, colonialism, and the enslavement of Africans and Indigenous peoples. The brutal treatment and dehumanization of African and African American people are well documented in American history. Given the abrasive history of the United States, it is no surprise that the initial efforts of social scientists were motivated by claims of racial dominance to falsely prove White physical and intellectual superiority (Richard, 2003). Take the example of nineteenth-century physician and anthropologist Samuel George Morton (1799–1851), who serves as one of the earliest documented social scientists to use science to reify racism. Ostensibly, he studied learning and intelligence, but he is infamous for his use of craniology, the pseudoscientific study of cranium size, to prove the correlation between cranial capacity and intelligence or intellectual ability (Michael, 1988).

Similarly, nineteenth-century American physician Samuel Cartwright conceptualized Drapetomania, a medical, mental illness characterized by an enslaved person of African descent attempting to flee his or her master to seek freedom (Willoughby, 2018). The medicalization of persons of color's humanity and desire for freedom speaks to the bias and Eurocentric nature present in the foundations of American social science and mental health approaches. These claims, of course, lacked evidence and reflected the dominant White supremacist ideologies of the time, with science being mainly based on personal opinion, religious beliefs, politics, and chronology. However, it would take a long time for science to address the racism evident in its research methodology, practice, and implications. In fact, many would argue that social science has made little effort to remedy scientific racism and its effect on the field at large.

While steps have been taken in the present day to reduce racism and other forms of oppression in mental health and psychological research (e.g., retractions of some overtly racist articles and practices), discrimination in research and practice still largely exists today. Since World War II, psychological research has made little progress in dismantling misconceptions concerning racial differences in intelligence, intellectual capacity, or propensity for violence. Most notably, American psychologist Arthur Jensen published several works throughout the mid to late 20th century claiming genetic differences, not systemic racism, were the cause of Black-White disparities in educational attainment and scholastic achievement (Jensen, 1985). In the 1990s and early 2000s, Canadian psychologist J. Phillippe Rushton provided further support for Jensen's claims of the intellectual inferiority of Black people. Rushton cited psychologist Glayde Whitney's report that people of African descent were inherently more prone to committing crimes to support the notion of Black moral and intellectual inferiority (Rushton & Peters, 1995; Rushton & Jensen, 2005; Rushton & Whitney, 2002). In 2002, psychologist Richard Lynn published a paper that asserted "the level of intelligence in African Americans is significantly determined by the proportion of Caucasian genes" (p. 365), thus supporting the racist notion of genetically determined lesser capacity for intelligence in those of African descent (Lynn, 2002).

Macro-level influences that have been shaped over time have a trickle-down effect on individual-level behavior.

Given the racist history of mental health and psychological science, modern-day racial and ethnic minorities are subject to centuries worth of scientific discrimination and abasement. Despite recent efforts to advance towards equitable scientific practices, the foundation of mental health research remains oppressive, exclusive, and persecutory. The flawed foundations of social science have consequences to this day, and, of particular note for us, on help-seeking and mental health services.

Help-Seeking and Mental Health Services

Many barriers prevent members of racial-ethnic minority groups from seeking and receiving quality professional mental healthcare. Stigma, systemic racism, inaccessibility, disregard for culturally relevant and responsive care, and a lack of clinicians of color deter many members of historically marginalized racial-ethnic groups from seeking professional mental health services. Let's explore ways in which minoritized groups have been discouraged or prevented from mental health services.

Stigma. The United States has yet to reach a place of complete cultural acceptance of mental health discussion and treatment. Broadly, mental health stigma refers to negative or unfavorable attitudes, feelings, behaviors, or perspectives concerning mental illness and any associated treatment or personal characteristics of mental illness (Overton & Medina, 2008; Penn & Martin, 1998). Communities of color often experience stigma both within and outside their social reference groups. Cultural values and norms, religious beliefs, and acculturation and language considerations pose further barriers to BIPOC populations seeking mental health treatment.

The African American community, for example, is traditionally one of high religiosity and spirituality. Historically, mental health challenges have been unfavorably regarded, often being considered as issues of faith and righteousness rather than of oppression, biochemistry, or interpersonal relationships (Ayalon & Alvidrez, 2007; Lukachko et al., 2015; Mojtabai et al., 2011). In Latinx families, mental health issues, especially if caused by intra-familial challenges, are often kept within the family and not brought to a mental health professional (Cabassa et al., 2006; Cabassa et al., 2007; Ramos-Sánchez & Atkinson, 2009; Villatoro et al., 2014). Those within the Asian American and Pacific Islander (AAPI) community are often confronted with the "model minority myth." The model minority myth poses the idea that AAPI people are the epitome of the perfectly assimilated, productive, and high-achieving minority race in America (Yi & Museus, 2015). This myth trivializes the AAPI experiences, making it appear that AAPI individuals do not experience negative emotions, personal or relational struggles, or other mental health issues (Museus & Kiang, 2009). With such pressure to adhere to this myth, mental health treatment in the AAPI community remains highly stigmatized, thus further invisibilizing AAPI mental health (Lee et al., 2009; Shih et al., 2019; Yoo et al., 2010).

Stigma may affect help-seeking behaviors as some potential BIPOC consumers avoid contact with a provider in fear of negative labeling or embarrassment (Sijbrandij et al., 2017). Attitudinal barriers have shown to be greater than structural barriers. Attitudinal barriers such as no or low perceived need for treatment or the belief that problems will alleviate over time have shown to have a great effect on racial or ethnic minorities' treatment access and early termination (Green et al., 2020).

Systemic Racism and Socioeconomic Inaccessibility. As we have discussed, systemic racism permeates virtually every institution in global society, including access to quality mental health services. Research suggests that racial-ethnic minorities are 20-50% less likely to seek mental health treatment services (Mongelli et al., 2014). This leads to the phenomenon known as the treatment gap, an indicator of health disparities. Mental health disparities are influenced by factors such as socioeconomic status, adverse childhood experiences, health system and policy factors, socioecological context, race, and ethnicity (Glasgow et al., 2019; Park et al., 2020). The poverty rate is much higher for Black and Latinx youth, and children in poverty tend to have greater difficulty receiving care (Bickman, 2020). Additionally, there is more exposure to adverse conditions such as housing issues and community violence in impoverished communities (Glasgow et al., 2019). Research suggests that disparities will continue to widen for BIPOC populations as there is less engagement in mental health services (Park et al., 2020). Furthermore, when racial-ethnic minority youth do receive an evidence-based practice in mental health treatment, the effect size of that intervention is typically smaller than that received by their white counterparts (Park et al., 2020). This underscores the importance of culturally relevant mental healthcare and research.

The treatment gap impacts BIPOC youth especially. This is partially a result of factors such as overrepresentation in the carceral state and child welfare systems (Alegria, et al., 2010; Gustafson et al., 2018). Additionally, racial-ethnic minorities are more likely to receive mental healthcare via law enforcement than their White counterparts as a result of racial bias in policing practice and correctional policy (Maura & de Mamani, 2017). Black and Brown communities are among the most uninsured, often making mental healthcare financially unattainable. Barriers to mental healthcare access lead to a lack of

Mental health stigma refers to negative or unfavorable attitudes, feelings, behaviors, or perspectives concerning mental illness and any associated treatment or personal characteristics of mental illness.

identification of youth with potential mental health disorders. This is problematic, as youth who have delays in the identification of their mental health challenges or whose problems go undetected altogether can have poorer health outcomes (Glasgow et al., 2019). This affects a child's overall life trajectory as undetected mental health problems tend to worsen and intensify as a child ages.

While the rise of teletherapy has increased accessibility and removed barriers related to transportation and time-related costs, these treatment modalities have been less researched on children and adolescents. Similarly, access to reliable internet and privacy remain a barrier when conducting teletherapy (Pickens et al., 2020).

Lack of Culturally Relevant and Culturally Adapted Care. While dominant in the United States, psychotherapy is not a globally exercised practice for treating mental health disorders (Koc & Kafa, 2019). Given this, the idea of talking to a stranger about personal and familial issues is unnatural and counterintuitive according to many cultures. Around the world, mental health is assessed and treated within the spiritual, legal, or family domain, or it is merely kept to oneself. While we know that talk therapy has proven to be effective (Durlak et al., 1991), most clinical samples are composed of majority White participants. Despite growing awareness of bias and the lack of cultural considerations, BIPOC populations remain disproportionately excluded from psychotherapeutic research. The lack of representation in these samples can be due to barriers such as lack of access to quality services, justified distrust of research participation, and limited parental mental health literacy (Glasgow et al., 2019).

This is precisely why we need culturally relevant and responsive care. Demonstrated cultural competency is rarely a required skill for clinical trainees. Culturally adapted assessment and treatment employs a multicultural lens that acknowledges cultural differences in mental health presentation and corresponding effective treatment. It is important to note that the Diagnostic and Statistical Manual of Mental Disorders (DSM) was developed with a Westernized, Eurocentric worldview. This further marginalizes BIPOC populations by using White individuals as the standard for normal and abnormal thoughts, emotions, and behaviors, often viewing cultural variances as deficits rather than strengths. Regardless of race and ethnicity, humans have universals; we all feel pain, happiness, jealousy, anger, and so on. However, the manifestations of mental illness or mental health issues can present differently.

Similarly, what is regarded as abnormal in one culture may be completely normal or even expected in another. Black and Brown people have the highest attrition rates in psychotherapy (Aggarwal et al., 2016). One reason for this may be the lack of cultural competency of their clinicians. It is the clinician's job to make clients feel seen, heard, and affirmed in their experiences. When we are not using a multicultural lens in mental disorder assessment and treatment, we may be causing further damage and distress to our clients by perpetuating the same invalidation and marginalization present in our society.

Lack of Representation. The mental health field is an overwhelmingly White industry (Lin et al., 2018). Even with culturally relevant training, it can be challenging for children to trust clinicians who do not share similar cultural or racial identities. As mental health providers, we understand the importance of the therapeutic alliance in allowing clients room to explore and grow in a safe environment. While cultural understanding and humility go a long way in providing a safe atmosphere for clients, the truth is that clients often have a preference for clinicians who share similar identities. Clients may prefer not to have to explain cultural values or norms to their clinicians. For children, this is especially important as they may not have the capacity or verbiage to express race-related stress to their mental healthcare provider. Given the current sociopolitical landscape in America, BIPOC communities experience direct and vicarious racial trauma at high rates (Liu & Modir, 2020; Lund, 2020). A clinician who cannot empathize or understand how sociocultural factors are affecting the child risks missing important diagnostic information, which would then be used to formulate an effective treatment plan.

Unfortunately, many barriers in higher education prevent racial-ethnic minorities from becoming mental health professionals. While there have been increases in minority mental healthcare providers, in recent years, a majority of the mental health workforce in the United States is White (American Psychological Association, 2015; United States Census Bureau, 2021). With the lack of representation in the mental health field, many people of color wait to seek help until absolutely necessary or refrain from using mental health services altogether. When working with a client whose identity differs from yours racially, ethnically, or otherwise, it is essential to acknowledge that the same imbalances of power and privilege which govern our society are also present in therapy. Additionally, sharing identities with a client may not automatically lead to mutual trust and understanding. It is important to consider cultural values and norms, identity, levels of acculturation and enculturation, and other facets of multiculturalism when assessing and treating children of color.

Developmental Systems and Child Psychopathology

As seen above, there are systemic, upstream issues as well as local, downstream issues for mental health care and mental wellness promotion. These issues infiltrate the meaning-making system of an individual. For BIPOC individuals (and the collective), racism and racial trauma are a central consideration for meaning-making, and for clinicians in general, racism and racial trauma are a central consideration with any intervention. Given the weight of these considerations, we will detail the influence of racism and racial trauma in mental health encounters with BIPOC children.

With the lack of representation in the mental health field, many people of color wait to seek help until absolutely necessary or refrain from using mental health services altogether.

Racism and Racial Trauma. Given the inescapable presence of racism in America, it is no surprise that the pervasive nature of racism and other forms of oppression are experienced as trauma, leaving psychological bruises on the human psyche. The effects of racism and other forms of oppression on the BIPOC human mind and body have been well documented in scientific literature (Pieterese et al., 2012; Williams & Williams-Morris, 2000). We know that exposure to racism is correlated with increased stress levels (Harrell, 2006; Peters, 2006), accelerated aging (Carter et al., 2019; Gee et al., 2019), and a variety of other mental health disparities in BIPOC populations (Jackson et al., 2010; Miranda et al., 2008). Racism may be experienced directly or vicariously and presents in various forms: interpersonal, systemic, institutional, and internalized.

When it comes to BIPOC children, the intersection of race, class, and gender is further nuanced by age, developmental status, and familial or community support and resources. According to a 2017 report from the US Department of Health and Human Services Office of Minority Health, suicide is the second leading cause of death in African Americans ages 15-24. Results from the 2011 CDC Youth Risk Behavior Surveillance Survey show that 14.3% of Latinx students (grades 9-12) had developed a plan for committing suicide at one point in their lives, and 10.2% had attempted suicide. Both rates of suicide ideation and attempt were higher than those reported by White and Black students.

So, what does this tell us? The research indicates that the life and mind of a child are more complex and intricate than most acknowledge. The same structural factors which influence adults have an exacerbated impact on the formative years of childhood. As mentioned before, it is often not until adulthood (if at all) that people begin to realize the impact of systemic oppression on their life experiences and overall development. BIPOC children carry an enormous weight as they are often invisibilized in mental health treatment and research, forcing them to internalize oppression and cope alone. Addressing racial trauma in children can be emotionally difficult for both the child and the clinician, thus underscoring the importance of a strong therapeutic alliance, cultural competence, and cultural humility when working with BIPOC children.

Case Illustration of Developmental Systems Considerations: Chrystal

Let's return to our case vignette with Chrystal. Unpacking race and ethnicity in children is challenging, albeit crucial. The DSM-V does not recognize racial trauma as a disorder. However, racism and discrimination are clinically acknowledged determinants of physical, mental, and emotional health. A comprehensive understanding of identity and the various systems that influence self-concept must be used to evaluate and treat children of color. While Chrystal explicitly shows signs of racial trauma and oppression-based anxiety, it should be noted that racism impacts each child differently. Many children cannot clearly link their sadness to racial injustice or oppression. They can, however, perceive differences in their treatment or the treatment of those who look like them when compared to others (Fox & Jordan, 1973; Stevenson & Steward, 1958). Unfortunately, children of color more than likely equate unfair treatment to personal attributions or self-worth rather than White supremacy, racism, or patriarchy. In other words, it is difficult for BIPOC children to differentiate the discriminatory treatment they receive from the humanity-affirming treatment they deserve. Therefore, the clinician's job is to provide a validating therapeutic atmosphere using unconditional positive regard to facilitate emotional and mental liberation from external and internalized oppression experienced by BIPOC children.

As we know, developmental systems theory (DST) provides an ecological and lifespan framework for understanding child development and behavior. This approach is particularly useful for understanding BIPOC children's development experiences as it relies on the integration of several sources of influence, both external and internal and interpersonal and systemic. While a person's race does not change over time, their conceptualization and meaning ascribed to their race will continue to evolve throughout their lifespan. Thus, DST provides a critical lens at the intersection of biological maturation, time, and contextual factors of influence in understanding the nuances of race and ethnicity in the psychological development of children of color. Most salient are the concepts of racial identity and race socialization which synergistically contribute to a child's understanding of self and race-related stress. These concepts will be critical in the evaluation and subsequent treatment of Chrystal and children with similar presenting symptoms.

> *Exposure to racism, in particular, is correlated with increased stress levels, accelerated aging, and a variety of other mental health disparities in BIPOC populations.*

Racial Identity. At the beginning of this chapter, we posed a question: How does one know their race? The Multidimensional Model of Racial Identity (MMRI) describes different stages of racial identity development experienced by people of color (Sellers et al., 1997). This model includes four aspects surrounding a person of color's racial identity: Racial Salience, Racial Centrality, Racial Regard, and Racial Ideology. These aspects are critical in understanding how a person of color may view themselves and others within and outside their racial group throughout the life course (Sellers et al., 1997; Sellers et al., 1998; Sellers et al., 2006).

Racial salience is a contextual component of a person's racial identity (Sellers et al., 1998). It refers to the extent to which a person's race is pertinent to their self-concept at a discrete point in time (Sellers et al., 1998; Scottham et al., 2008). Literature suggests that an individual's racial salience may be higher in situations in which they are surrounded by people who do not share their racial or ethnic identity (Douglass et al., 2016; Hurtado et al., 2015). Such may be the case for Chrystal as we know she experiences distress in a predominately White context.

Racial centrality refers to the extent to which a person underscores their racial group membership as a component of their comprehensive self-concept. Racial centrality contrasts from racial salience in that it is a more fixed factor of one's racial identity (Scottham et al., 2008). It appears that Chrystal's race is an integral component of her self-concept. As such, she is deeply affected by the brutal treatment of Black and Brown Americans and identifies strongly with her racial group.

Racial regard refers to how a person feels about their racial group membership. These feelings can be either positive or negative and are divided into two subcategories: private regard and public regard (Sellers et al., 1998). Private regard refers to how the individual themselves feels about their racial group membership as well as how they feel towards members of their racial group overall. Contrastingly, public regard refers to how positively or negatively an individual believes others view their racial group (Sellers et al., 1998; Scottham et al., 2008).

Finally, *racial ideology* comprises the most extensive dimension of the MMRI. Racial ideology refers to a person's guiding philosophy or principal beliefs regarding how members of their racial group should act and comprises four subcategories. Nationalist ideology is characterized by a desire to highlight the uniqueness and specialness of one's racial group; those who endorse this Ideology believe that their racial group's experiences are unlike those of any other group. This may be demonstrated through support for race-based organizations (Scottham et al., 2008; Sellers et al., 1998). Parham (1989) also found that ascribing to this Ideology may serve as a mechanism of resistance to racial oppression. Similar to the nationalist ideology, those who endorse the oppressed minority ideology are also critically aware of their racial group's marginalization. However, the oppressed minority ideology emphasizes the sameness between one's experiences in their racial group and those of other oppressed racial minority groups (Sellers et al., 1998). Assimilationist ideology highlights the similarities between African American and mainstream American society (Scottham et al., 2008; Sellers et al., 1998). While Sellers and colleagues (1998) maintain that this ideology does not imply a lack of critical consciousness or awareness, they suggest that those who adopt the assimilationist ideology may be more likely to support interactions and relationships with the dominant racial group. Lastly, the humanist ideology highlights the similarities among all people regardless of their racial group membership. People who endorse humanist ideology as their primary philosophy are less likely to define themselves and others by group memberships and more likely to emphasize individualistic qualities (Sellers et al., 1998).

Each of these domains relates to how a person relates to their race or ethnicity, which then corresponds to their psychological functioning, including a person's thoughts, emotions, and behaviors within a socially unjust and oppressive society (Sellers et al., 2006). BIPOC children begin to form their racial identities as early as three years old (Fox & Jordan, 1973). As clinicians, it is imperative to cultivate knowledge of racial identity to facilitate a meaningful bond and provide effective interventions for the child.

Racial salience, racial centrality, racial regard, and racial ideology are critical in understanding how a person of color may view themselves and others within and outside their racial group throughout the life course.

Race Socialization. Race socialization describes the process by which children begin to learn about race through messages received by the media, peers, caregivers, and other institutions. Race socialization also encompasses the values, attitudes, and behaviors transmitted to a child concerning their racial group (Lesane-Brown, 2006). While much research has focused on the family unit as the primary bearer of racial messages, children spend an increasing amount of time online and at school, making these institutions grounds for race-related communication (Brown et al., 2007).

In Chrystal's case, it is essential to acknowledge her racial-ethnic minority status within a predominantly White learning environment. While it is unknown whether her peers or school personnel have said anything directly to her related to race, it is common for racial-ethnic minority children to feel isolated and excluded due to their appearance, linguistics, or other cultural differences (Killen et al., 2002).

Chrystal demonstrates a heightened awareness of racial injustice and maltreatment of people of color. However, it remains unknown how Chrystal has been racially socialized within her home. Notably, silence around race or race-related challenges is one of the most common race-based messages that children of color receive (Rollins & Hunter, 2013). That's right! Race socialization is not always a conscious or explicit act of communication. The case description does not provide us with knowledge of Chrystal's relationship with her parents. However, as clinicians, we must be conscious of how race socialization may affect a child's conceptualization of race-related discourse and stress. In counseling Chrystal, you may ask her, "Have you ever discussed these scary feelings with your parents?", "Do you think anyone at school feels the same way you do about the news?" or "Who do you go to when you feel scared or sad?" to evaluate her sources of social support or feelings of isolation.

Implications for Clinical Practice

This chapter barely scratches the surface of examining race and ethnicity in clinical practice with children. By now you understand that addressing race and ethnicity when working with children can be challenging yet incredibly rewarding. Exploring race and ethnicity in an open and supportive environment can allow the child to feel confident and reassured in the often-silenced experiences of racial discrimination and oppression. To do this, clinicians must engage in self-reflection and develop critical consciousness around race, power, and privilege in order to provide the most effective treatment for BIPOC children. Talking about race may be a new and scary experience for children as few spaces allow for this level of vulnerability. Because of this, it is important that clients maintain cultural humility, utilize strengths-based approaches to counseling, and work collaboratively with the child in emotional exploration and problem-solving. Finally, it is essential that in developing cultural competency, clinicians acknowledge the vast diversity that exists within and between racial-ethnic groups so as to not over-generalize or over-individualize the child's worldview or experience. Sound like a challenge? It certainly is! However, facilitating holistic, positive growth in children requires patience, adaptability, reflexivity, and a relentless commitment to social justice.

Things Clinicians Should Know

It is important that clients maintain cultural humility, utilize strengths-based approaches to counseling, and work collaboratively with the child in emotional exploration and problem solving. Finally, it is essential that in developing cultural competency, clinicians acknowledge the vast diversity that exists within and between racial-ethnic groups as to not over generalize or over individualize the child's worldview or experience.

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3

Chapter

Assessment, Clinical Formulation, and Diagnosis: A Biopsychosocial Framework within the Developmental Systems Lens

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Alisha is an 8-year-old in the second grade. Her parents noticed that she was having more difficulty adjusting this school year than last. She was more worried at school drop off, and she forgot to bring her books home for homework more often. Her teacher said Alisha would play from time to time with the other students, but something seemed different. Her teacher recommended that Alisha's parents get connected with their school counselor to see what they could do to support. "There are many potential reasons for how Alisha is doing," the counselor said. "We should see if it's something about learning, her mental health, or maybe even a physical health problem. We can't know until we get some testing and assessments done." Alisha's parents responded, "We will take anything. We want the Alisha from first grade back! Please help us."

Introduction

When conducting assessments, the developmental systems lens can appear overwhelming at first, considering the various levels of systems at play (e.g., micro, mezzo, macro, etc.) and the developmental norms for a given age group. To help us navigate this, we will employ the bio-psycho-social framework. This model originated with George Engel (1977) who during his career sought to change the paradigm of medical practice away from the biomedical approach to an approach that incorporated social, psychological, and behavioral dimensions of illness. Engel (1977) argued that the traditional medical model was reductionist and that the multifaceted nature of human needs requires an approach that is contextual and interdisciplinary. He articulated that there is definitely a place for biomedical inquiry and that much of the advances in medicine can owe their origins with that model; however, this biomedical approach cannot be the only approach (Engel, 1977). We will explain more about the model in the formulation section in this chapter.

Considering the developmental aspect of our guiding theory, the clinical interview will vary greatly depending on the age of the child. Infant and toddler assessment is a specialty and will be discussed further within this chapter; however, it is challenging to discern what the baby is communicating to you unless you have studied and been trained in infant diagnostics. The quality of the information gathered may vary greatly depending on the interviewer/evaluator skills. There is even a different diagnostic manual developed around this age group. The DSM-5 does not claim to diagnose prior to age two or three and even then, reliability and validity are questionable. Zero to Three is an organization that has developed and published criteria and standards for diagnosing infant mental health.

When conducting and using assessments to guide diagnosis and treatment, it is essential to examine the potential social, cultural, and racial biases reporters, instruments and therapists may hold. Diverse communities may be targets of such biases and stereotypes which influence how their difficulties are perceived. For example, research shows that girls tend to be underdiagnosed with autism spectrum disorder while boys tend to be over diagnosed with Conduct Disorder. African American individuals tend to be underdiagnosed with Depression Disorder while over diagnosed with Substance Use Disorders due to what is often considered "typical" presentations of these conditions (Garb, 2021). Moreover, it is possible that the instruments themselves carry biases and limitations related to their development and methodology (Reynolds, Altmann, & Allen, 2021). Therapists, then, should select instruments and interpret results carefully considering the child's background, present context, possible limitations, and their own biases towards diverse groups.

The chapter is broken down into sections about age-specific approaches to assessment, data collection approaches, aspects related to formulation, diagnosis, and treatment planning. Age-specific approaches will span infants to adolescence; data collection will cover screening versus assessment, global versus specific measurement approaches, domains of functioning, and the role of collateral data; and the final sections will span the time-axis method in the biopsychosocial approach, the process of differential diagnosis, and the SMART approach to treatment planning.

In the process of an assessment, we may uncover a lot that is outside of our scope or purview, and it is important to note at the beginning of the chapter that we need to own our part of the service continuum; we can only work within the realm of a behavioral health provider. Skills as an advocate or as a connector to other services can broaden our influence on the various systems in the child's life, while still maintaining our focus on behavioral health. We can follow up on referrals made or received by us beyond initial assessment and make sure that the family and child are following through and doing well. If there are other referrals for therapy, we can check in with parents or caregivers regarding keeping their initial appointment. If we continue to work with the child, we can facilitate the family's ability to get to appointments and keep with any other types of therapy needed such as speech, primary care, or occupational or physical therapy.

Age-Specific Assessment

We want to preface any discussion of assessment by saying that working directly with the child and building a relationship is essential (Hilsenroth et al., 2004). A relationship with caregivers or any involved family member is also usually helpful. There are many barriers that families with young children may face to bring them to outpatient therapy. It is time consuming and can cost money to get back and forth. Home visitation is sometimes the only way that a parent or guardian of a young child would receive therapy. Not all programs will reimburse or even allow home visits so that varies with the agency or organization we are working with. Now that remote therapy has been more widely accepted, this may be a new trend. On the other hand, remote assessment through phone or videoconference is not ideal. Conducting therapy after meeting and assessing in person would be preferable if remote therapy is used.

Two child development theories will be weaved throughout this section, with a brief overview here and more commentary in the sections that follow. Piaget's theory of cognitive development (Piaget & Inhelder, 1972) and Erikson's theory of psychosocial development (Erikson, 1950). Piaget outlines four major stages of acquiring knowledge and building intelligence, with the sensorimotor stage spanning birth to 2 years, the preoperational stage spanning ages 2 to 7, the concrete operational stage spanning ages 7 to 11, and the formal operational stage spanning ages 12 and up (Piaget & Inhelder, 1972). Erikson (1950) articulated a lifespan theory that involves developmental tasks needed to master in order to maintain a healthy development, and these tasks include Trust vs. Mistrust (first year) Autonomy vs. Shame/doubt (1to -3 years); Initiative vs. Guilt (3 to 5 years); Industry vs. Inferiority (6 to 12 years); identity versus role confusion (12 to 19 years); Intimacy vs. Isolation (20 to 39 years); Generativity vs. Stagnation (40 to 59 years); and Ego Integrity vs. Despair (60+ years).

Assessing Infants and Early Years

Dulcan (2014) states that the most important assessment information when working with infants and toddlers comes from understanding the interactions and relationship between caregiver and infant. According to the author, the quality and consistency of care has the most impact on the physical and mental health of infants. Caregivers would perform the ego functions for infants and toddlers processing and organizing external and internal stimuli. The infant and toddler are extremely dependent on their caregivers physically, socially, and psychologically. Thus, family work is essential in the specialized field of infant mental health.

Understanding the relationship between infants and caregivers is key to assessing the well-being of the child (Larrieu, Middleton, Kelley & Zeenah, 2010). The nature of the relationship between the caregiver and infant can reveal a great deal about the child's present and indicate future functioning. The Working Model of the Child Interview (WCMI) is designed to assess quality of attachment relationship and can be administered as a clinical interview with the parents/caregivers. Larrieu et al. (2010) studied the test validity of the WCMI and reported that it has concurrent validity with the Strange Situation classifications of attachment and predictive validity for distinctions between clinical and nonclinical groups of infants. The WCMI (Zeanah & Benoit, 1995) was first developed in 1986 and updated in 1993, and it consists of 19 open-ended items aiming to assess the caregivers' internal representation of the infant and their relationship. These perceptions are hypothesized to predict the relationship between caregiver and infant and the infant's mental health. Another tool, the Infant Mental Status Exam, is an instrument that utilizes the clinician's observations of the infant's physical appearance, mood, and behaviors. A short interview with caregivers is also part of this assessment.

> *What infants and toddlers are expressing is difficult to determine because we must rely on nonverbal cues, and we cannot verify our intuitive interpretations.*

Evaluating the emotional and mental health of infants and toddlers includes assessment of very subtle and ambiguous symptoms. What infants and toddlers are expressing is difficult to determine because we must rely on nonverbal cues, and we cannot verify our intuitive interpretations. Parents and caregivers can be helpful when they seem knowledgeable, but even parents may struggle with interpreting infant and toddler expressions and communication accurately. Infant and toddler's nonverbal and preverbal expressions of emotional and cognitive processing are among the most ambiguous information. Many of the expressions of internalized disorders like depression, anxiety, or some trauma reactivity are communicated through affect, but infants only have a limited repertoire of behavior and expression of affect. Because infants are pre-verbal, they cannot tell us their internal feelings or thoughts, so any concern about a depressive or anxious syndrome can only be directly investigated by observing and recording behavior like sleeping, waking, affect, bids for attention, and other nonverbal communication. We rely on parental reports and collateral information from other adults.

Toddlers present with larger nonverbal skills and a growing set of verbal skills, but their concept of time, space, emotion, and the world are preoperational. This stage of cognitive development is formative (Piaget & Inhelder, 1972). The child can take in more than just through their senses and motor skills now that they have moved out of the sensorimotor stage of infancy. Once infants and toddlers gain object permanence, they form an internal representation of the object even when it is not present; this operation is the beginning of symbolic representations. However, as long as they are in the preoperational stage of cognitive development (generally ages of 2 to 6), they cannot operate in the symbolic world completely. According to Piaget and Inhelder (1972), children operate most of the time in the concrete world. Directed play therapy and narrative stories can elicit thoughts and emotions that the child is experiencing. Clinicians should take particular care in offering interpretation given their power in the therapeutic relationship, as it should reflect the client's world and not a projection of our own.

There are tools and trainings specifically designed for therapists who want to work with infant and toddler mental health. The DC:0–3 Diagnostic Classification of Mental Health and Developmental Disorders of Infancy and Early Childhood was originally published in 1994. The organization ZERO TO THREE: National Center for Infants, Toddlers, and Families was established in 1977 with only $12,000 of grant money and one employee. The Center has grown and been recognized by national organizations such as Head Start, who relied on their training and consultation regarding mental health issues in infants and toddlers. The organization offers training and holds a large annual conference each year. The American Academy of Child and Adolescent Psychiatry task force on research diagnostic criteria has also published diagnostic criteria for infancy and preschool children (Eger & Emde, 2011).

Assessment During Early Childhood (Ages 3 to 5)

The quality and nature of interactions between caregivers and the child remain critical parts of the assessment of preschool-age children. Thus, direct observations of these interactions are necessary during the assessment process. Measures like the Parent-Child Early Relational Assessment (Clark, 1985) rate observations and inform the clinician about the style and pace of both caregiver and infant, balance between autonomy and interdependence, as well as the qualities of attachment and bonding. The child's motor skills, language development and cognitive development can also be observed during this assessment.

The development of communication skills is exponential as the infant moves into toddlerhood and early childhood. The human brain grows 80% of its size by 36 months (Guide, Shaw, et al., 2006). In their first years, young children are learning about basic concepts such as space and time. As their concepts are constructed, each child creates a unique and somewhat magical understanding of the world, which is characteristic of the preoperational stage of development (Piaget & Inhelder, 1972). For instance, children may attribute superpowers to adults because they watched adults with superpowers on TV; this points to the concrete thinking children in this age group use to generalize knowledge about the world. Using and interpreting communication, particularly abstract and metaphoric, is still in development among young children, and they rely on concrete language. Similarly, their emotional life and self-concept are also developing, and evaluation of mood, affect and self-esteem may be challenging.

During early childhood, children are constantly changing and acquiring new knowledge and skills. As clinicians, we should be attentive to their development in multiple domains: speech and language, motor and fine-motor skills, toilet training and personal care, and ability to self-regulate. Knowing the expected developmental milestones of the child's age can help to identify possible challenges or delays. Assessments of adaptive functioning such as the Vineland-3 (Sparrow et al., 2016) aim to evaluate multiple skills that are expected for the child's age and allow them to function in their environment. Results can inform the need for early interventions and additional services for the child such as in-home visitations, physical therapy, speech therapy and others.

Evaluations for developmental disorders including autism are also common during early childhood as some repetitive behaviors and restricted interests start to be more evident. Instruments such as the Social Communication Questionnaire (SCQ, Eaves et al., 2006) is a useful screening tool that can be completed by caregivers and indicate if a child needs further assessment for autism. A comprehensive evaluation for autism would also include specific instruments such as the Autism Diagnostic Observation Schedule, Second Edition (ADOS-2; Lord et al., 2012) and the Autism Diagnosis Interview-Revised (ADI-R; Lord et al., 1994).

It is important to use different strategies to assess the internal emotional life of young children. The direct interview methods used with older children and adults may not be productive or engaging. Play can reveal themes throughout childhood, and in assessing three- to five-year-old children, it is crucial to include play. Interactive, nondirective, and directive play can reveal themes such as experiences, feelings about relationships and events, and self-concept.

Like playing, drawing is an interesting activity for many young children that can provide valuable information about them and their environment. After you develop a rapport with your new child client, a request to draw a self or family scene can be used to get a glimpse of the child's self-image and to begin to assess family tenor, make-up, rules, and style of interactions in the family.

Bettman and Lundhall (2007) review narrative assessments for young children, finding over ten that exist with varying degrees of reliability and validity. They report that the MacArthur Story Stem Battery (MSSB) (Bretherton et al., 1990) is the most widely used narrative assessment instrument for young children. Following the presentation of the story stem, the examiner asks the child to "show me and tell me what happens now." Story stems address a number of content areas, including child injury, oppositionality, exclusion, and parental conflict. Children are presented with the beginnings of a sequence in a story with matching doll, animal, and miniature household figures set up to dramatize the story. Then, the child is invited to complete the story in their own way and to use the toy figures to illustrate their sequence of events. Wolf et al. (2003) caution that we should not interpret the story as a direct observation of the child, but there are recognized correlations between the way the child completes the story and events in the child's life. For example, Toth and colleagues (1997) assessed representations of self and others among a sample of maltreated preschoolers and identified differences between those with and without a history of abuse.

Another measure, the Story Stem Assessment (Lees, 2016) was developed in the 1990s and includes themes of being lost, getting injured, and crying. An example of a story sequence is entitled "Picture from school." The story begins with the child making a picture in school and taking it home "When the child gets to the front door of her house holding her picture, someone comes to the door." Then, the assessor asks the child "Then, what happened?" There are official scoring manuals to provide additional validity to your interpretation (Lees, 2016).

Assessment During Middle Childhood

Middle childhood is marked by formal education through school or homeschooling. During this period, children usually learn how to read and write and are exposed to various fields of knowledge including mathematics, social sciences, and biological sciences. They develop operational thinking which allows them to better understand concepts such as time, area, and volume by using observations, comparisons, and logic (Piaget & Inhelder, 1972). Socially, children strengthen peer relations through more collaborative and complex play and games. They start learning about rules and their role in governing social interactions.

Critical developmental tasks of middle childhood occur in these years, such as development of self-esteem/ self-efficacy, social identity, internalization of evaluation of performance at many levels by both adults and peers, academic and athletic abilities, and behavioral and social/emotional competencies.

By later middle childhood (age 12 years or over), children grow in independence and can get dropped off or even use public transportation either on their own (if mature enough) or with siblings.

Throughout your therapeutic relationship with child/youth and their family, part of the ongoing assessment process includes good communication from the beginning and being proactive about contacting and staying in relationship with the family/child and remembering the many facets of their biopsychosocial make-up. This developmental period serves a critical juncture in terms of the individual biological and ecological factors. The gene-environment interaction is critical through childhood and adolescence, as genetic predispositions are susceptible to stressors and can emerge when triggered, or they may remain only predisposition and not develop when emotional and social environments are nurturing and supportive of the youth (Kalin, 2020). Some disorders are more likely to develop as a result of environmental factors during childhood and, if onset is not until adulthood, are less severe (Kalin, 2020). About half of those who develop a mental health disorder over their lifetime experience onset by age 14 (Kessler et al., 2005). Children between ages 6 and 13 years spend most of their time at school or engaging in educational activities so learning, social, behavioral and emotional challenges become salient to educators. As a consequence, this age group is frequently referred to school counselors, school psychologists, social workers, and other mental health professionals when issues arise.

Several key factors will determine how to approach assessment techniques with this age group. To assess these concerns, we should focus on establishing good rapport with the child by engaging in drawing or playing. We can rely more on the child's report by asking them questions about their routines, thoughts, and feelings. Asking the child to draw their family and themselves continues to be an interesting way to explore their family system and self-concept. Gathering information about the child's history and behaviors across different contexts is extremely valuable as well. We can notice variations in how a child behaves at school and at home. This may indicate challenges and strengths that are specific to certain environments or relationships (e.g., a supportive teacher or a caring family member). Depending on the child's literacy, they may be able to fill out self-report measures that have been validated to their age group. A mental status exam for children starting during middle childhood (6 to 12) can be most useful.

Cognitive and Intellectual Functioning. As mentioned, a hallmark of the middle childhood period is formal education. Assessments of cognitive and intellectual functioning, as well as academic achievement are commonly conducted during these years, particularly when the child experiences difficulties in learning. Individualized Educational Programs (IEP) are important documents that provide additional services in school to students including speech therapy, occupational therapy, reading remediation, and counseling.

These plans rely on psychological evaluations that usually assess intellectual functioning and academic achievement.

Intelligence or cognitive functioning tests are often used to determine if a child is placed in an appropriate educational setting, if there are any learning or developmental disabilities present, and to help families and educators develop educational strategies to best help a child succeed. Many of the most common intelligence tests that are used today have been largely influenced by the psychometric approach, which is based on the premise that there are certain mental factors that make up a person's intelligence that then influence performance on specific intellectual tasks (Whiston, 2017). Spearman (1927) first postulated that all people possess a general ability factor, or g, that is made up of different cognitive abilities and influence overall performance on mental ability tests. Following Spearman, Thurstone (1938) proposed a model of seven factors that collectively accounted for most of the variation in level of intelligence, including verbal comprehension, word fluency, number facility, perceptual speed, memory, space, and reasoning. The Cattell-Horn-Carroll model, perhaps the most well-known contemporary theories of intelligence, expanded on Spearman's g factor theory by proposing that g included both a fluid intelligence factor, which refers to cognitive abilities that involve being able to reason, analyze, and manipulate novel information, and a crystallized intelligence factor, which refers to specific skills and knowledge that are acquired over time through educational experiences, culture, and the social environment.

Alisha was connected to special education services. The assessment team explained to Alisha's parents that "Each kid is unique, so all the different tests help us to understand your kid's circumstances." The team asked for a social history and developmental history and asked the teacher for behavioral observations. They administered the WISC to see if there were any learning or cognitive difficulties.

"Mom, I didn't really like that long test. The blocks were fun, but I got bored of it pretty quickly. Is this test going to go on my report card?" Alisha seemed a bit nervous.

The Wechsler scales of intelligence are the most widely used tests to measure individual intelligence in youth (Archer & Newsom, 2000). He developed a series of three instruments designed for specific age groups: The Wechsler Preschool and Primary Scale of Intelligence IV (WPPSI-IV; Wechsler, 2012), for ages 2.5 to 7, the Wechsler Intelligence Scale for Children, Fifth Edition (WISC-V; Wechsler, Raiford, & Holdnack, 2014), for ages 6 to 16, and the Wechsler Adult Intelligence Scale, Fourth Edition (WAIS-IV; Wechsler, 2008) for ages 16 to 90. The Wechsler all include the calculation of the Full-Scale IQ (FSIQ) score which represents a global and aggregate measure of cognitive abilities and is considered the most representative indicator of an individual's overall intellectual functioning. In addition, all of these instruments are made up of a certain number of subtests that aim to measure different domains of cognitive functioning and intelligence. For example, the subtests on the WISC-V map onto five indices that the assessment is trying to capture: Verbal Comprehension Index (VCI), Visual Spatial Index (VSI), Fluid Reasoning Index (FRI), Working Memory Index (WMI), and Processing Speed Index (PSI). The VCI measures an individual's ability to verbalize meaningful concepts, think about verbal information, and express oneself using words. The VSI measures a child's visual-spatial reasoning, integration and synthesis of part-whole relationships, attentiveness to visual detail, and visual-motor integration. The FRI measures a child's inductive and quantitative reasoning abilities, broad visual intelligence, simultaneous processing, and abstract thinking. The WMI measures a child's ability to identify verbal and visual information, maintain information within immediate memory, and re-sequence information to problem solve. The PSI measures a child's accuracy and speed of incoming visual information, decision making, and decision implementation.

Interpreting scores on the Wechsler scales of intelligence not only includes an analysis of the results of the FSIQ, primary index scores, and subtest scores. It also involves identifying a child's areas of strength and weakness, and comparison of scores both within indexes and between indexes to get a better understanding of a child's overall cognitive functioning. In addition, behavioral observations during testing administration are crucial in helping a clinician interpret scores—for example, if a 7-year-old child is observed to have difficulty following instructions, is fidgeting throughout, and is easily distracted during testing, it would be important to note in the assessment report whether this could have impacted their performance on the WISC-V and thus could be an underestimate of their true cognitive abilities. Additionally, children with attention-deficit/ hyperactivity disorder (ADHD) tend to score lower on WMI and PSI because the subtests on these two indices measure aspects of executive functioning (working memory and processing speed), which is commonly impaired in individuals with ADHD. If behavioral observations during testing align with lower scores in WMI and PSI, a clinician may be better able to make a stronger argument for a diagnosis of ADHD.

Other tools and batteries that are commonly used for assessment of cognitive and intellectual functioning in youth include academic achievement tests such as the Woodcock-Johnson IV Tests (WJ-IV; Schrank et al., 2014) and the Wechsler Individual Achievement Test-III (WIAT-III; Wechsler, 2009). Both assessments specifically measure a child's reading, writing, math, and oral language skills and have both grade-based and age-based norms in order to assess patterns of strengths and weaknesses in a child's academic functioning.

Academic achievement tests may also help in the diagnosis of Specific Learning Disorders that are classified in the DSM-5, such as Specific Learning Disorder with impairment in reading. If a specific learning disorder or language disorder is suspected, assessments may be administered that are specifically tailored to measure language domains. Language and phonological processing tests such as the Comprehensive Test of Phonological Processing- Second Edition (CTOPP-2; Wagner et al., 2013), the Test of Word Reading Efficiency- Second Edition (TOWRE-2; Torgeson et al., 2012), and the Clinical Evaluation of Language Fundamentals- Fifth Edition (CELF-5; Wiig et al., 2013) can help in ruling out language and communication disorders.

Assessment During Adolescence and Early Adulthood

Adolescence can be considered a dramatic developmental transition. Bodies are changing triggered by puberty and brains are transforming in various areas (Arain et al., 2013). Their use of cognitive skills is being consolidated in relation to gathering and organizing information, planning, modulating behaviors, regulating emotions, and navigating interpersonal relationships. According to the cognitive stage model (Piaget & Inhelder, 1972), adolescents employ more consistently abstract thinking (e.g., reasoning, hypothetical scenarios) and manipulate theoretical concepts to understand and explain the world. Moral and ethical reasoning also become more prevalent during this period, nuancing their views on social, political, and philosophical issues. Psychologically, adolescence is marked by the development of identities which may lead to confusion but also to deeper understanding of self and one's role vis-a-vis others (Meeus et al., 1999).

In most states, adolescents have legal confidentiality and should assent to their treatment. Fostering their self-determination and empowerment is the goal. On the other hand, the combination of an excitable limbic system, growing sexual hormones, and inclination to risk-taking may lead adolescents to display more impulsive behaviors and experience intense emotions (Casey et al., 2008). Their skills to regulate their behaviors and emotions is still developing and consolidating which may lead to difficulties and poor decisions (e.g., drug abuse, risky behaviors). Nevertheless, therapists should respect the self-determination of the adolescent even if they feel protective of their inexperience. Adolescents who are struggling with disruptive emotional or learning disorders are having to negotiate difficult terrain as they grow up.

Regarding the assessment process, adolescents become the primary source of information regarding their functioning, social interactions, and problems. Building rapport with your teen client then becomes vital, which requires flexibility and creativity to engage them in the process. Self-report measures assessing psychological symptoms such as depression, anxiety, and attention and hyperactivity tend to be reliable sources of information. Personality inventories that examine developing personality traits in adolescents can also be helpful to explore internal representations of self and their relationship with others. These instruments provide insight into adolescent's internal world organization and patterns of interactions which may inform appropriate treatments.

Balancing between their autonomy, confidentiality, and ensuring their safety may be a delicate process. This is particularly true when conducting risk assessment and asking about substance use and alcohol drinking, sexual behaviors, trauma history, suicidality, and homicidality. In most states, therapists have the mandate to report to child protective services and other authorities' cases of maltreatment, neglect, and abuse. Thus, it is important to consult and be knowledgeable about your responsibility as a provider. Additionally, adolescents may disclose self-harm thoughts and behaviors which should be addressed in therapy and, if needed due to higher or imminent risk, referred to psychiatric services or emergency rooms.

The Columbia-Suicide Severity Rating Scale (C-SSRS; Posern et al., 2008) a questionnaire used to assess suicide risk and is available in multiple languages. It can be completed by the adolescent or the therapist as a semi-structured interview. Such an instrument helps therapists to determine the immediate level of suicide risk a person may be experiencing so that appropriate steps can be taken. In case of positive risk, therapists should conduct safety planning with the adolescent. Safety planning is a brief intervention that aims to reduce suicide risk by identifying triggers to suicidal thoughts and helpful coping strategies including internal strategies (e.g., distraction), contacting social supports (e.g., calling friends or family members), contacting mental health providers, and restricting access to lethal means (Stanley & Brown, 2011). It is helpful to collaboratively construct the safety plan with the adolescent to make it more relevant, accessible, and meaningful for them. Additionally, having it written and providing the adolescent with a copy of it can increase the chances of them using it when needed.

Talking about suicidal ideation and behaviors can be daunting for adolescents, so it is important that therapists are comfortable with bringing up these topics and normalizing their experiences. Inconsistencies in reporting past self-injurious thoughts and behaviors may exist and be even adaptive among youth (Klimes-Dougan et al., 2022). Moreover, screening tools such as the C-SSRS may not fully capture the spectrum and complexity of suicidality and related behaviors, missing important signs relevant to clinical practice (Giddens et al., 2014). When working with those at risk for self-injurious thoughts and behaviors, the therapist should conduct the assessment carefully and thoughtfully, using follow-up questions, indirect assessment, and collateral information from caregivers and significant others.

Data Collection

Conducting assessment with children and adolescents requires using multiple strategies of data collection and sources of information. Data collection is meant to quantify information related to the frequency, duration, and intensity of behaviors, as well as the contexts in which they occur and the various facilitators and moderators involved. From a developmental systems perspective, we would consider this as looking for the proximal processes (see Chapter 1).

The clinical interview is an opportunity to ask and answer questions from the child and caregiver(s). Although there is a focus on gathering information, it is a unique moment to build rapport by creating a safe and accepting environment for the family. Therapists should be aware of potential cultural differences and personal styles when conducting clinical interviews. For example, it may be disrespectful to sustain eye contact with a person in authority such as the clinician among diverse families (Alcantara & Gone, 2014). Thus, the clinical interview should be carefully carried out combining the clinician's expertise, developed through case experience and ongoing supervision, with the data made available by the child and their family, including their identities, background history, and communication styles.

Rating scales and instruments are another way for clinicians to provide systematic coverage of behaviors for comparison over time, setting, and context.

How do we begin with collecting data in a systematic way? There are multiple semi-structured interview protocols tailored to assist clinicians in systematically collecting data. The Kiddie-Schedule for Affective Disorders and Schizophrenia – Lifetime Version (K-SADS-PL; DSM-5; Kaufman et al., 2016) is a comprehensive semi-structured interview that aims to assist clinicians in identifying current and past mental health symptoms. The interview should be conducted with children ages 6 to 18 years old and their caregiver(s) separately. Being familiar with the protocol is essential before administering it since the questions and probes should be adapted to the developmental level of the child, family unique characteristics, and the clinical hypothesis.

Rating scales and instruments are another way for clinicians to provide systematic coverage of behaviors for comparison over time, setting, and context. These tools offer helpful structure to the clinical interview and may allow youth to more easily disclose worrisome or covert symptoms. Rating scales can provide language and normalize thoughts and feelings experienced by the youth, perhaps for the first time. Many agencies routinely employ scales and other instruments for intake and monitoring purposes. It is important to be familiar with the tools used in the agency where you work and integrate them into your assessment and clinical interview.

The use of rating scales does not come without some drawbacks or limitations. There can be limitations with self-report or collateral report. How many times has a child just circled all zeros or a teacher circled "all the time" on the classroom rating scale of a disruptive child (also known as exaggerated response bias or, more commonly, "a cry for help")? The numerical scores may not be accurate, and clinical interpretation is required. For some children, it can be extremely exhausting to complete long batteries, especially for those with inattention problems. Therapists working with children should include other significant people in the assessment process such as caregivers, teachers, and extended family. However, this may also lead to disagreement between respondents. To further complicate, your observations of the child may similarly differ from reports from caregivers or teachers. While discrepancies may be due to lack of observational capacity, awareness, concern about the symptoms themselves, or sometimes rifts in the family system, discordance is normal (Hahn et al., 2019). The rating scale can at least provide a common language when talking about the presenting problem.

There are a few key considerations when selecting a rating scale. First, the instrument should have good validity and reliability to assess the child's presenting problems. These terms refer to the extent to which the instruments measure what they intend to measure (validity) and that they are consistent across time and across items (reliability). Secondly, ensure that the measure uses language and terms accessible to the child and family. They may have limited English fluency, literacy, or comprehension, especially if you are working with low-resourced or immigrant communities. As an alternative, reading items for the respondent, clarifying questions, and using pictorial rating scales can be helpful. Lastly, make sure the instrument is relevant and feasible for you and the client. Clinicians should be familiar and comfortable with the content of the measure so they can explain items to the child or caregiver.

Alisha's parents were asked to fill out a Vanderbilt questionnaire. "Oh wow, we don't really know how to answer these. It might make our child seem like a bad kid. But she really could use some help. The doctor said that she scored on the lower side on that long test they did."

Alisha's teacher also completed the Vanderbilt based on what she was seeing. "It can be really hard to get an accurate read on an individual kid. Our class size is big. I gave it my best shot, but I can really say that she does need something to help. She seems checked out during class."

Instruments can be used to monitor progress throughout treatment. The systematic and repeated use of instruments would fall under the category of measurement-based care. Measurement-based care involves the routine assessment of the severity of symptoms with rating scales. It also entails the use of assessment in treatment decision-making in order to generate clinician workflows, decision-trees, and uniform protocols for action (Aboraya et al., 2018; Lewis et al., 2019; Waldrop & McGuiness, 2017). Clients benefit from this approach through improved psychotherapy outcomes, and better identification of the patients who are improving and those who need additional services, as well as enhanced therapeutic relationships and better communication between providers and clients (Aboraya et al., 2018; Lewis et al., 2019; Waldrop & McGuiness, 2017). Clinicians stand to benefit because it enables them to monitor symptom reduction, improve collaborative care efforts among providers, improve the accuracy of clinical judgment, and enhance their decision-making process (Aboraya et al., 2018; Lewis et al., 2019; Waldrop & McGuiness, 2017).

Screening Versus Assessment

Time is a scarce asset of clinicians and the families, especially when under the constraints of the billable hour. In an ideal world, we would be able to spend hours with a family across multiple sessions to conduct a comprehensive assessment. However, the reality is that our time and the family's time is extremely limited. Thus, therapists have to consider the amount of time that will be dedicated to assessment. This involves deciding between employing short screenings versus comprehensive and longer assessment. Screening is an excellent strategy to determine whether to further assess a particular cluster of problems. For instance, the PHQ-2 (Kroenke et al., 2001) is a two-question screener for depression, and if the patient does not have a significant score, it saves the clinician time and resources that would be needed to complete a longer battery, such as the 47 questions on the full Revised Child Anxiety and Depression Scale.

One of these systematic approaches is known as Screening, Brief Intervention, and Referral to Treatment (SBIRT; SAMHSA, 2011). SBIRT is meant to be brief, universal, and targeted, thus making it a feasible and effective practice in a variety of settings like primary care or community health centers (SAMHSA, 2011; Agerwala & McCance-Katz, 2012). This approach may improve access to care and brief interventions for those who are at risk for developing or already experience a problematic behavior or disorder. It has mostly been used for detecting and intervening with substance use disorders (SAMHSA, 2011; Agerwala & McCance-Katz, 2012). In this context, the clinician may quickly determine the level of risk of substance use and the appropriate level of treatment based on that risk level (SAMHSA, 2020). The brief intervention aims to increase insight and awareness of the target behavior and to increase motivation towards change. Lastly, referral to treatment entails determining those clients who require access to specialty care. Some studies show that the screening and referral to long term care aspects of the model is effective for other conditions such as depression and trauma (SAMHSA, 2011; Sterling, Kline-Simon, Weisner et al., 2018; Russo et al., 2013).

What about those that need more than a screening or more than a brief intervention? Or, what if you received a client who was referred after the screening? Comprehensive assessment provides a deeper look at the client's presentation and attempts to evaluate the nature of the problem as opposed to its potential existence (which is the focus of screening). Assessment involves understanding the frequency, intensity, and duration of symptoms through further probing to determine alignment with diagnostic criteria or to gain clarification from the client about their initial screening responses. The symptom screening then is viewed while taking contextual factors into account. Risk formulation also requires contextual factors in light of the responses. For instance, if someone is assessing for suicidality, the suicidal ideations reported by the youth would be viewed against risk factors such as previous suicide attempts, recent self-injurious behavior, preparatory behaviors like writing a note or giving away possessions, or even consider things like the youth's age (e.g., adolescents have more likelihood of suicide attempts than children). It is not enough to base clinical decision making solely on the child's report of ideation. Risk factors are also not enough. Protective factors need to be considered, and, in the case of the suicidal child, are they engaged in treatment? Is there restricted access to lethal means? Do they have a support network? Furthermore, the level of functioning plays an important role in the assessment. Is the child having difficulty regulating their emotions, or do they require assistance from an adult or teacher's aide?

On a diagnostic level, let's say you use the PHQ-9 for depression (Kroenke et al., 2001), and the child scores in a clinically significant range. How much of that score is influenced by the items related to inability to concentrate or feeling fidgety and restless (i.e., items that could be better explained by ADHD)? This is a scenario where you would do a deeper dive into depression symptoms using a tool like the RCADS, or, if you are confident in the presentation representing a depressive disorder, you may want to rule out ADHD through a different battery of questions.

Global versus Specific Measures

Global rating scales cover various symptom clusters across diagnoses, such as including both internalizing and externalizing problems. There are global screeners such as the Pediatric Symptom Checklist (Jellinek et al., 1988) and the Strengths and Difficulties Questionnaire (Goodman, 1997) that can highlight which types of behaviors or challenges warrant further assessment. These global rating scales can also be called cross-cutting measures, as they "cut across" different symptom profiles. Specific measures focus on symptoms related to specific diagnoses (e.g., depression, anxiety, post-traumatic stress disorder). Clinicians often employ these instruments when they already have a clinical hypothesis regarding the issues experienced by the client or when they would like to rule out certain diagnoses.

Global rating scales or specific symptom screeners can indicate the need for a more thorough investigation into the child's problems. For instance, a child is given the PHQ-9 (Kroenke et al., 2001), a commonly used depression screener, and if they score above a particular clinical threshold, further assessment is warranted to understand the severity or specificity of the potential disorder. Scales such as the Revised Child Anxiety and Depression Scale (RCADS) (Chorpita et al., 2000) or the Mood and Feelings Questionnaire (Wood et al., 1995) look at self-concept, depressive thought patterns, and more detailed responses about difficulties, being adequate tools following the PHQ-9.

Collateral Information

Let's revisit the beginning of this chapter. If we are looking at the developmental systems lens, it can be overwhelming trying to cover all the domains and the potential information that could contribute to the presenting problem. This is where the art of assessment comes into play. Too little information, and we cannot have any certainty what is contributing to the presenting problem. Too much information, and we may still think we do not have enough to make a clinical decision. While too little information may lead to biases such as reliance on perceptions of recent or archetypical cases, there are also biases that may emerge from too much information. There is a measurement bias known as information bias, in which a researcher believes that more information is required in order to decrease uncertainty and guide clinical decisions (Lighthall & Vazquez-Guillamet, 2015).

With children, there are important thresholds, not necessarily in the overall amount of information, but from the information as it pertains to the different domains in a child's life. There are several other sources of information about the child we should include in the assessment beyond caregivers. School collateral is critical, whether this comes from school officials or teachers, or reviewing the report cards or attendance report provided by the caregiver. There are times when extended family members care for the child, so it would be important to incorporate their observations, particularly if the child lives with them or spends weekends or after school time with them. There can also be other prominent adult or community figures who can provide valuable information, such as prosocial behaviors on a sports team or in an afterschool program.

There are several ways to gather and incorporate collateral information in the assessment process when working with children. One way is to talk directly with caregivers, teachers, and other past or current health providers to gain more insight into the presenting concerns about the child. Additionally, several measures of social-emotional functioning and academic achievement often have separate forms for the child, caregivers, and teachers to fill out. For example, the Behavioral Assessment System for Children, third edition (BASC-3;

Reynolds et al., 2015) is a comprehensive assessment tool that includes child's self-report, caregiver and teacher rating scales, and clinician observations to gain a holistic understanding of a child's behavioral and emotional skills across school and home settings.

There are times when more formal and comprehensive testing is required that involves other professionals. For instance, psychological testing that covers intelligence testing or certain tests of adaptive functioning require clinicians with advanced training in assessment. At times, a medical etiology may be underlying the behavioral symptoms, so physical assessment and laboratory tests by a physician may be necessary.

Telling the Clinical Story from the Data

Clinicians are not just data collectors who facilitate checklists and measurements. Our clinical judgment is our key skill, and this judgment is on display most with the steps of clinical formulation, diagnosis, and treatment planning. These three components of the assessment process help to make sense of the phenomena presented by the child and family, as well as provide organization and explanation and offer a way forward.

Clinical Formulation

Formulation is the process of synthesizing a) information that was collected, b) considerations of a provisional diagnosis, c) understanding of the various risk and protective factors that could be contributing to the problem, and d) clinical reasoning guided by a theoretical approach. This synthesis creates the context or narrative of the client's presenting issue: the diagnosis (if any), contributing factors, and possible prognosis. This ultimately will lead to a differential diagnosis. The formulation serves as the foundation for treatment recommendations, as it explains the given diagnosis and provides background on how intervention should target particular parts of the problem.

In the biopsychosocial model, there are variables that encompass biological factors like medical issues; genetic or family predispositions; natal variables (e.g., prenatal exposure to substances, complications in labor and delivery, or early postnatal CNS infection); psychological factors such as the child's coping style and the family's belief system; social factors including peer influence, culture, and racial and ethnic identities; and community resources.

Part of the biopsychosocial formulation are the four Ps, which are part of the time-axis approach to organize risk factors in relation to how the factors unfolded across the client's history. Most of these factors come from the biopsychosocial domains, but the emphasis here is on the influence of timing and history of the given factors. Predisposing factors are those risk factors that create a vulnerability towards a negative health outcome. For instance, there may be biological vulnerabilities such as in utero exposure to substances. Precipitating factors are much like the activating event in the plot of the story; for instance, if a child has aggressive episodes, those episodes may have been precipitated by recent instances of victimization (e.g., being bullied) or life stressors such as a recent move, family death, or separation. Perpetuating factors are those that maintain the problem. For example, a child facing a death in their family may utilize avoidant coping strategies that, in fact, contribute to the presenting behavioral issues. Protective factors, on the other hand, are those that increase the likelihood of positive health or developmental outcomes. These can range from motivation for treatment, good physical health, to parental involvement, or a supportive school environment.

As mentioned above, recommendations should flow from the narrative created in the clinical formulation. There are times when extravagant intervention recommendations can miss the point, such as when manualized protocols and wrap-around services become the go-to intervention, when all the child may need is an IEP and a positive adult figure to develop social skills. Consider that structural interventions may significantly change a mental health presentation, such as if a child is facing homelessness and presents as anxious. Although Cognitive-Behavior Therapy is indicated to treat anxiety, it will not address the structural problem of homelessness that is driving the anxiety.

Relatedly, a thorough clinical formulation includes careful assessment of all cultural identity factors and influences. Patricia Hays (2001) introduced the ADDRESSING model as a framework that can be used to conceptualize the complex, multidimensional aspects of one's identity and how they can influence one's mental health and symptomology. Specifically, ADDRESSING urges the clinician to consider a client's Age, Developmental and acquired Disabilities, Religion, Ethnicity, Socioeconomic status, Sexual orientation, Indigenous heritage, National origin, and Gender to make a culturally responsive diagnosis and treatment plan.

Clinician Exercise

Read through the questions below. What is your hunch? What could be the outcome of the evaluation? What else would you need to know to confirm your hunch?

Alisha and her parents were given other rating scales to complete together. This allowed the team to ask more probing questions.

"It seems like she can't concentrate really well in class. How were her grades last year? Did she have any learning trouble? Would you say that she was ever an anxious child? Or does she seem like she’s always on the move?” asked the team.

Diagnosis

Diagnosis is the identification of an illness through examination of symptoms. The debate about diagnosis ranges from the politics of how diagnostic criteria are developed, what it means to diagnose someone with a disorder, and the overall utility of diagnosis given the broad variability and need for stronger evidence (Zachar & Kendler, 2007; Stein et al., 2010). The diagnostic process requires clinical judgment, and following a set protocol helps to improve accuracy. Differential diagnosis is the process of differentiating conditions that can share similar signs, symptoms, or features. It is important to differentiate mental health disorders to provide more adequate recommendations and treatment.

According to the DSM-5 Handbook of Differential Diagnosis (First, 2014), differential diagnosis requires six steps:

1. Ruling out Malingering and Factitious Disorder,
2. Ruling out a substance etiology,
3. Ruling out an etiological medical condition,
4. Determining the specific primary disorder(s),
5. Differentiating Adjustment Disorder from the residual Other Specified and Unspecified conditions, and
6. Establishing the boundary with no mental disorder.

With the first step, it is critical to understand if the client has motivation for deception in their presentation. Malingering is considered a goal, such as compensation or avoidance of responsibility or incarceration, that may be achieved by receiving a mental health diagnosis. Factitious disorder is considered a mental health disorder and is characterized by deception without obvious external rewards. Oftentimes, the client may enjoy being a patient and only knows how to be taken care of if they are seen as sick.

The second step looks at the potential influences of substances on the presenting problem. For instance, the effects of methamphetamine lead to manic- or psychotic-like symptom; however, the treatment is significantly different. Step three works in a similar way by attempting to rule out if a medical condition is the underlying cause for the behavior. For instance, someone who may appear anxious may have a hyperactive thyroid, and treatment should focus on the endocrine system.

Once these preliminary factors are ruled out, the clinician moves to step three to consider the primary disorder that could explain the symptomatology. For instance, a clinician may observe low mood, irritability, and decreased sleep in a client and consider a depressive disorder. Step five attempts to understand if there is impairment related to a known stressor (like an adjustment disorder) or if there is not enough specific information, which then would point to one of the residual Other Specified or Unspecified categories (American Psychiatric Association, 2013). The last step is attempting to discern whether there is enough evidence that the impairment is significant to justify a mental disorder. Not all mental health issues are disorders. Clinical judgment is required to distinguish the boundary between pathology versus normative behavioral response.

When making a diagnosis, it is important to consider the implications that the diagnosis can have for the child in terms of gaining accessibility to systemic supports and services. The assessing clinician should be knowledgeable of the laws and regulations related to special education as a psychoeducational assessment and diagnosis can often be a determining factor on whether a child is eligible for special education services. For example, the majority of school districts in the United States use guidelines in the Individuals with Disabilities Education Act (IDEA) to determine eligibility for special education services (U.S. Department of Education, 2022). IDEA was a piece of legislation that was passed in 1975 to legally guarantee a free appropriate public education in the least restrictive environment, as well as related services such as occupational therapy to all eligible students who possess a disability falling with one of 14 disability categories. Notably, there has been a history of discrepancies between IDEA guidelines and the DSM regarding criteria for developmental disorders such as autism spectrum disorder (Tsai, 2014). The most recent DSM-5 attempted to address some of these discrepancies for autism by revising the diagnostic category from Pervasive Developmental Disorders in the DSM-IV to Autism Spectrum Disorder and removing subtypes of ASD including Asperger's Disorder and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). This decision has been met with some controversy, as some have argued that it may disqualify higher functioning children with ASD from receiving a diagnosis that would meet eligibility criteria for IDEA (Grant & Nozyce, 2013; Prykanowski et al., 2015). Diagnostic criteria are constantly being revised as we have more nuanced understandings of psychiatric disorders, and it is imperative that clinicians stay up to date on the most current information while also considering how these criteria may be impacted by cultural context.

Treatment Planning

The treatment plan should start with the end in mind; clinicians should ask themselves, “what would tell me this client no longer needs treatment?” That is, the clinician should define specific treatment goals and indicators that would address the issues identified in the assessment. There are a few main considerations. One is time and figuring out how to benchmark progress. There are long-term goals which tend to be more global, and short-term goals are typically more specific aspects or behaviors. Another consideration is scope; that is, whether or not the goals are achievable through counseling work or changes in the environment such as implementing school supports, improving parenting, and increasing access to extracurricular activities. Lastly, treatment plans should consider the level of risk and functioning; for instance, acute crises, significant safety concerns, and issues that have a high impact on functioning (e.g., depressive symptoms that prevent adequate eating or sleeping) should be prioritized.

All of these considerations underscore providing the best treatment in the most efficient way, and we want to be precise with our interventions and other palliatives. Precision care has its origins in medicine, but its approach can be applied to psychosocial treatments. Precision care is understanding which approaches will be effective for particular patients based on their genetic, environmental, and lifestyle factors (MedlinePlus, 2020). As psychosocial clinicians, we will not administer genetic testing, but we can understand genetic influences when capturing a family history. The approach is only as good as its planning and execution. Once the approach to care is clearly identified, goals should be just as precise. The SMART goals technique is a way to gain specificity and relevance with goal setting. SMART stands for Specific, Measurable, Achievable, Realistic, and Timely. Goal setting can only go so far. Matching the goal with the appropriate intervention puts the treatment plan in motion.

Typically, when elaborating a treatment plan, a clinician tends to consider the child problem area or what is known as a disorder-driven approach (Deleiden & Chorpita, 2009). For the clinician, it is important to understand the common practice elements of EBPs as well as understanding which common elements are most representative of the approach for a particular disorder (Deleiden & Chorpita, 2009). These considerations will guide the clinician towards designing a plan that can be tailored to the child’s distinct presentation and also be responsive to the changes that occur in client presentation over the course of a treatment episode (Deleiden & Chorpita, 2009; Ng et al., 2016). Furthermore, because clients’ needs vary, it is critical for the clinician to match particular EBP components to each client, in order to enhance the uptake and use of coping strategies or other potential palliatives for the youth to use consistently (Ng et al., 2016).

Clinical Dialogues: Talking about Assessment of Youth with Emily Hunt

Sean E. Snyder, LCSW: The clinical dialogue around assessment is with Emily Hunt, who finds her home in counseling psychology. So, Emily, could you start with introducing yourself, and how does assessment fit into your clinical practice?

Emily Hunt, MA/MSEd.: I'll start off by saying, I'm a trainee as a fourth-year doctoral student in counseling psychology. I am still learning about how to incorporate assessment into my clinical work, but what I've really appreciated about assessment is that I mostly work with youth and their families. Assessment has really been helpful in allowing families to feel empowered in understanding their presenting concerns about their child. So, this past year, I worked at the Child Mind, and I did an assessment-focused externship at their branch called the Healthy Brain Network. We provide free assessments to members of the community in New York City. I worked with a range of families from diverse backgrounds and helped them navigate the assessment process in order to help their children get services that they needed in and outside of school. At Child Mind, I did full neuropsychological assessments, and these assessments can really provide a lot of support for diagnoses, which can help families feel empowered as they navigate mental health and the school system.

Snyder: It can definitely open a lot of doors for folks, and then that also gives relief, clarity, or even the knowledge of a rule out; at least we know it's not X, Y or Z thing. We will talk about assessment in more routine care settings, but you mentioned neuropsychology, which we don't delve into with this book. What are neuropsychological assessments? What's their utility?

Hunt: These evaluations are probably the most comprehensive type of evaluation a child can get because they include both psychological and psychoeducational assessment, and we are testing many domains like behavioral, cognitive, neurological, and motor functioning. We're measuring things like attention; memory; visual, spatial, and motor abilities; language; learning; personality; emotion; and social and emotional functioning. One way that this has been phrased to me is through this example: Let's say that you have a child with some learning difficulties. A psychoeducational assessment might help to determine if a child qualifies for special education service, but a neuropsychological evaluation will tell you why they need those services. For instance, they may qualify for services, but the neuropsychological evaluation can pin down that this child has a visual processing difficulty or a language deficit. It could very well be anxiety, or it could be a weakness in working memory. So, it really helps to understand why a child needs particular support and services.

Be transparent about the process and say that for the most part, an assessment is not a diagnosis.

Snyder: It gets on a very granular level to tailor interventions, to match them to the specific supports that they need. Thank you for explaining that very unique type of assessment. So now onto our general assessment found in routine care assessment. One of the core themes of the book is engaging families within the scope of the chapter topic. So, for this dialogue, how do we engage folks around assessment? Do you prep families before doing an evaluation? Or are there any engagement strategies you have with assessment when you think about the nuances of presentations across the lifespan?

Hunt: Open communication with the family is probably one of the most important things, especially if you're working with families from more historically marginalized backgrounds in psychology. When you're talking with families beforehand, what's most important is to keep going back to the referral question: what is the family or the child's main presenting concern? How long has it been going on? How's that impacting functioning? And how often are the symptoms happening? As you're talking with the family and prepping them for the assessment process, be very clear about your rationale for why you're evaluating each domain that you're choosing measurements and assessments for. Taking the mystique out of that process is really important, and you do that by going back to the rationale. The family can really understand why you're doing each thing and what the purpose of each thing is.

Snyder: I think of the imagination for children and families when they envision psychological testing and assessment in those popular depictions of a child wearing an EEG cap or that it is an 8-hour multiple choice standardized test. It's being clear, and I'm sure that fosters collaboration.

Hunt: If you have a client in psychotherapy, it can be very helpful that you are not the person that's doing the assessment as well. It separates something that can help the treatment from being a part of individual psychotherapy treatment itself. For instance, things like more cognitive intelligence testing, which is something that is not meant to be done in a psychotherapy session. Keeping those roles separate is very helpful with the overall process of helping a family.

Snyder: Diagnostics is very different from assessment of needs within psychotherapy. Practitioners get the referral, but they have to assess how can my particular approach or service help this client with their particular problem. It's always an ongoing process.

Assessment is different with different age groups. The common elements about transparency and openness are great standards for any age group, but do you have any nuggets of wisdom when it comes to assessing a 5-year-old versus a teenager versus a transition age youth?

Hunt: The biggest difference I saw was that the middle schoolers and high schoolers were really nervous that this was a test in school, that they were being graded. Or they were in that mindset that there was a consequence of taking this assessment. I will be really open and not frame it as a test. For example, I may say to a youth, "We're trying to understand maybe how your brain works, and I know that you and your family were talking about how you're having some difficulty in math or paying attention in school. Doing these activities is actually going to help us understand you better and find the best ways that we can help you." Framing it as something that can really, really help them gets buy-in and gets their guard down.

Open communication with the family is probably one of the most important things, especially if you're working with families from more historically marginalized backgrounds in psychology.

Snyder: Reminds me a lot of the teens I see who automatically think you're judging them or say, "Stop analyzing me!"

Hunt: For older clients that have a little bit more capacity to understand what a psychiatric diagnosis might mean, again, be transparent about the process and say that for the most part, an assessment is not a diagnosis. If you have a certain score on a test, it does not mean that you have a diagnosis; that's not how these assessments work. It's really about the whole picture. A scale or test is one piece of the puzzle that can help us understand the whole picture.

Snyder: As youth get younger, parent involvement in assessment and treatment should go up. Collateral is particularly important. I work a lot with child-welfare-system youth. What's your approach like when we have blended families or nontraditional families?

Hunt: Trust the caretaker of the child as the expert or the child as well. It's much of the same with more traditional families: allow them to tell you their story and what they're observing, ask a lot of open-ended questions, and give them the ability to tell you what's going on in their own words. And with blended families, or nontraditional families, unfortunately, psychological assessment and psychoeducational assessments have had a history of being marginalizing and oppressive towards certain groups of people, especially people of color, communities of color, LGBTQ communities. When you're working with families that are less traditional, make more of a concerted effort to really collaborate and destigmatize the assessment process. For blended families, collateral is even more important to especially make sure everyone feels like they're included in the process for those that want to be included in it.

Snyder: It's a lot about participation, the bigger picture, not making assumptions. Any last things with the engagement with assessment of youth?

Hunt: Speaking of the bigger picture, be transparent about who you are including in obtaining collateral, like a school member, or be transparent about who is getting your report if it is for a court setting. Make sure there are connections so that all this valuable information can further engage a child in care.

Snyder: Now what about predictability for yourself? How much preplanning goes into an assessment for you versus how much is it based on run-time adjustments?

Hunt: It's mostly preplanning. There is typically a triage or intake interview that can give you a sense of what the presenting concerns are and what they're looking for. For a neuro psych assessment, there are standard assessments that you do in each area of functioning. Once you get a picture of what the symptoms are in each area of functioning, you can start building a case conceptualization. Typically, you have a pretty good sense of what you're going to be administering before you start the process.

Snyder: Right, it's tying all this back to the rationale for the assessment and trying to be targeted.

Hunt: The practical issue is that assessments are really tiring because they take a long time. You don't want to keep adding assessments as you go along because it's probably going to affect how the clients report their symptoms. If they are exhausted, you're not going to get an accurate picture of what's going on.

Snyder: And the clinician can get exhausted too and that impacts the assessment process. So, let's look at the opposite side, the fun of doing assessments. Do you have any favorite assessments you do? And then go-to batteries you use?

Hunt: I love administering the Purdue Pegboard test that tests fine motor functioning. The child puts pegs in a board in a row, and then they do their other hand. That test usually engages clients, especially younger clients in the assessment process, because they think this is fun. The Bender Visual-Motor Gestalt Test is also a really great one to engage clients, where the child looks at pictures on a card, memorizes them, and then draws them. I like more tactile assessments because you can they see clients getting really engaged in them, and it helps a buy-in. As far as the go-to batteries, for instance with emotional behavioral functioning, the Beck inventory is usually a go-to.

Supervision helps to make sure that you're getting another person's perspective [to help with] case conceptualization created specifically for that client.

Snyder: That paints the picture of assessment as not checking off boxes. I like those interactive tests; reminds me of the mini mental status exam, where the client draws shapes or does the three- step instruction.

Those tactile tests make me think of lifespan considerations and seeing how to engage different age groups or what goes into assessments for each group. What does your assessment approach look like, considering that there are different needs across the lifespan?

Hunt: The first things that come to mind are engaging teachers and parents. If you can speak with a teacher and get a sense of the child in the classroom, and then talk with the parents around the child at home, that can tell you so much, especially if there's incongruence in their reports. Also, if the child has been in therapy, being able to talk with the therapist can be really helpful collateral to have. There are assessments that are specifically designed to get information from these sources; the Behavior Assessment System for Children (BASC) is an example that can get those different viewpoints.

Snyder: So, after we get all this data, we need to formulate. What does a good formulation entail?

Hunt: There are different ingredients to it: a really thorough intake interview of background history, having a sense of what functioning looks in multiple settings, interpreting the data from assessment instruments or the child performance on the tests, and then noting if there is anything particular that's happening during the day that could be impacting the child's participation in the assessment (for instance, were they especially tired or hungry, were there any stressors right before the test, or are they in a great mood and were really engaged in the process). Behavioral observations are huge. Make sure that you're making observations about the client's behavior throughout the process, especially in a case like a child with performance anxiety.

Snyder: Absolutely, those contexts of what literally is happening in the room are huge. I've known youth in the justice system being assessed while being shackled at court. That's a huge factor in how that interview goes. Then we need to think of the big picture: what's happening in a child's neighborhood, what's the temperature of current events.

Hunt: Absolutely, all to make sure you're really getting the whole picture.

Snyder: In treatment, there will be ongoing assessment. For instance if there is a measurement-based care model being used in a clinic. Do you see measurement-based care being done in training programs? Is it being used in the field in the settings you're in?

Hunt: My initial training was in a person-centered psychodynamic lens, which can discourage use of measurements throughout treatment. As I've switched to working more from a behavior orientation, like with CBT and DBT, measurements are used quite often. In my CBT cases, we'll do a mood check first thing. How would you rate your overall mood on a scale of one to 10? It helps the client track their own process, and it helps the therapist as well.

Snyder: You bring up a really good point, too, that points to my own bias because I am very CBT oriented. I realize that all the readers out there don't have the same theoretical perspective as me. What would you say for folks in a more dynamic orientation if they want to track progress?

Hunt: In that perspective, most of the tracking is supervision based and thinking about your countertransference. Progress tracking is a little more subjective because clients gain insight into their defense mechanisms, and so there are more therapeutic markers or signposts in sessions, like when the clients becoming more self-aware of those insights and bringing them up in sessions; you may notice moments of catharsis. So, you might not be measuring them, but supervision can be the way to help you track countertransference, track insights, cathartic moments.

Snyder: Great points, and we need to merge both our subjective judgment with the more objective measures. Both really inform each other, so that's critical to note; any objective measure does require subjective interpretation and clinical judgment.

This can lead into how our biases can develop too. With seeing a lot of cases, someone can develop a set of case history or archetypes. How do you buffer against bias your own personal bias with case histories, other types of anchoring biases? How do you keep yourself sharp?

Hunt: Supervision is one of the best ways to do that consultation, and supervision helps to make sure that you're getting another person's perspective. Case conceptualization is so key because you are creating specifically for that client. Even if they do remind you of a previous client, when you conceptualize that case uniquely to that person, it prevents the bias a little bit more. As we mentioned with dynamic theory, the idea of doing your own work and noticing counter transference and transference is useful.

Understanding your own biases that you have in terms of stereotypes that you might have internalized without realizing it, that you might be projecting onto the client. Be honest with yourself about examining those biases and how assessment might be affected by those biases. For instance, you may see that gender non-conforming clients or transgender clients may score higher on paranoia subscales of personality assessments. If you look at the societal context that they're in, where they're facing extreme discrimination for these identities, the paranoia makes sense. When you're conceptualizing the personality instrument in that way, it can be really pathologizing if you don't examine the societal context and some of your own biases that you might have.

Snyder: That was a very developmental systems perspective right there, considering macro forces and how that influences an individual assessor/ clinician behavior and how those forces produce a behavior in a client.

Our time is coming to an end soon, so I think it would be great to hear more about any last clinical nuggets you have. Are there things you wish you knew earlier in your training?

Hunt: Counseling psychology, as a whole, is not known as much for using assessment a lot, so I was really nervous going into it, thinking that I wasn't going to enjoy it, that it was going to be too data driven, too numbers focused and pathologizing. After experiencing the process and seeing how much it helps, it is so powerful. I think of the first client that I had an assessment with a client, who was a boy who that we ended up giving a provisional diagnosis of autism spectrum disorder. We were able to see how relieved the mom was to finally hear that from someone, that something that she'd been, suspecting all along but felt like the school wasn't helping her. Being able to go through the assessment process and really help him get the services that he needed really highlighted how helpful assessment can be in opening the door for opportunity and growth. As an aside, I wasn't expecting administering them to be fun. When you build a nice rapport with your client, it's a really fun process, and you can develop a nice bond.

Snyder: It's a very intimate experience when you're asking all these types of questions. When we work with kids, it's helpful to remind us that we can have fun; we don't need to be so serious in order to get the work done. We might need to let our fun side out to really join with the client, knowing that it is about them and hopefully opening those doors, hopefully being an empowering gatekeeper.

Things Clinicians Should Know

In applying a developmental systems lens to assessment, diagnosis, formulation, and treatment planning, we can observe the variety of techniques and tools depending on the developmental moment of our clients. Across the lifespan, clinicians should understand normative ranges and the various ecological systems that interact with the child. Check your understanding with these key areas:

- Age-Specific Assessment
- Screening Versus Assessment
- Formulation
- Diagnosis

In the chapter that follows, we will delve into intervention approaches, selecting an evidence-based practice, and how to match client need with clinician competence.

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4

Chapter

Psychosocial Intervention and Treatment: From Problem to Action

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Charlie is an 11-year-old who is struggling with a lot of mental health challenges. Their grandma says that they feel overwhelmed a lot, talk back to their grandparents all the time, don't feel like doing anything, and stay up "practically all night." "We went and got an evaluation, and they gave us a lot of these diagnoses: anxiety, depression, PTSD, ODD. I don't know what that all means, but there's a lot going on. Charlie really doesn't want to do therapy because they think they are going to be in it for years and years. That's what happened to their sister, she took meds for a bit, saw a lot of different therapists. We're just hoping to get off on the right foot this time."

Introduction

The previous chapter discussed assessment, diagnosis, and formulation. To reiterate here, assessment and intervention go hand in hand. While that may appear obvious, the reality is that in community settings, treatment options may not be appropriately matched for reasons such as clinician training and competence, availability of a broad range of evidence-based practices (EBPs) at a clinic, or even limitations of insurance authorization (e.g., attempting to deliver cognitive-behavioral therapy (CBT) in an ecosystemic structural family therapy program). This chapter aims to equip clinicians with a baseline understanding of psychosocial intervention. The chapter will be broken down into sections about treatment modalities, theoretical approaches, and responsive treatment.

A Cursory Note About Evidence

Evidence-based practices (EBP) are interventions supported by evidence consistently demonstrating that the intervention is effective in improving client outcomes (Drake et al., 2001). The term evidence-based practice was articulated in Sackett's (1997) definition of evidence-based medicine as the conscientious, explicit, and judicious use of evidence in care decisions for patients. This definition includes three core components for decision-making: 1) the best external evidence, 2) the individual practitioner's expertise or competence with the intervention, and 3) the patient's preference regarding their care (Sackett, 1997).

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> *1) the best external evidence,*
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> *3) the patient's preference regarding their care.*

There are varying levels of external evidence based upon strength. The original tiers of evidence strength from Sackett (1986) comprise the following: Level 1 includes large, randomized control trials (RCTs) with clear cut results; Level 2 includes small RCTs with unclear results; Level 3 includes cohort and case-control studies; Level 4 includes historical cohort or case-control studies; and Level 5 includes case series and studies with no controls. Different professional bodies and journals have adapted these levels (Burns et al., 2011), but RCT studies are consistently considered the gold-standard for evidence. Southam-Gerow et al. (2014) present another way to view levels of evidence across the following tiers: Level One: Works Well, Well-established Treatments; Level Two: Works, Probably Efficacious Therapies; Level Three: Might Work, Possibly Efficacious Therapies (i.e., “promising therapies,”); Level Four: Unknown/Untested, Experimental Therapies; and Level Five: Does Not Work/Tested But Did Not Work. As you read through the chapter, keep in mind the three tenets of EBP, and hopefully this baseline understanding will allow you to be more confident in matching client need with available interventions rooted in the scientific literature.

Intervention and Treatment Modalities

When working with a child or adolescent, be mindful of *who* you are treating, *where* you are treating them, and in *what capacity* you are intervening. The following section covers individual versus family approaches, considerations of setting (particularly the school setting), and the scope of how to intervene with a youth.

Who’s Involved: Individual Treatment

Individual treatments focus on the youth themselves. The developmental systems approach should still be present here; even if treating individually, the youth is situated in a particular setting and among a constellation of other ecological and developmental factors. Individual treatments discussed in this chapter fall under three categories: behavioral, cognitive-behavioral, and psychodynamic, and these categories do not represent individual intervention in its entirety.

We discuss theoretical approaches in more detail later, but here is a brief summary of the major types of therapies. *Behavior therapy* involves techniques or protocols that have some elements of classical conditioning or operant conditioning (Donnelly, 2015). These models are based on stimulus-response pairings, intended to increase or decrease behaviors (Donnelly, 2015). Techniques under this umbrella of therapy include behavior modification, behavioral activation, exposure, desensitization, and parent-training. (Donnelly, 2015) *Cognitive-behavioral therapy* (CBT) builds upon behavioral therapies and emphasizes the cognitive mediation that occurs between a stimulus and response (Rice, 2015; Sperry, 2015). CBT has been widely researched and is known to be effective for various conditions such as anxiety and depressive disorders, substance use disorders, attention-deficit/hyperactivity disorder, externalizing disorders, and psychosis (Rice, 2015; Sperry, 2015). *Psychoanalytic or psychodynamic* therapies tend to focus on insight building, with the assumption that increasing insight and awareness about patterns of behavior can lead to changes in those patterns (Bishop, 2015). *Transdiagnostic approaches* synthesize different theories and protocols to broaden the coverage of treatment (Barlow et al., 2004; Ehrenreich et al., 2009) Again, these approaches will be detailed later in the chapter. It should be noted that a review of all modalities is beyond the scope of this chapter.

Who’s Involved: Family Involvement and Family Therapy in Treatment

Family involvement is a general clinical rule for working with children and adolescents. Family work will vary by the developmental age of the child or youth and the extent to which engagement with the child/youth and involvement of the family is possible. As children get older, especially after age 13 or 14, respecting the youth’s wishes is usually the most important consideration for how much to encourage family involvement. We should be able to build and maintain our relationship with the family and youth if we understand some of the family dynamics. Assessment of family functioning is always helpful, even if you choose to work individually with a child. Every family is unique with its own blend of strengths and competing demands, and it takes some effort, engagement, and partnership to make things work. The definition of family may vary, too, so be mindful of how families organize themselves. Family-based therapies operate through engagement of the family systems and viewing child behavior as the process of interactions between family members (Tabbi, 2015).

There are different approaches to family-based therapy. Focusing on parenting alone has shown great impact, with studies evidencing that parent involvement in therapy is a moderator for child conditions in general (Hoagwood et al., 2010), and specifically for concerns such as trauma (Gutermann et al., 2016), child internalizing disorders (Diamond et al., 2016) and child externalizing disorders (Ward et al., 2016; Baldwin et al., 2012; Woolfenden et al., 2002). Involvement can include direct parent-management training such as Parent Child Interaction Therapy (PCIT; Ward et al., 2016), incorporation of parents into individual treatment protocols (Gutermann et al., 2016; Epstein et al., 2017; Cohen et al., 2010), or work with child-parent dyads (Diamond et al., 2016). Social-ecological models of family therapy, such as Multisystemic Therapy, have demonstrated favorable results for families with children at risk for out-of-home placement (Henggeler & Schaeffer, 2016), and Functional Family Therapy has consistently demonstrated effectiveness for children with conduct problems (Hartnett et al., 2016). These family interventions are delivered with the family unit and usually conducted in the home. Thus, whether there is a focus on the parent or on the unit as a whole, families are the context for youth treatment in family therapies.

Be mindful of who you are treating, where you are treating them, and in what capacity you will be intervening.

Where's It Happening: Settings and Contexts

Youth often spend a majority of their day at school, so it is important to understand how to harness the natural setting of the school as a place for mental health promotion. Meta-analyses indicate that when compared to community-based services, school-based services are more accessible, decrease disparities in service use, and keep youth in treatment longer (Sanchez et al., 2018; Barnes et al., 2014). The treatment gap especially affects racial and ethnic minorities who tend to receive less treatment and less effective treatment compared to their non-Latinx White peers (Barnes et al., 2014). Intervention in schools spans treatments such as Cognitive Behavioral Intervention for Trauma in Schools (Stein et al., 2003), social skills interventions, behavior therapies, brief counseling, or intervening in a way to support the child as a whole through functional interventions. Functional interventions are those that focus on the relationship between the youth and the environment, oftentimes the school environment (O'Neill et al., 2017). Considering our developmental systems focus, our direct practice occurs in the context of the various systems in a youth's life, so functional intervention is essential. These types of interventions can arise through formal plans like Individualized Education Programs (IEPs), Section 504 Plans (which incorporate changes from the Americans with Disabilities Act (ADA) Amendments Act of 2008), or other school accommodations.

Functional work directs us to take a step back to look at the overall context of a child's life. There are many other domains to consider when delivering interventions that broadly impact functioning. As a clinician, you may be the one to initiate discussions about attending to physical health (e.g., ensure connection to pediatricians, dentists); sexual health (e.g., direct psychoeducation or connection to healthcare agencies with the collaboration of the parent); prosocial and community engagement opportunities, (e.g., linkage to school programming, mentoring, opportunities for employment, volunteering, civic engagement), and accessibility across these domains (e.g. considering disability supports).

Teletherapy Considerations. The onset of the COVID-19 pandemic has led to the rapid global adoption of telehealth and teletherapy practices (Moreno et al., 2020). Overnight, community mental health providers have been compelled to turn to video or audio-conferencing platforms as their primary and, in many cases, only method of delivering therapeutic services to their clients. While teletherapy has long been supported as an effective method of delivering EBPs for various mental health disorders, including depression, post-traumatic stress disorder, and serious mental illness (Backhaus et al., 2012; Miu et al., 2020), it was not widely implemented prior to the pandemic due to provider concerns about client safety and privacy, negative perceptions of its feasibility and acceptability, and lack of financial and reimbursement incentives (Cowan et al., 2019). While the shift to telehealth was unprecedented and sudden, maintaining teletherapy as a part of routine care beyond the crisis may lead to long-term advances in children's mental health service delivery and reductions in mental health care disparities. Teletherapy has the potential to increase access to evidence-based mental health care for marginalized communities, especially for socioeconomically marginalized, disabled, or rural populations with barriers to transportation or low proximity to quality mental health providers (Kataoka et al., 2002; Wright et al., 2017). Recent literature has identified several vital recommendations to support the continued use of telehealth services, such as reimbursement through permanent policy changes, training of mental health professionals in telehealth topics (e.g., technology, administrative aspects, clinical engagement), and technical and other support provision to clients using telehealth services (Lombardi et al., 2021).

Additional research is needed to understand who should implement these supports and at what level, as well as how these supports might address barriers to teletherapy. Furthermore, certain therapeutic strategies may need to be adapted or supported by additional telehealth resources (e.g., visuals such as PowerPoints or videos, interactive functions like Zoom whiteboards and screensharing, and use of chat functions) to increase therapeutic engagement, clarity, and efficacy in teletherapy settings (Craig, Iacono, Pascoe, & Austin, 2021). Lastly, it should be noted that teletherapy may not be an effective method of delivering EBPs for certain populations who have difficulty using or engaging in telehealth services, such as older clients with low technological literacy, clients with hearing loss, and young children.

"We did a lot of family therapy in the past for Charlie's sister, and it's her that needs the help! Same with Charlie, I really hope the therapist focuses on them to get them the attention they need," said Charlie's grandpa.

"It sounds like you all didn't get what you were looking for," replied Charlie's therapist. "You and I can work together to see how we can fit your needs to what treatments we know work for kids. Some of it can involve family work, and Charlie will have their own work to do too. We also will have to tackle a few problems here, so we will have to be talking a lot about progress so we can shift course as needed."

Theoretical Approaches to Intervention and Treatment

The developmental systems lens considers ecological and developmental aspects of caring for youth. Within this, a clinician may have a particular or eclectic theoretical orientation regarding theories of change.

Psychodynamic

The psychodynamic approach has roots in the theory developed by Sigmund Freud. The core aspects of this theory are that human behavior and functioning can be explained by dynamic drives of a human being towards pleasure, aggression when well-being is threatened, mastery to influence the environment, and competence (Bishop, 2015; Walsh, 2014). In psychodynamic theory, these drives are understood through the functions of three structures of our psyche, which Freud labeled as the id, ego, and superego. The id contains drives whereas the superego functions as the moral compass and ethical center of the psyche. The ego is the glue that holds these structures all together, and it attempts to bring balance to the psyche through defenses that can help facilitate the activities of our psyche. These defenses include (1) awareness of external environment, or the actual perception of world; (2) judgment, or the capacity to choose behaviors likely to promote our movement towards goals; (3) sense of identity, or the coherent physical/psychological sense of self; (4) impulse control, or the ability to distinguish between primary (drives) and secondary (planned) mental processes; and (5) thought process regulation, or the ability to remember, concentrate, and assess situations to initiate appropriate action (Bishop, 2015; Walsh, 2014). For more on Freud and his influence on psychology, consult the open access materials of *Psychology*, 2nd edition.

Direct Applications. In working with children and adolescents, psychodynamic approaches focus on insight building and on the emotional life of the child. Play therapy is suggested to be heavily influenced by psychodynamic theory through its use of projective techniques (Kool & Lawver, 2010). Another treatment concept influenced by psychodynamic theory is understanding a child's attachment style in early relationships, which can dictate how a child attempts to get their needs met from their caregiver. A child's early attachment relationships can have influences on the quality of that child's later relationships in adulthood.

Behavioral

Transdiagnostic treatment merges common elements of protocols that can have greater coverage of problem areas with generalizable therapeutic takeaways.

Behavior theory focuses on increasing or decreasing behaviors based on stimulus-response pairings (Donnelly, 2015). A behavior therapist helps the client learn a new response to a stimulus with a previously undesired behavior response. One example is exposure therapy for a phobia or trauma. It is common for a client to engage in an automatic avoidance response of the feared stimulus, and the momentary relief reinforces the behavior of avoidance. The problem with this cycle is that the client will continue to avoid the feared object, which can in turn lead to functional impairments. Exposure therapy attempts to break the avoidance cycle so the client can learn that anxiety is not dangerous and that the feared object is not inherently dangerous.

Direct Applications. Exposure is one type of behavioral approach to therapy, and other common approaches include use of a token economy (Donnelly, 2015) that resembles a points or rewards system for engaging in desired behaviors. This is used frequently in parent training-based therapies, an approach focused on using behavioral learning principles to modify undesirable behavior (Baer et al., 1968). Behavior activation is a technique commonly used with clients with depressive symptoms; for instance, exercise or socialization can be a way to break a cycle of inactivity or anhedonia.

Cognitive and Cognitive-Behavioral

Cognitive theory has many influences: pragmatism where challenges are naturally met with inquiry or problem solving; logical positivism which focuses on verifiable information, analysis and clarification of language; information processing theory which centers on processing information and on correcting cognitive “errors” (Rice, 2015; Sperry, 2015, Walsh, 2015). Cognitive Theory was developed by psychiatrist Aaron Beck in the 1960s (Beck et al., 1979), and his legacy lives on through the Beck Institute.

Core components of cognitive theory include a focus on cognitions, which span our beliefs, assumptions, expectations, and ideas about the causes of events, attitudes, and perceptions in our lives. It also includes emotions that are physiological responses that follow cognitive evaluation of input, as well as activating events that produce a belief or thought that in turn produces an emotion reaction or action (Rice, 2015; Sperry, 2015, Walsh, 2015). In other words, this model indicates a linear process wherein an activating event (or stimulus) is filtered through a belief about the event, and results in a consequence by way of an individual's emotional reaction or action based on their belief (Rice, 2015; Sperry, 2015, Walsh, 2015). This model extends beyond behaviorism, where there is only a stimulus and a response. In this model, cognitions mediate the relationship between the stimulus and a person's response. Furthermore, in cognitive theory, a person develops core beliefs about themselves, others, or the world as a result of their life experiences, which can become the lens through which they view the world (Walsh, 2015).This potentially gives rise to frequent unhelpful or negative interpretations of events.

As mentioned previously, cognitive-behavioral therapy (CBT) builds upon behavioral and cognitive theories (Rice, 2015; Sperry, 2015). This theory considers a bidirectional relationship between thoughts, feelings, and behaviors (Walsh, 2015). If one can reframe or balance unhelpful or maladaptive thoughts, then there can be a resultant impact on feelings and behaviors; conversely, a behavior change can exert influence on thoughts and feelings.

Direct Applications. When working with thoughts, some basic approaches involve psychoeducation about the cognitive model and the cognitive triangle. The cognitive triangle demonstrates the bi-directional influence of thoughts, feelings/emotions, and behaviors. Cognitive coping strategies center on understanding and identifying automatic thoughts, particularly automatic negative thoughts. These thought types include cognitive distortions or "thinking traps," such as overgeneralization, all or nothing thinking, shoulds/oughts, or filtering. For more about these types of thoughts and explaining them to children, consult Trails to Wellness. Understanding someone's thoughts can help to understand the notion of managing positive or negative self-talk. Thought records can be helpful tools for clients to develop awareness of and insight into their own thoughts, feelings, and actions, as well as any patterns that emerge. Behavioral approaches have been described above, so consider now, what are the effects of behavior changes on someone's thoughts?

Solution-Focused

Solution-focused therapy is considered a postmodern theoretical approach that borrows from other theories, with the overarching goal to develop solutions, discover exceptions to problems, enhance awareness of strengths, and learn to act and behave differently (Walsh, 2014). It is a brief treatment model that focuses on changing, not curing, the most pressing (not all) concerns of the individual, where problem origins are not essential for intervention. This approach theorizes that people have learned behaviors from their family of origin and develop a limited range of response patterns in relation to life problems; further, it theorizes that language shapes reality (Walsh, 2014).

Direct Applications. Assessment and intervention can occur simultaneously.

Techniques used within the solutions-focused approach include (1) employing a scaling exercise to gauge client willingness to invest effort into problem resolution; (2) refraining or ignoring limitations and negative attributes; (3) asking strengths-reinforcing coping questions such as "How have you been able to manage so far? How has this not gotten worse?"; (4) using exception questions such as "What was different in the past when the problem wasn't a problem?" or "What are you doing when the symptom isn't happening?"; and (5) guiding the client to imagine a life where the problem is no longer there and work towards steps to actualize that imagined life. For more on different approaches, consult the work of the Institute for Solution-Focused Therapy.

Narrative

Narrative therapy is another post-modern approach that borrows from various theories and philosophies such as existentialism, symbolic interactionism, multiculturalism, and postmodernism. It focuses on the subjectivity of the individual, the possibility of choice and freedom, and the understanding of knowledge and power dynamics that contribute to grand narratives that are rooted in social context (Walsh, 2014). The overall approach of narrative therapy is to help the client recognize that they are already engaged in an ongoing process of constructing a life story, and therapy becomes the opportunity to reauthor a story that uncovers cultural influences, unique outcomes, and "sparkling moments" of the person's life.

Direct Applications. Narrative therapy theory suggests that the problem is the problem. Techniques include externalizing the problem from the person and focusing more on insight rather than on problem solving, as well as mapping the effects of the problem on the person (and vice versa), considering the person's strengths, expectations, and competence. Narrative therapy is used in other therapies such as narrative processing within trauma-focused cognitive behavioral therapy (i.e., trauma narrative). In the context of racial socialization and racial identity development, narrative approaches can help to build the individual's story against the backdrop of their collective narrative.

Family Systems

Family systems approaches originates from the Bowen family systems theory, which uses systems thinking to understand the interactions of the family as an emotional unit (Bowen Center for the Study of the Family [BCSF], 2021). It assumes that family members are interconnected and reactive to each other's thoughts, feelings, and actions (BCSF, 2021). The eight core concepts identified within Bowen Family Systems therapy consist of: triangles, differentiation of self, nuclear family emotional process, family projection process, multigenerational transmission process, emotional cutoff, sibling position, and societal emotional process (BCSF, 2021).

Direct Applications. Family systems therapy should be employed with as much of the nuclear family as possible in session, as the family can serve as a microcosm to their home life (BCSF, 2021). Patterns of communication emerge in these sessions, along with the different alliances, rules, and expectations of the family. Intervention is very process oriented and emphasizes reflecting on the process, blocking negative patterns of interaction, or helping the family reframe their problem.

Responsiveness of Treatment

Publicly funded systems of care serving youth and families, such as community mental health settings, are likely to differ in complexity from controlled research settings under which most EBPs are developed and tested. Youth and families served in routine care are more likely to be racially and ethnically diverse (Southam-Gerow et al., 2012; Gellatly et al., 2019), and experience greater chronic and acute stressors (Marques et al., 2016; Southam-Gerow et al., 2008), socioeconomic marginalization (Alvidrez et al., 2019), complex and comorbid clinical presentation (Marques et al., 2016; Gellatly et al., 2019), and exposure to violence (McKay et al., 2005). Providers in community settings also often vary in professional background, therapeutic orientation, exposure to EBPs, and intensity of job demands (e.g., managing immense caseloads) that can relate to burnout (Kim et al., 2018; Lasalvia et al., 2009). Finally, publicly funded care settings frequently face organizational challenges, including limited resources to support the delivery of complex multicomponent EBPs, including resources to support ongoing training and consultation, fidelity monitoring, and performance feedback (Aarons et al., 2009; Beidas et al., 2016; Regan et al., 2017). Overall, multiple factors complicate the delivery of EBPs in routine care, given that clinical trials are often designed to filter out this variance (Chambers et al., 2013).

Lack of attention to addressing diverse needs during intervention delivery can pose barriers to treatment success, responsiveness, and client engagement. It can also widen mental health disparities for systemically marginalized groups, including Black and African American, Indigenous, Latinx, Asian American, Native Hawaiian and Pacific Islander, or multiracial youth and families, particularly those who are socioeconomically marginalized. It can also impact disabled and neurodivergent youth, as well as linguistic, sexual and gender minorities, (Barrera Jr. et al., 2017; Baumann & Cabassa, 2020). Thus, evidence-based practice necessitates clinician responsiveness to client heterogeneity and flexibility in adapting intervention delivery to youth and family needs across diverse care settings (Kendall, 2021).

Charlie’s therapist read the evaluation and did their own assessment of psychotherapy needs. “Hmm, I know that some approaches will work for depression, for anxiety, for PTSD, and for behavior challenges. And I really need to think through Charlie’s gender identity in the process too. How can I adapt based on this really unique part of them?”

Charlie’s therapist knew that some skill-building specific to the problem was needed, that caregiver involvement was integral, and that there had to be some work around the story of Charlie’s problems. “Should I take a broad strokes approach to cover it all? Or maybe sequence one problem after the other?”

Adaptation

Adaptation of treatment has been defined as a “process of thoughtful and deliberate alteration to the design or delivery of an intervention, with the goal of improving its fit or effectiveness in a given context” (Stirman et al., 2019, p. 1). Scholars from the cultural adaptation and implementation science literatures recommend a proactive, iterative, and dynamic approach to adaptation, wherein the reasons for (why, when) and process of (what) adaptation are systematically evaluated and documented (Aarons et al., 2012; Baumann et al., 2017), as well as informed by community stakeholder input (Barrera Jr. et al., 2017). Researchers have discouraged using assumptions or stereotypes about diverse groups to make unjustified changes to EBPs, in favor of a more selective, directed adaptation approach (Lau et al., 2006). Within this approach, adaptations are made only when supported by qualitative and quantitative data, such as when incorporating unique sociocultural factors or address limited engagement. Appropriate adaptations are designed with these data in mind (Castro et al., 2010; Lau et al., 2006). Although adaptations to EBPs have the potential to optimize care, they can also produce unintended consequences, such as omission of core EBP functions, if not guided by research, theory, or local expertise or context (Kirk et al., 2020; Stirman et al., 2019).

Of note, there has been some debate in the literature on the relationship between fidelity and adaptation to treatment. Fidelity to an EBP has been

Adaptations can be made prior to an intervention's introduction into a service setting ("design-time") or during its delivery in a setting ("run-time").

defined as the extent to which an intervention is delivered as intended in accordance with the EBP's theoretical principles (Breitenstein et al., 2010; Hogue & Dauber, 2013). Treatment fidelity is thought to be associated with an EBP's intended treatment outcomes (Collyer et al., 2020; Hogue et al., 2008; Thijssen et al., 2017), and thus substantial research has been invested towards understanding how to support providers and systems to deliver EBPs with fidelity (Eslinger et al., 2020; Garbascz et al., 2014; Lyon et al., 2018). Earlier debates in the literature centered on concerns of adaptations compromising EBP fidelity to the detriment of treatment outcomes (Elliot & Mihalic, 2004). However, there has been greater acknowledgement in recent literature that different types of EBP adaptations are likely to differ in their impact on outcomes and can complement intervention fidelity, and may enhance EBP implementation if consistent with an intervention's key principles (Anyon et al., 2019; Pérez et al., 2016). Furthermore, the value an adaptation produces in EBP delivery and implementation can be overall positive, for example if it achieves goals of improved fit or reach, even if there are some costs (von Thiele Schwarz et al., 2019). However, given the need for more research on definitive links between different types of adaptations and outcomes, providers should aim to preserve the EBP's core functions when making adaptations.

Direct Applications. Numerous frameworks within the cultural adaptation and implementation science literatures have been developed to guide the adaptation process. Common processes within these adaptation frameworks include identifying the core elements of the EBP known to impact treatment outcomes, establishing why adaptations are needed, delineating a process for making adaptations in ways that preserve the EBP's core elements, piloting the adapted EBP, and finally monitoring and evaluating the adapted EBP (Texas Institute for Child & Family Wellbeing, 2016). Thus, the common elements approach to treatment may be a helpful foundation for guiding adaptation. This approach aims to identify the common elements of EBP for a given presenting problem by distilling the large number of available treatments in the literature down to the most common elements spanning these treatments (Chorpita et al., 2005). One way to adapt treatment effectively is to start with an EBP's common elements and organize them into a tailored plan adapted to the specific needs of a child or family based on qualitative and quantitative data (Chorpita et al., 2014).

Relevant to psychosocial interventions, this section will discuss a few adaptation frameworks from the cultural adaptation and implementation science literatures. However, the authors acknowledge that there are many reasons to adapt, including to enhance treatment fit for different systemically marginalized groups, including for youth who are sexual and gender minorities, or who are socioeconomically marginalized, disabled, or neurodivergent, as well as for differences in provider, organization, and service setting characteristics.

Adaptations can be made prior to an intervention's introduction into a service setting ("design-time") or during its implementation or delivery in a setting ("run-time") (Chorpita & Daleiden, 2014). Interventions can also be adapted through a top-down approach, in which an already existing intervention is adapted for other groups, or a bottom-up approach, in which an intervention is developed within a particular context to address the culture-specific aspects of that context, informed by the local community (Hall et al., 2016).

Cultural adaptations have been defined as those that "consider language, culture, and context in such a way that it is compatible with the client's cultural patterns, meanings, and values" (Bernal et al., 2009, p. 362). One influential cultural adaptation framework, the Ecological Validity Framework (Bernal et al., 1995),identifies eight dimensions that developers and providers should consider when assessing intervention fit: language, persons, metaphors, content, concepts, goals, methods, and context. Prior studies have used the Ecological Validity Framework as a guide for adapting youth and parenting interventions for culture, including for Puerto Rican, Haitian American, Hispanic, and Latinx youth and families, (Lee & Smith, 2013; Kuhn et al., 2020; Matos et al., 2006; Nicolas et al., 2009; O'Connor et al., 2020), as well as for autistic (Kuhn et al., 2020; Martinez-Torres et al., 2021), and deaf youth (Day et al., 2018). Some meta-analyses have suggested small to moderate improvements in outcomes for culturally adapted EBPs, including for Black and African American, Indigenous, Latinx, and Asian American youth and families (Hernandez Robles et al., 2016; Hodge et al., 2010; van Mourik et al., 2016). These studies have primarily focused on researcher-led, design-time adaptations.

Other well-recognized frameworks delineate the process of adaptation. The Cultural Adaptation Process Model (Domenech-Rodríguez & Wieling, 2005) and the Formative Method for Adapting Psychotherapy (Hwang, 2009) are two examples of bottom-up approaches that outline the process of adaptation in three and five phases, respectively. Both recommend consulting the relevant literature, notably collaborating with community stakeholders to gather knowledge and assess needs, integrating these knowledge bases to adapt the intervention, testing the adapted intervention, and introducing iterative adjustments if needed. Domenech Rodríguez & Bernal (2012) discuss other frameworks and guidelines that can be used to guide the adaptation process.

The Framework for Reporting Adaptations and Modifications–Expanded (FRAME; Stirman et al., 2019) is a prominent framework from the implementation science literature that offers a way to document the adaptation process and enumerates types of modifications that are made. The FRAME recommends documentation of when modifications occur (e.g., pre-implementation), how they arise (e.g., planned/proactive, planned/reactive), who initiates the modification (e.g., researcher, community member), the goals and reasons for modification, what was modified (e.g., content, context), at what level of delivery (e.g., individual, organizational), and the nature or type of modification. Examples of content modifications include tailoring the EBP, changing its packaging or materials, adding elements, removing/skipping elements, reordering modules, and integrating parts of another treatment into the EBP. Examples of contextual modifications include changes to the EBP format, setting, personnel (i.e., who delivers the intervention), or population that receives the intervention. The Model for Adaptation Design and Impact (MADI) expands on the FRAME by providing a decision aid for designing adaptations and assessing their intended and unintended impacts on implementation and intervention outcomes, as well as potential mediators and moderators of these impacts (Kirk et al., 2020).

There is a growing literature documenting local run-time adaptations that occur in routine care settings, including those that augment the EBP by adding to or taking away from the intervention in some way (Lau et al., 2017; Kim et al., 2020), there is some uncertainty regarding what adaptations in which contexts can maximize treatment outcomes. Thus, it is encouraged to characterize, document, and evaluate the impacts of these adaptations on client care and implementation outcomes in order to inform improvements to client care as well as to the reach and sustain EBPs in routine care (Chambers & Norton, 2016). It is important to understand what EBP adaptations optimize mental health outcomes for diverse youth and families, as these can inform improvements across care settings to reduce mental health disparities for marginalized groups.

Transdiagnostic Approaches

How would you treat someone with a problem list like the following: anxiety, depression, PTSD, substance use disorder? Protocol by protocol? Treatment as usual? As clinicians would agree, comorbidity is the rule, not the exception, and our clinical samples often show great heterogeneity (Norton, 2017). Transdiagnostic treatment is an approach independent of diagnosis that merges common elements of treatment protocols to enhance coverage of problem areas with generalizable therapeutic takeaways. In one study, 67% of participants with multiple diagnoses experienced remissions of their diagnoses to subclinical levels after participating in a transdiagnostic treatment (Norton, 2012). Similar data suggest that clients are amenable to transdiagnostic treatments delivered in community mental health settings, finding it acceptable (Norton, 2017). There are also benefits to delivering transdiagnostic treatments for both providers and supervisors. For providers, there is a reduced burden in being trained in one protocol compared to being trained in multiple protocols. Likewise, supervision may be easier to manage when using a unified approach.

Two protocols employing the transdiagnostic approach have been shown to be effective for youth: the Unified Protocol for the Treatment of Emotional Disorders in Youth (Ehrenreich et al., 2009) and the Modular Approach to Therapy for Children with Anxiety, Depression, Trauma, or Conduct Problems MATCH-ADTC)(Chorpita & Weisz, 2009). The Unified Protocol for the Treatment of Emotional Disorders in Youth was adapted from the Unified Protocol for Adults (Barlow et al., 2004), and studies of this intervention have demonstrated effective outcomes for children (Carluci et al., 2021). MATCH-ADTC developed out of multiple meta-analyses of effective treatments for children, in which the active ingredients of those treatments were distilled (Weisz et al., 1995; Weisz et al., 2006), along with a clinical decision-making system matching different presenting problems to intervention elements.

Direct Applications. Individuals who have difficulty accessing resources and trainings for these approaches or other manualized protocols can take the common elements approach. Chorpita et al. (2005) extracted common elements of evidence-based treatments addressing youth mental health problems, distilled them down to the most common elements among these treatments, and matched these elements to specific youth presenting problems. Through the common elements approach, clinicians can deliver treatment flexibly while remaining in alignment with the tenets of evidence-based practice (i.e., what the literature says, what the clinician feels competent delivering, and what the client thinks of the treatments). PracticeWise, an organization dedicated to improving human health and welfare through the use of evidence and information technology to advance behavioral health care, has allowed us to reproduce a table from their work that outlines the common elements. Please consult the literature around common elements, the clinical dialogue below, or consult other PracticeWise materials to understand how to use them in a systematic way to maximize their effectiveness and clinician use of evidence.

“I know from the literature what works for most kids for specific problems. I can take a common elements approach because I’m not trained in transdiagnostic protocols. I can make this work,” thought Charlie’s therapist. “I can make some adaptation to fit their specific situation during sessions and really personalize it.”

Charlie’s therapist then started constructing a protocol for Charlie, taking in behavior activation strategies, problem-solving approaches, considerations of automatic negative thoughts and self-concept. “I know the trauma history is in the background too. I’ll be prepared. As long as I’m transparent, collaborative, and track our progress, we can make it work.”

Table 4.1. Common Elements of Intervention

Anger management	Exercises or techniques designed to promote the youth's ability to regulate or prevent anger or aggressive expression, and seek productive resolutions to conflict
Assertiveness training	Exercises designed to promote the youth's ability to assert their needs appropriately with others
Cognitive coping	Any techniques designed to alter interpretations of events through examinations of the youth's reported thoughts
Communication skills	Training for youth in how to communicate more effectively with others
Family engagement	The use of skills and strategies to facilitate the family's positive interest and participation in programming
Insight building	Activities specifically designed to help a youth achieve greater self-understanding, including emotion regulation
Maintenance	Exercises and training designed to consolidate skills already developed to minimize the chance that gains will be lost in the future
Praise	Training of parents, teachers, or others involved in the social ecology of the youth in the administration of social rewards to promote desired behavior
Problem solving	Training in the use of techniques, discussions, or activities designed to bring about solutions to targeted problems
Psychoed child	The formal (usually didactic) review of information with youth
Psychoed parent	The formal review of information with youth's caretaker
Relaxation	Techniques or exercises designed to induce physiological calming
Social skills training	Providing constructive information, training, and feedback to improve interpersonal verbal or non-verbal functioning
Tangible rewards	Training of parents, teachers, or others involved in the social ecology of the youth in the contingent administration of tangible rewards to promote desired behaviors
Modeling	Demonstrations to the youth of a desired behavior
Role play	Practicing a desired behavior during session

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Clinical Dialogues: Psychosocial Intervention with Bruce Chorpita, PhD

Sean E. Snyder, LCSW: Thanks again, Dr. Chorpita, for joining me for this clinical dialogue. I heard you speak at the ABCT Convention in 2019, and your talk about increasing the world's therapeutic intelligence through strategic alignment of individuals, institutions and industries left a lasting impression on me. In the spirit of that talk, what would you say is the current state of intervention science? What do our readers need to know about what we need to know where we're at with our interventions?

Bruce Chorpita, PhD: It's a good question, because intervention sciences is not one thing. We're doing pretty well at EBP testing, having documented what things work and what things help. Where we're doing less well is the actionability of what we know. We have over 1200 randomized trials now for children's mental health, and we have over 800 evidence-based treatments that meet what would be the equivalent of an APA, evidence-based standard. We have a wealth of knowledge about how to do things that will help children do better, and we are good at creating knowledge through testing protocols and discovering things in trials, and I would say that the state of the science now is not as far along with developing our strategies for how to make that science come to life.

Therapeutic intelligence refers to the idea that at any given moment, if you knew everything in those 1200 randomized trials, what would you do at any given moment with a child, whether you were a therapist, or whether you were a teacher, or a bus driver, or a soccer coach or anyone else who comes into contact with children? How would you behave in a way that fosters the psychological development, the emotional intelligence, the health and wellness of that child? Again, we know a lot about what to do if you read and knew all those trials. But even people like me who read for a living, I have to have a team of people help read those trials, and we still are catching up with the literature. So, our problem now is, how do we manage the fact that people have limited attention? They have limited time; they encounter an enormous amount of complexity if they're helping children who have challenges. The question of how do we help them know what to do when that's the case is highly underdeveloped at this point.

> *Anything that's known to any human about what's healthy should be knowable to every human, so we can be healthy... We as a field need to measure ourselves against that: how quickly can we get to that vision?*

Snyder: The point of the book here, too, is to join that cause of making knowledge actionable through accessibility. The hope is to make things a little bit simpler for folks where they can rely on knowledge of common elements or thinking about what are those key ingredients that they need in order to get a child what they need.

Chorpita: We're going to get into the elements piece, but fundamentally one of the issues that when we talk about the state of intervention science is that the unit of analysis of our intervention science is not the unit of analysis at which decisions are made in the service world. Fundamentally, in the literature, the policy now is you pick a program, and you administer the program with fidelity to a child; but decisions in the service world are made moment by moment, week by week. We don't have units of knowledge from our literature that speak to that week by week, moment by moment decision making. Our literature is organized around the idea "a child has a problem, a child gets this program," and "not tell me what happened this week, this is what's in the foreground, what should we do in this moment?" The literature doesn't answer those questions as well. And so, the whole idea of studying elements gets us closer to a unit of analysis that people in the service world tend to make their decisions, e.g., are we going to do relaxation skills this week? Are we going to work on our thinking patterns or social skills? Intervention science and the literature we have, it's not as good at speaking to that decision, as opposed to which program should we pick for depression? It's really a matter of how our literature is organized.

Local individuals have local expertise of the context, and they are allowed to drive the treatment as it unfolds.

Where we would like to see things in the future is that, given the dynamic situation that we're in, what should we do today? What we've been studying now in our lab is what happens in the middle of a session, if something goes wrong, and answer the question: what should we do? We call it the fire extinguisher principle; we don't put a lot of fire extinguishers in our treatment programs that tell somebody, in writing, that "if this happens in runtime, this is what you do to get through this hour and consolidate some gains and be productive." And what happens, as you might imagine, when we study folks who don't have fire extinguishers? Things burn. We have lots and lots of hours of listening to therapists who get into these situations following a program, and either something goes wrong, or there's a crisis that comes up, or some surprise happens. Everything goes off the rails, and it stays off the rails sometimes for multiple sessions even. We need to do better at preparing people in the service world, at answering that question, what do I do right now? Yes, this child has a diagnosis or problem, but also, what's the present circumstances unfolding in front of me?

Snyder: There are two consequences I see from a system on fire. Clinicians get burned out because they feel “I am getting nowhere with my clients,” and their emotional burden increases. And then the flip side, clients aren’t engaged in the service because it’s not effective or the clinician is burned out, and the client might drop out. We are left with a burned-out therapist that may quit and a child that’s not getting treatment. It’s a snowball effect. We have to train more therapists because we have a shortage in an already small workforce and children do not get any better which impacts their quality of life, their schooling, their social life.

Chorpita: One of my wishes for intervention scientists is that people think more in terms of workforce capacity and not in terms of interventions. What we are trying to develop is a prepared workforce that, as you described, is a leaky bucket, right? Every year people are dropping out of the workforce, and you need to replace those folks. That expertise is always leaking out, because people are leaving, and we’re bringing in a new set of folks. Twenty years ago, the belief was “Train people in every EBT, or one for everything, then we as a field and workforce would be fine.” No one really thinks that you have to deal with turnover, you have to deal with the fact that the literature gets larger. Even if you train everybody in everything (which will never happen), the literature continues to grow, and knowledge always leaves the workforce, which means that we’re always losing ground on what’s known. Those are the kinds of things I don’t think we have enough people worrying about; how do we fill the capacity of that workforce, given that we’re always losing ground? It’s like walking up a down escalator. It feels like, how do you make progress when you’re always losing people from the workforce? And the literature keeps discovering new things that we didn’t know last year when we had cohorts of new trainees. The idea that we can train everybody in everything is a fantasy, and that failure has played out in multiple venues now.

Snyder: My mind instantly goes to task shifting or task sharing. Is that the ultimate path the field will have to take?

Our interventions need to be dynamic, developmental, and diverse.

Chorpita: Absolutely, that’s what I mean when I mention the world’s therapeutic intelligence. Our mission is to democratize knowledge relevant to raising children in a healthy way, so the knowledge of evidence-based treatments doesn’t belong to credentialed people, some elite group of professors, or certified professionals. Ideally, anything that’s helpful to children that’s known through science is something that should be known to everyone immediately, and it should be made available when they need to know. So absolutely, our future with intervention delivery means taking on that idea of task sharing. It’s even a step further to say that everyone's identity should be organized around this idea that we should behave in a way that's therapeutically intelligent, that's healthy to those around us. For instance, we should know when it's best to be assertive with a child, and how to give instructions effectively. Or, if we expect compliance, we know how to notice and praise good behavior. This is a collective thing, where everybody from the grocery store clerk praising a child for good behavior to the baseball coach giving instructions clearly; it goes beyond "how do we recruit other roles into the healthcare workforce?" and it flips that to, "how do we make everything that is known actionable by anyone who is around children?" That's the ultimate form of task shifting.

Snyder: It should be a natural instinct for us. For instance, a parent has a child who has a scrape on their knee. They go into the medical kit or cabinet; the parent knows what to do right away. Mental wellness needs that same thing, where people can have these things that are rooted in science ingrained in our identities of who we are and into our social fabric. All things being therapeutically intelligent.

Chorpita: That's the world we want to live in, a world where, if your child can't sleep, the worst-case scenario is you ask your wristwatch, "My child can't sleep, what should I do?" And if there is an answer for that, you get the answer; if there are conditional answers, your wristwatch would ask you, "Before I can give you a good answer, I need to know: is your child a teenager? Well, here's the best answer." The fact is, the most common thing is not that we don't know. It's that we do know, but we don't know how to get it to the person who needs to know. That's the big problem we need to solve; that's what the next 15-20 years is, developing that architecture of taking what's already known and making it deliverable, and messaging it right to the person who needs to know it. If therapists are involved, great, I think there'll always be a room. We'll never have enough therapists.

Snyder: One of the core things I've taken away after reading your papers and looking at your body of work is this distillation and matching approach. That's actually one of the inspirations for this book, considering the core things that clinicians need to know and what to implement in session, and the hope is to pull the curtain away from therapy and make that process less mysterious (thank you PracticeWise for letting us reproduce the common elements table in the chapter). So, let's talk about getting necessary knowledge to the community clinician. How can a distillation and matching approach help them in their everyday practice?

> *Messaging is how we get the appropriate message delivered to the right person, at the right time, in the right unit of analysis, so that they can act.*

Chorpita: I've two answers. The first one formally, is about that actual methodology and the tree view of the literature when you do this approach. We're actually redoing it this year, by the way. In the last one, there were about 600 study groups and 300 randomized trials, and we now have about four times the size of the literature now, where there's about 2800 psychosocial treatments and 1200 trials out there that we've looked at. This year, we're rebuilding that tree, and we're going to see what it looks like now that the literature is so large, now that we have a much bigger data set. The big takeaway from that methodology is that we need to think about the literature as a tree and not as a collection of separate buckets, with each bucket being for a particular population, like anxious kids in East LA or older kids in juvenile justice from South Carolina. That's a fragmented model or view of the literature.

A tree has layers, and the first layer of the tree always seems to be the problem. If we put ethnicity, or age, or another factor in the model, what comes out in that first layer is based on the problem and the literature seems to show that different practices are suited to different problems. So, if you're dealing with depression, there is a set of practices that seem to characterize what is helpful for depression. And those are different than the practices that are helpful for having disruptive behavior problems. And folks may ask, "Well, what about, representing diversity in the literature?" Well, that layer does come in, and when there's evidence that effective treatments for one age group or gender or ethnic group are different than another, that's a branch in the tree, but those branches are always higher up. If you can't get into that complexity, it's not a bad thing to start lower in the tree and consider what's worked for anybody with depression. If you're working lower in the tree, then you start looking at those interactions, you may find out older kids need a slightly different approach than younger kids, so then you adjust your approach. That methodology of thinking of the literature as this tree is helpful because our knowledge base and the tree keeps growing. It's necessarily ending branches, but those branches are getting more robust.

Researchers are incentivized in academic science to produce or to accentuate the points of difference among all of these different interventions. As an intervention developer, I'm supposed to say, "how is my thing different from this other thing that already exists?" That's literally the nature of getting a grant. It is to say, "What am I doing that's different, and that's better," and so forth. At the end of the day, it produces this fragmentation. When you look at most CBT across hundreds and hundreds of CBT manuals, it's pretty darn similar. As we were talking earlier about the actionability of the evidence base, actionability diminished when we

> *Be aware that our natural bias is to keep going in the absence of guardrails. Our biases are to move out and be more flexible probably than we should be.*

disguise that similarity. When we say there are patterns here, in 1200, randomized trials and that there's really only 30 or 40 things that represent the majority of what most providers will need to know, if we disguise that for the provider, we're making it very hard to act on that evidence base.

The other big message about common elements is that in looking over the past 20 years since we've been starting to do this project, we found that level of analysis really has resonated with people almost to the point, beyond my comfort level sometimes, where people really have grabbed on to this idea of elements as a very helpful way of thinking about the science. People have really resonated with this idea of saying, "What are the secret ingredients to all these protocols?" And as a side result, it's created a lot of amateur chefs in a way. People could put them together in a way that works for what's in front of them, and as it turns out, the evidence seems to suggest that when given a set of elements and some guardrails and guidance, clinicians do remarkably well. If we control some decisions and offer some flexibility, people do remarkably well. The other big surprise from the elements is that there's something intermediate between ultimate flexibility of doing anything you want and the highly structured approach of a protocol to manage uncertainty. There's something in between where developers want to give you lots of structure, but we also want to allow you to make choices, moment to moment and week to week, within a set of limitations that we think are going to keep you going in a promising direction.

Snyder: That would probably take a lot of anxiety out of the process for therapists, that you can be within these parameters and really adapt to your setting. Social workers, we're going to get thrown in places where there wasn't a therapist before, like an afterschool program or park program. This elements approach can be a great roadmap from starting from the ground up in unique or non-traditional settings.

Chorpita: I do a lot of work with social work, and it's very humbling. The world that most therapists live in is more complicated and less filtered than the world that intervention developers tend to work in. I don't mean to broad brusque. I know there are some intervention developers who work with incredibly complex populations, but in general, the notion of inclusion and exclusion criteria right away tells me that you're simplifying the world for a study in some way and saying we're going to homogenize this group. We're going to homogenize the set of options for a provider in a study by saying there's one manual they can use, so you don't have to deal with complexity. Use this one thing? That's not the world providers face;

Our problem now is, how do we manage the fact that people have limited attention… and encounter an enormous amount of complexity?

they face like they have an infinite number of choices of what to do. In the research world, we're pretending there's only one manual in the world, and we're now filtering down that there's only one youth within a certain thing.

When you go into the real world of social work or community practice, you realize that complexity, that every child is dealing with something different. You the clinician have too many choices in some ways of what to do that day with your client. So, we try to hit this balance of saying, there is a clear message from the evidence base of things that work, and we're trying to give you that toolbox. We're trying to prepare you to know which tool is for what, we get very good results when we do that, and therapists seem to like that, too. Do whatever you want is less desirable than being prepared with the toolbox, which is more desirable than simply following a manual step by step by step without any choices at all.

Snyder: The golden mean! Building off of the common elements approach, you have the toolbox, you have the things in it, but what about the process of therapy? One of the articles that I loved reading, written by Dr. Alayna Park and company, was about therapists modifying content versus sequencing. What's the takeaway for community practitioners from that article, the idea of modifying content versus sequencing?

Chorpita: First off, I'm so proud of Alayna because that was an honors thesis; she was an incredibly astute undergraduate here at UCLA, and now she's a professor out of Palo Alto University. This was a topic that most undergraduates would not have touched, this idea that there's more to practice than elements. To use your baking metaphor, you can't throw together a bunch of ingredients and expect to get a good result. There is a recipe for how things are put together, and that recipe matters a lot. One of the things that made me uncomfortable in the past decade or so with the overwhelming enthusiasm for common elements was that it often turned into this idea that all we need is elements. I found myself a little concerned about that because that's not the message that I got from the MATCH trial. For example, the first trial we did with John Weisz in Hawaii and in Boston, in which we actually compared two conditions that had the same elements and got different results. There were standard manuals using the same procedures as the MATCH program, which we literally designed that study. They had the same procedures and two conditions, and one did much better than the other. That tells you, the recipe really, really matters.

What Alayna was studying there was what do providers do when you give them a recipe, and what was interesting is that everybody seems to like to improvise. If you give people a very strict recipe, they still will improvise a little bit beyond the recipe. In other words, if you put up guardrails, people will go a little bit over the guardrail. If you move that guardrail out, or you move the fence out, people still like to lean over it anyway. And so, it was an interesting pattern that no matter what you do, where you set the flexibility in something, we found that providers would go right to the edge of that all the time. A takeaway for providers is to be aware that our natural bias is to keep going in the absence of guardrails. Our biases are to move out and be more flexible probably than we should be. We need some counter force to say, stay within a reasonable range here. No matter where we put the fence, everybody ended up leaning over the fence, and almost going over it.

Snyder: Here's what you need to go crazy with it. But don't go too crazy, right?

Chorpita: All things being equal, humans will see exceptions more than we see commonalities, right, that we ask that we're good at detecting exceptions, and we sometimes are too quick to adapt before saying, "Let me try this before we adapt." Some people might hear that and say, "Well, that doesn't sound like the common elements guy." But that's really what I mean, like the distillation tree says, "Hey, start with what's worked; the base of that tree has 600 studies on this topic that say, across all kids of every age, every cultural group, and so forth." This is what we're like, we want to start in these places, and if they work, we don't necessarily need to be adapting all the time. It is our bias to want to customize everything.

Snyder: When you were initially giving your response, the first question about how do we make things actionable in real time made me think of behavioral economics, specifically the nudge framework. Are there things like that framework that can be helpful for clinicians with the problem of actionability, of how to make decisions in real time?

Chorpita: I think that will be the future. Eric Daleiden and I wrote in a paper in 2014, that the future of evidence-based practice is going to have to contend with ontologies and messaging. Ontologies is about how we apply a standardized set of terms and a known set of relationships among terms that allows us to synthesize the entire evidence base at once. The messaging part is how we then get the appropriate message delivered to the right person, at the right time, in the right unit of analysis, so that they can act. I like that you're raising the idea of nudges. If you think of a treatment manual as a stimulus to produce change in a therapist, it's really not how you would ever expect anyone to change their behavior, right? If I said, "I'm going to try to blast all of this training material in a three-day workshop, I'm going to have you read a book, you're going to put the book on your bookshelf, and six months from now, when a case comes up, I'm going to expect you to recall smoothly, all those things."

Now, that's not exactly how we train; we do try to do practice cases and so forth. But the idea of having someone whisper to you moment by moment, "Try this, try that" or have your watch tell you, "Hey, you're taking too long setting an agenda, or you didn't set an agenda, it's time to set an agenda. It's time to move on to a roleplay," contends with the fact that human attention will always wander and respond to different things. We do benefit from having those supports in everything we do. For instance, that's why we have stop signs, right? We don't have capacity for the mental effort of processing an intersection while driving and weighing the safety risk ratios of going through the intersection. It's better to have those cues there to say, "this is when you stop." Our ability to interact with other human beings and respond to those messages becomes smooth. We become coordinated; we become organized.

That's the world we're building for therapists, we want to democratize that and say anyone interacting with children should be getting those nudges, right? For the recess monitor on the school playground, what should they do if a child is crying? There's probably an answer for that, and someone's probably done a dissertation on that about; how do we message that to that person so they know how to provide the right type of support at that moment? That's the world we want to build, to get science to people that need it in order to build healthy lives for children.

Snyder: It reminds me of PCIT, with the clinician in the caregiver's ear, giving them those prompts on how to interact with the child in a therapeutic way. It's working with the parent's natural instincts that sometimes get crowded out with stress, et cetera.

Chorpita: That's what's brilliant about PCIT, that's how you teach a parent, in vivo with the child in front of them. That's how we should be teaching how to be a therapist. The only downside to that is that it represents a small evidence base of 10 of 1000 trials. It's a chip off the tip of an iceberg of the evidence base that's being represented through in-the-ear prompts. The other thing is that it's not a cost-effective way to scale that evidence to a human. We need to somehow get machines to whisper, have machines to read, understand and organize our evidence base in a way where it behaves the way the semantic Web behaves. For example, with commerce, you can ask the internet a question about where to buy gas, and you get a great answer. We have not organized our evidence base of intervention that way yet.

Snyder: And that is the runtime aspect of care which is complex, and that is definitely the ideal, to harness AI and build that therapeutic infrastructure. So that's the ideal, and let's look at what's happening in the community. The client cases we get are complex because they represent the rule, not the exception of comorbidity, and that makes me think about your team's work with the Child STEP trials because they are in LA, it's community clinics, where it's not a lab setting. What did your team take away from those trials in the community clinics?

Chorpita: Aside from the fact that it's always humbling to work in communities where there's a high level of poverty and there's all kinds of community stress going on and things like homelessness, we also had challenges among the providers themselves who were living in very stressful circumstances. It's humbling to say, "let's try to bring the evidence base to life in these particular contexts." One of my takeaways for the MATCH trials is that it allowed us to answer a question that we were being asked based on a paradigm of evidence-based treatments. Prior to MATCH, we were doing common-elements type of work in Hawaii and enhancing the performance of that mental health system. As a result of that community level work in Hawaii, I was brought into the MacArthur Network, and over a period of about a year or so, we thought, "how would we configure the things we're doing in Hawaii successfully, and put it in a trial?" The original design for the MacArthur Foundation trial was not to have a modular treatment condition. It was to test evidence-based treatments versus usual care in communities.

One of the things we do through Practice Wise is called Managing and Adapting Practice. It's the big toolbox of everything in the literature, and for the trial, we picked 33 things that are equivalent to the same things in these three evidence-based manuals and put them into one toolbox that's flexible. We predicted based on what I was doing in Hawaii that MATCH would be as successful as standard EBTs, but that therapists would like it better. The rationale we gave to the MacArthur Foundation was that if it's as effective as EBTs, but therapists like it better, it will scale more quickly, and it will take off on its own. When the study is over, people will keep doing it and so forth. So, we set out to show it is as good as EBTs, but therapists like it more. Well, it turns out, we were right about one of those things: therapists do like it more, and we were wrong that it's as good as established EBTs. We were surprised to find it actually was more effective than the standard EBTs. We believe it is because of the fact that dynamic delivery of treatment is more important than we realized.

So a key takeaway from intervention design from those MATCH trials (and even from some of the stuff we do with MAP) is that there are three things that intervention developers and therapists need to be aware of. One is that interventions need to be dynamic. We got burned with MATCH when we weren't dynamic. In those trials, even though kids got better, and we did better than the gold standard EBTs, a lot of kids didn't finish treatment. We had 40% of kids not really finishing a full course of treatment. Why? It's because the treatment wasn't dynamic in that way to deal with comorbidity. So if comorbidity comes up, we have tools in the toolbox. It was not dynamic enough regarding engagement. If engagement was poor in the middle of treatment, there was not a something in the flowchart that said, "Try this, and this will get you back, this will reengage the family, get you back on track." We're now building in that set of features into the next generation of MATCH. Being dynamic means having your fire extinguishers, assuming that things can go wrong, or things can change, and in real time, you have to be able to decide as things unfold in front of you.

The second thing is that treatment design needs to be developmental. Developmental means that not everybody needs to get the same protocol, because some people are already pretty skilled, and they need to get a few things, and they can stop treatment more quickly. Not everybody needs 16 sessions. With MATCH, some of our best cases were done in four or five sessions. And so being developmental means following people's progress, meeting them where they are, and leaving them when they're ready for you to leave them.

Most of our interventions are not as developmental in nature, nor, by the way, are ways of training therapists how to do things. We always assume therapists know nothing when we meet them and that they have to learn everything again from us, even if they've learned it somewhere else. Be developmental.

The third one is diversity. Not everybody wants the same experience, even when they're getting the same manual, so you may have to do the same procedure in a different way for a different child. A treatment developer is never going to anticipate the diversity, the dynamics, and the developmental characteristics of the treatment context. The person who writes the manual cannot say "I know all the different diverse individual differences you're likely to encounter (e.g., poverty, homelessness, have a parent in the military)." There's no way I could sit and write a manual and imagine all the things that are going to go wrong. I'm not going to imagine what are the starting points of different families, and I'm not going to imagine the different preferences and values that people are going to bring to the table. Putting those capabilities into the hands of the provider and preparing them not to respond on the fly and wildly improvising that may not actually be helpful. We don't want therapists to improvise because we want to give them the tools to be able to be responsive on the fly.

So, the second takeaway from our community trials is that we don't want people to improvise in ways that do more harm than good, but we also don't want people to be reading a script. We want to give them something in between.

Snyder: That all reminds me of conversations I've had with colleagues at my clinic, where a common phrase is "When you've seen one case of autism, you've seen one case of autism."

Chorpita: Exactly. That's the reality, and we need the humility of saying that an intervention developer only knows what works for anxiety when a child's cooperating with exposure. How often is that situation going to present itself, pure cooperation? Someone's going to need to figure out what to do about that. That's very humbling to know that a lot of what's going on in session is in the therapist control because they're looking through the window.

Snyder: As a clinician, if you feel good about your work, you'll feel more in control, and if you feel more in control, you're ultimately going to perform better. And when clinicians perform better, the child benefits, and if we go down this casual chain, systems benefit if we're getting kids more quality treatment, and we can be more efficient with services which could hopefully reduce waitlists and treatment gaps.

With the last set of questions, I want to shift towards something that's been in the public conversation in the past couple of years, that there's a lack of representation of diversity in our scientific literature and that there is a lack of representation in who is doing the research (which is its own conversation). So, what would you say in regards to the idea that there is a lack of representation in the scientific literature? Does adaptation become the avenue forward?

Chorpita: This is a complex topic. There are so many assumptions, some of which aren't always helpful. There are 200 evidence-based protocols for Hispanic youth, for instance; there are 235 for Black youth, and many clinical trials that have included Black youth and have produced an evidence base. I've seen claims that there's no representation, but to me it's more along the lines that there is no substantive representation. This points to the problems that come from those trials: what are the contexts that are going to create additional challenges for success? I don't see it talked about nearly as much about in terms of racism and other contextual things like limited resources in someone's community. We see it discussed in global mental health a little bit, where people talk about resource limitations and things. Those contexts can present extreme challenges for therapy to work well, which gets back to what I said before, what are those challenges going to unfold in front of people?

When we talk about adaptation, I'll go all the way back to that distillation tree and say I still think we always have to start with the problem. In the absence of any other evidence, do we know what works for anyone for a particular problem? Because therapy is about managing the uncertainty of trying to help someone meet their goals. The best way to manage that uncertainty is to offer our best ideas (because total certainty is not realistic). Right, but we say where do I get my best ideas?

I should start with something that's worked for somebody with a similar problem. You still do exposure with everybody who has anxiety, and we may need to tailor exposure considering that clients have different values, different beliefs, different cultural preferences. The challenge is to say how do I successfully manage to fit a procedure that I know to make this work in a particular context.

The word adaptation is tricky because I think of it more as how do I fit the best idea I can get from the evidence base into the context that I'm dealing with. Sure, we need to consider representation of underrepresented groups, but there's also the neighborhood you're in. What's the level of violence, what's the level of quality of education, what are the peers at that school modeling? All of those things are factors that are going to play in, and it's not going to be as simple as saying a particular cultural group is going to get a culturally adapted treatment. There's so much diversity within a cultural group. Aside from the fact that I think that making adapted protocols simply would create a factorial explosion because humans are so diverse, the actionability problem that we have now would be worse.

Some expertise is going to come from the evidence base like behavioral activation is a good idea for depression, exposure is a good idea for anxiety; and some expertise is going to come from local knowledge of the context. For instance, the evidence base that says humans tend to have elevated moods when we force them to do behaviorally activating procedures like going for a walk or calling a friend, and there's the local context of knowledge of our clients, and the art of therapy is considering "How do I fit those two-evidence bases together?" I don't think we're ever going to store and document all of that stuff in a clinical trials evidence base because once we do, we will have a cohort effect. For instance, 10 years from now, we will say, "Well, the context changed, we didn't have social media." Ninety percent of these clinical trials in our evidence base were done before there was social media.

The evidence base is never going to give us all the answers, and so I might try to make this into a concise thing. I would say, we're managing uncertainty, we have to be humble, and we have to say the evidence base has something to give us in terms of general messages, and the client's contexts gives us other messages. We always need therapists who are local experts to say, "I am the translator of that science into this context." Everything is local at the end of the day. If we try to imagine that the evidence base will always, always give us all the answers, we will never finish that project, and if we could finish that project, the evidence-base would be too large to be usable. We can't read it; we can't act on it. We have to get comfortable with this idea that local individuals have local expertise of the context and that they are allowed to drive the treatment as it unfolds. That's what MATCH is all about, that the evidence basis is there to be helpful, and we can highlight a few principles from over a thousands of trial.

Snyder: The way forward then is setting up the architecture to make our knowledge actionable. You're saying, how do we set up a therapist for success, how do we bridge those gaps of knowledge, how do we harness the context?

Chorpita: We call it a collaboration between the scientists and the therapists. A manual should be a collaboration. If I write out every last little thing you do in a manual, that's not really collaborating because I'm not letting you, the therapists, do anything except what I tell you. Collaborating is saying what I know from science, and you're going to make that unfold in a way, where what we both know is going to. Our job is to provide the messages when we feel, but, by all means, therapists are always going to be dealing with runtime issues of what's in front of me. That's what makes that job so cool and so interesting to me and keeps you going.

Snyder: I'm left with the theme of democratizing therapeutic intelligence, from scientists collaborating and practitioners, with practitioners joining with and collaborating with clients. So that's the person-to-person democratization. And that springboards us to consider: how do we get people involved at large in active mental health promotion and wellness? Could you leave us with your last thoughts on that idea?

Chorpita: Anything that's known to any human about what's healthy should be knowable to every human, so we can be healthy. If humans have discovered something that's helpful, everyone deserves to know it as soon as they need to. We as a field need to measure ourselves against that: how quickly can we get to that vision? We need to ask ourselves, how do we set up our institutions, the right way, to get things to people who need them.

Things Clinicians Should Know

This chapter provided an overview of the approach to intervention. There can be various theoretical approaches to guide intervention and ways to package interventions to match a child's problem area. The key is to start with the bigger picture: what is the presenting problem, what do we know generally with what works for that problem, and then tailor to the individual context. An understanding of common elements can serve to facilitate this process.

Keep this common-elements approach in mind for the disorder specific chapters. Examples will pull from common elements of intervention for that particular area. As always, ensure you have good feedback to guide intervention, feedback from the client, from progress monitoring, and from ongoing supervision!

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5

Chapter

Psychopharmacology through a Developmental Systems Lens

Sean E. Snyder, MSW; Barbara Robles-Ramamurthy, MD

Tre is a 14-year-old that has been struggling with their mood. “They’re just tired all the time, don’t feel like doing much,” said their caregiver. “I don’t know what’s happened; they used to be so happy-go-lucky, now this. We’ve tried therapy at the school, but nothing seems to be breaking this pattern.”

“I’m glad that you brought Tre in and mentioned the therapy done at the school. I’ll ask some more questions to get a more detailed picture. This way we can know what type of treatment could be most helpful,” replied Dr. Johnson, the child psychiatrist.

Introduction

Psychosocial treatments have been the bedrock for addressing child emotional and behavioral problems, and pharmacology is increasingly seen as a core treatment option for children and adolescents. This shift reflects historical trends in the development of medication therapy and the cultural shift that accompanies such advances. Psychopharmacology for children has a start date of 1930, associated with Charles Bradley's 1937 study of Benzedrine on youth with emotional challenges. Much of the research from then until the 1980s extrapolated findings of adult studies on child use, and in the 1990s, pediatric psychopharmacology cemented itself as an independent field (Dulcan, 2016). Children can only meaningfully engage in treatment if it is tailored to their developmental and contextual situation. Cognitive ability, social connectivity, physical growth, and development all factor into this, along with the family context particularly, as the family is responsible for the treatment of the child (AACAP, 2019). Other contextual factors to consider include all child- and family-serving systems that the individual patient is interacting with. All of these considerations are no exception to psychopharmacological treatment.

Psychopharmacology practices vary based on place of practice. The overall rates of prescription of psychotropics to children and adolescents in the United States is higher than rates in Europe, and rates have considerable variance between countries (Bachmann et al., 2016). There are increases in prescription rates globally regarding three classes of medications: antidepressants, antipsychotics, and stimulants. With antidepressants, Bachmann et al. (2016) have noted increases from 2005-2012 in antidepressant prescriptions in the United States by 26.1%, in the United Kingdom by 54.4%, in Denmark by 60.5%, in the Netherlands by 17.6%, and Germany by 49.2%. During that same time frame, average rates of antipsychotic prescriptions increased between 32%-84% in those countries (Kalverdijk et al., 2017), and rates of stimulant prescriptions increased by an average of 14.6% from 2005-2012 in Western Europe, Asia, Australia, and North America (Ramen et al., 2018). There are trends of increased prescription rates worldwide, and it is hypothesized that this is related to an increase in people who are seeking psychiatric services. Additionally, systemic and structural factors play a role in how our society perceives human behavior and what is labeled an illness that requires treatment. By definition, psychiatric illness must cause functional impairment in the individual, but we cannot forget that functionality is determined by the social parameters that have been established by non-disabled individuals.

Across samples, stimulants tend to be the most prescribed medicine, followed by antidepressants and antipsychotics (Sultan et al., 2018). There have been concerns about over-prescription of medications for children (Olfson et al., 2010), but it appears that the patterns of prescribing coincide with the developmental onsets of common mental disorders in children and adolescents (Sultan et al., 2018). The data set pulled from the national prescriptions database indicates that 6.3 million youth were prescribed a stimulant, antidepressant, or antipsychotic (Sultan et al., 2018). A cohort study highlighted that in the US, children on Medicaid tend to be exposed to psychotropics at high rates and with higher rates of polypharmacy (Pennap et al., 2018).

We can support clients to be better informed and learn how to incorporate health-promoting behaviors into their daily lives.

Sultan and Olfson (2016) found that in the United States, there were sex differences in prescribing rates, with males being more likely to be prescribed a stimulant and with girls being more likely to be prescribed antidepressants. They also found no differences in rates of antipsychotic medications across sex. These differences may be linked to the overall prevalence of ADHD in males and mood disorders in females. Cook et. al., (2017) highlight disparities in psychotropic prescription rates between white children and black/Latinx children. Their findings show that medication use is lower among racial and ethnic minorities, and they point to a need to understand if minority youth are not offered or do not accept medication recommendations, despite having psychological impairment that could warrant such intervention.

Social policies and practices can also affect child and adolescent health and thus the need to diagnose and treat medical conditions. For example, the educational system has been developed in a way that conforms to the social expectations of adulthood. In the U.S., the need for two-income households is inevitable, and if parents are expected to be at work early in the morning, then children are expected to be at school before then. However, more and more evidence demonstrates that children and adolescents are not biologically equipped to conform with these social expectations. Evidence shows that there is a circadian delay that occurs in adolescence, which does not align with our current expectation that teenagers must wake up early to attend school. As is usually the case, decades of scientific discoveries and the subsequent development of scientific consensus must occur before policies and practices adapt to respect the human experience.

The Pathway to Pharmacological Intervention

The following sections will cover aspects of the psychiatric assessment used to determine the need for pharmacologic intervention, as well as considerations about treatment planning and the ethical concerns involved in consenting for medications.

The Psychiatric Assessment

A psychiatric assessment by itself can be considered a comprehensive biopsychosocial assessment. There are some nuances to this that build upon the assessments that behavioral health clinicians perform. The psychiatric assessment will cover a psychiatric symptom screen and assessment; a review of the chief complaint; the history of present illness; a psychiatric review of systems; a review of the patient's past psychiatric history, including any history of medication trials; substance abuse and chemical dependency history; suicidality and homicidality history; developmental and early childhood history; and family, school, social histories. During the evaluation, the physician will perform a mental status examination, physical evaluation, or assessment. With all of this data, the psychiatrist will present a formulation and diagnosis, then present treatment options which may or may not include a recommendation for a medication trial.

The counselor's role acts as a guide for the client to problem-solve around decisions regarding their medication treatment.

As you can see, many of these areas are covered in the clinician's assessment. In the realm of collaborative documentation, where a masters-level clinician performs part of the overall evaluation, the physician can review the clinician's initial assessment and ask follow-up or probing questions. There are two key tasks that only physicians can perform: the physical evaluation and pharmacological recommendations. They have the authority to state that treatment recommendations can be medically necessary.

Physical evaluation and assessment. This physical assessment is needed to understand the physiological baseline of the patient, as certain behaviors can be attributable to medical conditions; for instance, an overactive thyroid can lead to the appearance of anxiety. Patient health conditions have an influence on medication selection by the psychiatrist if indicated. If a patient with ADHD has cardiac problems, for example, a stimulant would be contraindicated. The prescriber will check height and weight, as well as do diagnostic testing to establish a baseline for organ-function monitoring. Lab work tends to track levels of glucose, triglycerides, A1C, WBC, creatinine, and lipid levels, among others, to help monitor any potential effects that may occur after starting a medication. For instance, if a child warrants starting on an antipsychotic medication, it is critical to have these baseline labs; the medications can have metabolic side effects and affect triglyceride and blood glucose levels. Although psychiatric assessments are comprehensive, there is new evidence demonstrating the need for additional factors to be considered and better incorporated into treatment planning. For example, the role of diet, sleep and exercise are well established regarding their effects on mental health. However, the current medical model does not fully support clinician's ability to address these issues due to low reimbursement fees, which limits the time spent with patients. This is an important consideration for non-physician mental health providers, as we can support clients to be better informed and learn how to incorporate health-promoting behaviors into their daily lives. Most importantly, as non-prescribing mental health providers, we will encounter conversations with clients regarding their medications, so it is important to develop tools, understanding and collaborative approaches to skillfully support both the prescribing clinician and the client we serve.

Pharmacological recommendation. The physician understands the neurobiological aspects of pathology, and pharmacological treatment recommendations are based on these impairments in neuroconnectivity. At this point, it will be helpful to review one of the essential aspects of pharmacology, neurotransmission. Neurotransmitters are considered the chemical messengers in the body, and they help bridge the gap (synaptic cleft) between neurons throughout the body. There are two major functions of neurotransmitters: they either excite or inhibit neural signals. These neural signals are the hardware for human behavior, acting as the circuits and the electricity that powers the body. Neural signaling is the response to stimuli (both internal and external).

It can be helpful to recall the main neurotransmitters associated with psychiatry. *GABA* is largely responsible for processes related to relaxation, and it has an inhibitory function which can decrease anxiety and involuntary muscle contractions like those in seizures (Heldt, 2017). *Glutamate* is an excitatory transmitter, and it acts opposite to *GABA*. It can be helpful with learning and memory. *Acetylcholine* affects the parasympathetic nervous system including functions like arousal, lacrimation, and GI motility; it can also affect learning, memory, attention, and muscle contraction (Heldt, 2017). *Dopamine* plays a role in psychosis, motivation, reward, reinforcement, and motor control; low dopamine is related to Parkinson's disease, for example (Heldt, 2017).

> *From the physician point of view, there is an emphasis on beneficence, non-maleficence, and autonomy.*

Serotonin is linked to sleep, appetite, mood, and memory; its influence can be seen with migraines, anxiety, and impulsivity (Heldt, 2017). Much of the body's serotonin is located in the gut, so this may account for the GI distress experienced after the start of an SSRI (Heldt, 2017). *Norepinephrine* impacts concentration, alertness, vigilance, and it plays a role with the sympathetic aspect of the central nervous system, affecting blood pressure and heart rate, as well as other organs (Heldt, 2017). *Histamine* is responsible for things related to the sleep-wake cycle, and it can play a role with other hormonal functions (Heldt, 2017).

In addition to understanding these pathways, the prescriber will consider pharmacokinetics, or the “absorption, distribution, metabolism, and excretion” of a medication (Nnane, 2005). Knowing the mechanism of these processes is not as important as understanding that treating a child is different than treating an adult. Child body composition is vastly different, in terms of fat tissue, organ development, and excretion of the medication (Lu & Rosenbaum, 2014), which ultimately affects how the medication works in a child. Additionally, what may work for an adult in terms of medication type and/or dosage may not work for a child, largely based on the idea of pharmacokinetics (Lu & Rosenbaum, 2014). Another related term is pharmacodynamics, or how the medication affects the receptor it is targeting. With a constantly changing neural system as related to synaptic sculpting, medications need to be considered in terms of chronological age and maturation (Lu & Rosenbaum, 2014). Understanding pharmacokinetics and pharmacodynamics conceptually is helpful to a clinician when they provide basic psychoeducation to parents about how medications work and what influences their effectiveness.

Treatment Planning

Three categories of psychotropics receive the most attention with child psychopharmacology: stimulants, antidepressants, and antipsychotics (Sultan, 2018). While there are other classes of medications used, such as anticonvulsants for mood lability or benzodiazepines for panic disorder, most of the literature points to the use of stimulants, antidepressants, and antipsychotics as common practice. Sultan et. al (2018) confirms from their reviews of the child psychopharmacology literature that stimulant medications are established for the treatment of ADHD, antidepressants for the treatment of depression and anxiety, and antipsychotics for the treatment of psychosis, bipolar disorder, and clinical aggression in children with and without autism. Consult the Quick Reference to Psychotropic Medications for common medication classes, various preparations of the medications, and other helpful information.

Syndromes, not symptoms. Treatment planning involves targets for behaviors or symptoms in the hopes of reducing the effects of a given disorder. With psychopharmacology, targets are critical in treatment planning; however, medication intervention is not aimed at specific symptoms but the syndromes or clusters of problems. Take a medical example: someone that has a runny nose would not necessarily take an antibiotic. The runny nose can be due to hay fever or a cold (not excluding the possibility of a bacterial infection). An antibiotic can be used for a sinus infection, and the efficacy of the antibiotic can be measured by its effect on the runny nose. Let’s now take a psychiatric example. It would be hasty to prescribe a stimulant if the child complains of inattention. There are potential causes of this symptom that need to be accounted for- is this child suffering from anxiety or depression, which is causing racing or ruminative thoughts? The stimulant would be warranted to treat diagnosed ADHD only, and the indicator if the stimulant is working would be any decrease in inattention. There are some exemptions to this rule. For instance, if a child with autism spectrum disorder has externalizing problems, an antipsychotic can be prescribed to help with aggression. However, the antipsychotic is not treating autism itself. There may be comorbid issues to be ruled out with this autistic youth.

There are times too when a prescriber uses an off-label use of a medication; one of the more common of these being the choice of Seroquel, an antipsychotic, as a sleep aid. It is critical to understand risks, benefits, side effects, and targets of the medications, as well as have an understanding that medication has a particular role in treatment; it is not the sole modality or rationale for treatment. As non-prescribers, we can also meaningfully assist in the overall treatment for youth and their families by incorporating our training in ecological treatment models. With that, we can assess what needs to be treated in the child themselves as opposed to what can be addressed by shifting the child-serving systems interacting with that youth, including the family and the school setting.

Dr. Johnson completed a psychiatric assessment of Tre. “Seeing that there are not any physical health problems that could explain what’s happening, and that Tre has been in therapy for around 6 months, this might be the right time to try out medications. This along with psychotherapy can hopefully get the health outcomes you’re looking for. Make sure to ask Tre’s therapist if they are doing CBT or another treatment that works for depression.”

“Will this medicine change my personality?” asked Tre.

“No, it won’t change your personality,” replied Dr. Johnson. “It can help with your depression, and the depression probably has made you feel not like yourself. Let me tell you about the expected benefits of this medicine, the risks, side effects, and other potential treatment options. If you’re ok, then I can get this called into your pharmacy, and we can meet again in a few weeks. What questions do you have for me?”

Ethics

While there may be professional differences between the physician and the clinician, there are similarities in ethical approaches to care. From the physician point of view, there is an emphasis on beneficence, non-maleficence, and autonomy. Regarding beneficence, the physician is obligated to promote optimal well-being and development of the child, and this may be communicated to the patient in terms of the benefits of starting a trial of medication. Conversely, the physician will operate from the position of non-maleficence, or what is commonly known as the “do no harm” principle. Regarding medication treatment, this principle is communicated through discussion of the side-effects of medication and the risks associated with starting a trial of medication. For instance, the physician would need to present the risks of starting an antipsychotic medication for psychosis (e.g., metabolic side effects) and the benefits of the medication (e.g., decrease in hallucination) and allow the child’s family to make an informed decision based on the information provided. Additionally, non-maleficence plays a role in the importance of prescribers performing a thorough psychiatric assessment that clearly defines whether the symptoms are causing dysfunction and distress to the child, ensuring that we are not treating developmentally normal and expected behaviors that have not been accepted and welcomed in the child’s environment.

Consent can only be considered valid if the child and caregivers are able to make an informed decision about their care without external pressures. Informed consent requires three components:

1. Information-sharing: knowing the risks, benefits, and side effects of treatment, as well as alternatives to the proposed treatment.
2. Voluntariness: making a free decision without coercion.
3. Capacity for decision-making: sometimes legally referred to as competence, being able to comprehend information and reasoning and appreciating the significance of one’s choices.

Assent involves the agreement of someone who is not able to give legal consent, such as children under 18. It is important to note that studies indicate that 14 year olds have similar ability to adults in making complex decisions; however, laws governing age of consent for children vary from state to state.

Oftentimes, a child may refuse to take medications. It is important to consider the function of the refusal behavior. Is it in the presence of oppositionality? Is it related to side effects? Is it related to undesirable physiological states (e.g., “I feel like a zombie”)? Or is it that they disagree with the diagnosis and adult-determined presence of a condition that needs medical treatment? Refusals may happen if the child is not aware of the ongoing benefit, or maybe it has reached its benefit, and the child does not feel the need to take it anymore. Refusals that are in line with a desire to discontinue medication should be discussed with their prescriber to ensure necessary tapering schedules to limit adverse effects of abrupt discontinuation. The medication is seen in the context of treatment, so it is helpful to reiterate that there is some medical necessity; if there is no longer the feeling that it is medically necessary, the family should talk to their provider.

Interdisciplinary Roles of the Behavioral Health Practitioner

Bentley and Walsh (2006) outline seven potential roles for social workers who have clients receiving medication management service. The *collaborator* role supports the physician and the recommendations made in efforts to maximize the intervention. The *consultant* role appropriately screens clients for the need for medication evaluations, makes referrals to prescribing clinicians, and monitors the process of medication management. The *counselor* role acts as a guide for the client to problem-solve around decisions regarding their medication treatment. The *advocate* role positions the social worker as a support for the client and family to either receive services, to advocate the client position within clinical decision making or to link to supplemental resources in the context of medication management (e.g., prescription discounts with pharmacies). The *monitor* role acts like the collaborator role; however, it is more in regard to monitoring side effects and helping the client work through any side effects as indicated. The *educator* role provides information to families about medication treatments and further addresses questions related to risks, benefits, or side effects. Lastly, the *researcher* role uses single subject or case study designs to convey how the intervention has impacted the client, hoping to contribute to the knowledge base about medication interventions. In practice, one provider may assume multiple roles.

The collaborator role supports the physician and the recommendations made in efforts to maximize the intervention.

Regardless of role, it is important to have a baseline understanding of how the psychiatric assessment unfolds; the decision-making process of the physician; the collaboration strategies with the physician, the patient, and their family; and ultimately, the considerations with consent for treatment transition.

How to Talk to Families about Medication

Consider how medication fits into the whole treatment plan for the child. After the clinical formulation, recommendations cover various domains such as social activities, education supports, supportive psychotherapies, and medication therapies. When talking with the family, discuss how medication is not the sole focus of the treatment plan and how it may affect other domains.

Ensure that the child is on a predictable schedule and that it is easy to take the medication; this is meant to limit defiance and forgetfulness. As a behavioral clinician, it is important to remind the family that the psychosocial work is the context for the therapeutic relationship and that medication issues fall in the realm of the medical provider.

Another aspect to consider is how medication works. There have been previous paradigms of medications addressing a “chemical imbalance,” and this explanation lacks the current state of the evidence about psychopharmacology and neural functioning. Additionally, this type of explanation may lead to negative labeling. Consider working with a child and saying that they have a chemical imbalance in their brain. How would they react? They may personalize their problems; they may think that their brain is “broken” or not working right, or they may think that if they are imbalanced, that the rest of their body is imbalanced too. For a child with ADHD, it may be easiest to compare the brain to a computer, where the computer has a lot of wires, buttons, and electricity. Medication can be seen as a way to help the computer run as effectively as it can. Or it can prevent having too many apps running in the background, where it can interfere with what we need the computer to do right now.

Encourage patients to call their physicians and also offer to communicate patient concerns directly to them.

As a non-prescribing mental health provider, you can help advocate for your patients by encouraging them to call their physicians and also offering to communicate their concerns directly. When you communicate with the prescribing physician or other providers, ensure that you objectively describe the information; for example, you may describe the behaviors you observe during your clinical encounters with the child and family, or you may describe the side effects that the patient is expressing during your visits. It is ultimately the physician’s or prescriber’s decision that determines the next steps for medication adjustments.

Stigma about Medication. Communities and cultures may have perspectives that do not view medication as an appropriate intervention. Some will rely on folk medicine or other types of healing practices relative to their culture. In the western perspective, this can be characterized by Complementary or Integrative approaches to medicine (NCCIH, 2018). Complementary practices are those that are not mainstream but used together with conventional medicine, whereas alternative practices are considered those that replace conventional medicine approaches, typically seen in the form of use of natural products like herbs or use of or mind-body practices like acupuncture, yoga, or tai chi (NCCIH, 2018). Related by complementary or alternative medicine by association only, integrative health relates to treating the whole person for instance, as opposed to one system in the body (NCCIH, 2018). This often is supported by coordination between different practitioners (e.g., an internist with a psychologist or clinical social worker in an obesity clinic). Regardless of approach, it is critical that options be discussed with the medical provider, as there are mixed or varying results in studies about natural products for particular medical conditions (NCCIH, 2018). Psychopharmacology as part of a treatment plan needs to occur within a culturally competent framework. This translates to understanding the family views of medication, presenting the proposed medication treatment in the midst of information about the alternative treatments or other remedies they may better understand through their culture. Transparency in communication builds the trust that is needed for the therapeutic alliance.

Clinical Dialogues: Psychopharmacology with Dr. LaToya Floyd, MD

Dr. Latoya Floyd MD is a board-certified child and adolescent psychiatrist. She attended Drexel University for medical school and adult residency. Her child fellowship was conducted at Yale's Child Study Center, where she was grounded in trauma theory and how psychiatry can support resiliency in youth after trauma. Dr. Floyd has worked mostly in community psychiatry in Philadelphia with high-risk youth who often had contact with the child welfare and juvenile justice systems.

Sean E. Snyder, LCSW: To start, Dr. Floyd, your impact goes way beyond your brief introductory paragraph. To our readers, I had the pleasure of working with Dr. Floyd, and she was instrumental in my development as a clinician. In a way, this book is a product of her influence on me, so I want to start by saying thank you. Ok, now to business.

With child psychiatry, it's a very scarce resource. There's a lot of training involved which may or may not be a barrier. What's it like knowing that you're a scarce resource and that there may not be many reinforcements waiting in the child psychiatry pipeline? What's it like being at your clinic, having a full caseload, feeling like there are not enough hours in the day, being that scarce resource?

LaToya Floyd, MD: I think that there's a realization that it's under-resourced in general; then in certain areas, it's even more so. If you're outside an academic setting or if you find yourself in rural America, you may feel under-resourced. If you are in areas that may be well-resourced, such as the coastal areas, sometimes you're under-resourced because of the population that we work with, namely youth and families that are economically disadvantaged and probably on public insurance (which affects reimbursement rates, which may scare off clinicians with loads of medical school debt). So, there's the big perspective of seeing the more structural limitations and the economic underpinnings of it.

> *My lens is I'm trying to get you back on to your "psychological growth chart" and that is an evolving process.*

On a more individual, personal level, it takes trying to scale back and understand where your proficiency is, so you can be the best provider for the people in front of you. So, for me, I focus on school-aged children, and I do a lot of trauma work. I think that if you can identify what you do where you have some proficiency or competency, or dare I say even mastery, then you're able to be more efficient at what you do. When you get that sweet spot where you've honed your practice, you will be in a better position to serve a larger group of people.

The other thing is it's trying to consider that a treatment team should be like a pack; psychiatry really shouldn't be practiced alone. You should have an interdisciplinary team and be connected to well-trained therapists like I had when I was in Philadelphia. You should work with your amazing team and the system infrastructure to affect change, whether it's an in-home team or a family-based team. Otherwise, as a psychiatrist, you're stuck with pharmacology, and at that point, if all you have is a hammer, then everything becomes a nail. So, if a child is acting out and this child has an intellectual disability, someone may choose to get them Abilify (and you may argue that it's FDA approved for irritability associated with autism), but you may not actually pull back to look at the entire problem. There's a skill set in the family, or there's a misunderstanding about the condition, and this actually could be figured out with psychoeducation. So, I think it's wherever you are, wherever your practices are. It's knowing what your proficiency is, and it's showing where your reach is, and not relying solely on medication to be the bridge between what the family needs and what you can do.

Snyder: So that kind of dovetails nicely with the idea of engagement. With some clinics, a youth needs to see a non-physician clinician first, and the clinician refers to you, or you may get direct referrals from pediatricians or schools. So, what's it like when families finally get to you. How do you engage families in the first session?

Floyd: The first session I define what I do. I tell parents who I am, that I'm a medical doctor, and if it's a young child, I talk about the fact I'm not a doctor that is going to give you a shot. I talked about the fact that I work with healing, and I think that the first thing is setting that tone. And it's listening, listening to what the family has been through. Sometimes, by the time families have gotten to me, there's been contact with multiple providers, multiple prescribers, multiple settings like acute inpatient hospitalization or partial hospitalization.

For me, I like to start with what their experience has been like, what they're hoping to get out of the first meeting with me, what other clinicians have done that's been super helpful, and what other clinicians have done that has not been helpful. I think during that first moment or that first appointment, it's about understanding what got them in that chair today and what they're hoping for. Anybody can prescribe Concerta; I think it's trying to figure out what brings them to the point that they need some help with their child.

> *I'm always keeping my eye on what my treatment goal is and what the family is hoping to obtain from being with me; sometimes when those two things are out of sync, that's when you see a slowdown in therapeutic traction.*

So I'd like to start there. I think in forming a therapeutic alliance, I tell parents, "It has to be a good fit. I'm not a cardiologist. If you hate me, and you don't talk to me, then I can't help you. I can't just put a stethoscope there and say, 'Yes, I hear a heart murmur. No, I didn't hear anything.'" There's this need to have a working relationship, and I think that a relationship is important overall, and say if the treatment is stagnant or things aren't moving along. Sometimes it's looking back at the relationship and realizing, "Is this a population I can work with, is this family I can serve? "As a provider, I'm always keeping my eye on what my treatment goal is and what the family is hoping to obtain from being with me; sometimes when those two things are out of sync, that's when you see a slowdown in therapeutic traction.

Snyder: Fit is so critical because the work of a psychiatrist is interpersonal. I'm thinking of different types of presentations that come to doctors; some may just be seeking medication treatment from the start. And as a provider, you don't jump right into medication, right, you want to treat the whole person as part of an ecosystem. And the reality is, their hope is different than what you think is best for them. Specifically with that example, when the parent leads with questions pressing you for medication, what's your initial reaction? As a non-physician, I get reactions when the youth get disappointed that I can't give them medications. So, I'm wondering for you as a physician, what's that reaction like; is it "Here we go again…" or some other visceral countertransference reaction?

Floyd: That's a good place to start, your reaction to the client. I think it's recognizing what is happening to you in the process as you are meeting with families. Once you recognize what's yours and what's the patient's, it's easier to bridge. For instance, if somebody says, I need Xanax, that's a hard place to kind of be at. Is this person really suffering or am I writing off this person because of my personal reaction to a statement like "I need Xanax." So, for me, it's again defining what the presenting problem is, what the diagnosis is. So you have to suspend that reaction to really see. Is it an anxiety disorder or a trauma-related disorder? And let's just say it's a trauma-related disorder. And then I may be thinking, maybe they want Xanax because that's where they're at with their mental health literacy (Xanax is probably more talked about than SSRIs in our popular imagination). So, it's talking to the patient saying this is actually what evidence-based treatment is for anxiety; it would be an SSRI right now. And some patient education is needed too, to help them understand that what they asked for is really addictive.

And the other thing is, try not to make assumptions. That's really hard. So, if you can check the prescriber inventory to see what the patient is prescribed, or if you can check with the pharmacy that they commonly use, try to ground yourself in some truth about this individual. Really ask yourself, "Is this really a med-seeking individual?" This is an important question to ask ourselves because we are in the midst of a crisis with opioid use and deaths. Somebody that prescribed something very short term (opiates) directly or indirectly created a longer-term problem for a lot of people. From here, I need to kind of position this person for more appropriate care or help this person in a different way. As a healthcare provider, I have to consider: have I created a more nosocomial issue? What if we do create dependency?

Your instrument has to be calibrated, and if you're feeling this way about the person, you're not calibrated; you're not in the moment to use your best self.

I think in that situation, the first and most important thing is acknowledging your own experience of what's going on. What's really important for people to realize is, for psychiatrists, you're the instrument. Like a surgeon that has their scalpels, we do our work with ourselves. Your instrument has to be calibrated, and if you're feeling this way about the person, you're not calibrated; you're not in the moment to use your best self. So, if you are feeling some reaction towards the patient, don't suppress them. Find supervision, talk about them, think about them. Think about what interaction that brings, and then it's trying to ground yourself to let your logical brain kick in. If you balance the logical brain and the emotional brain, much like wise mind in DBT, you'll likely be able to make a good decision.

Snyder: That is such a great analogy. We are the instruments, and we need to be sharpened or calibrated. Otherwise, we become dull, and from my Eagle Scout days, dull knives lead to injuries, and dull knives make for longer, less efficient work. And frankly, less fulfilling work!

Floyd: Right, and consider other aspects of care: with a treatment plan, do you actually believe in them? Or are they laborious and formulaic, and they become actually just box-checking drudgery? A treatment plan doesn't have to be 9 million goals, it could be 1) diagnosis: trauma 2) decrease hyper-vigilance and 3) will work PRACTICE skills. It can be very simple. It could be the end of a note, but it's having the patient agree this is the treatment plan, and this is something their provider believes in. If that patient (I'm still talking about the Xanax-seeking patient) at that time doesn't agree, then they aren't a good fit. And then it's making a referral, but it seemed very clear documentation of "This is what I thought. I thought it was trauma. It actually wasn't depression. Treatment recommendations were to bring down the hyper-vigilance, I recommended the TF-CBT, and the patient refuses fees to do that. I recommended other pharmacological options, and the patient refused to do that. At this point, we had decided that a referral for another provider would be appropriate." So, in all of what I just said, I'm not saying kick the can down the road. I would say to that patient, "I think that you need help, I think you need to come off Xanax. This isn't a problem that is going to go away on its own or by taking more of it." It's just being true to what you can do, what you can practice, and knowing your scope.

Snyder: It's really thinking with the end in mind, and being empathetic with someone doesn't mean just giving them what they want. For example, with parents, it may seem unfair to the child that they can't have ice cream for dinner, but as a parent, you know what is in the best interest of your child to grow up healthy. The big picture approach also has to recognize that here is what we can do now, here is what we can do later if this doesn't work...here are the people in your world. We need to get on board and help support you...And I'm stuck on the idea that you are your instrument in psychiatry, probably because we talk about self-care so much. That calibration metaphor can translate a lot differently to non-physician clinicians, that we are the instruments, that we need to make sure that we have our countertransference calibrated.

That's why we become physicians, to help people live healthier lives across the different parts of their life; domains of health and wellness are all connected to each other.

Floyd: Right, you are the instrument; you're also the intervention. Your detection and care after identifying the problem are from your brain! So, if you are tired, or if this is not the population that you can work with, or if this isn't a great time in your own life, or you just have too many trauma patients right now, or you're just doing too much, that's going to impact your clinical work. It's actually going to change your view of your patients and yourself.

Snyder: It is hard not to personalize when you can be so many things in a therapeutic relationship. So, here's my pitch for spiritual self-care. Clinicians! Make sure to check in with your worldview, your view of your patients, your value systems. We can have personal missions drift over time. Ok, so last couple of questions for the engagement portion of our talk. Let's focus on the family. We're looking at the family as a system, caregiver, and child. And the family is situated in systems, and the child is developing. So, there are a lot of moving parts. I want to pull apart those systems to focus just on the child. So, what's it like to engage with a child?

Floyd: Oh, that's the best part. I think that for me, it's engagement around play. That's something that's come back into my life in this new kind of practice and engaging in its ability to find out if there is play and what comes with it like reciprocity, seeing how the child responds to praise, trying to see if it can get a little bit of frustration. I'm not pushing for a meltdown but setting expectations to see if the kid can actually meet them in the office. So, whether I have an expectation like "it's clean up," or "if you've been respectful, you can have a sticker," or "I have a treasure box in my office, let's see how you behave during our visit. Setting the expectations early and trying to see how the child kind of responds in that moment is where I start.

For me, the engagement in that first session with the child is about the kid feeling comfortable with me at that moment. And so, the first interview or the first visit, the parent and the child initially come in together. I introduce myself; I tell them what I do, I let them know no shots, and after this introduction, I ask if anybody has any questions that they really need to know, got to know right now before we go on. And even though I say no shots, kids will ask me, "No shots, right?" and parents will ask me, "Is it really going to be over an hour?" After that, I ask the hardest question of the day, "So somebody's going to come with me to my office, and we're going to get to know each other a little bit. Who wants to go first?" And I kind of watch what happens with the parent and the child at that moment. If it's the parent, then the parent in that way is able to speak freely about the child. I find it really hard when parents and adults have non-developmentally appropriate conversations in front of the child about their behavior. It's trying to interrupt blaming behavior and so that the parent can speak freely without the child internalizing a working model that their parent doesn't love them. So, I let the parents talk freely alone, and they're not expecting that.

And then I have my time with the kids, I'll do my play activity, and then we all come back together and get the general feedback of "what did you think?" And then I tell them what I would need from them, whether it's labs or additional releases or whatever. I have a shorter appointment for follow up to check in, see if I'm a good fit, see if the treatment plan is feasible and appropriate.

And it's just helping them on their journey. And I have to look at it as a family journey. If a parent has other issues, for instance, I've had parents with their own substance use issues or have their own trauma, sometimes I need to have a parent-only session to pare those things out. Again, these are the things that do not necessarily need to happen in front of a seven-year-old at that first visit. I feel a sense of responsibility to give them an opportunity because they have carried a lot of things for a long time.

Snyder: I think you're getting at when the child's therapy ends up becoming the parents' therapy. So, engage with them, set clear boundaries of who we're here to support in this child's appointment and help the parent out in their own sessions or ensure that they have their own clinician for their own long-term care.

Floyd: Right, and it doesn't mean I won't have parent-only sessions. I have a parent right now that is very triggered by something their child did and that person needs their own treatment to deal with that trauma trigger that they've experienced from their child. But when we are here for your child's treatment, I'm here to kind of talk with you about how that's changed your lens, how you discipline, and how you parent. But that adult's own individual work can't be the focus of my sessions with your kiddos, because we need to address the child's stuff and how to parent them through it. I have to make a strong partnership.

Snyder: Right, it's coming at it on how the trauma affects their relationship to their child; it won't be exposure therapy or cognitive processing about the event itself.

Our readers will have hopefully looked at the assessment chapter and may know some things about the biopsychosocial approach. And in the pharmacology chapter above, we will see what a psychiatric evaluation is. In your own words, what makes it different doing an evaluation as a physician?

Floyd: So as a physician, we understand the biologic, neurophysiological, and medical aspects of a presenting issue and of pathology. I may find out something about the child's medical history and how it pertains to developmental ranges. When you think about differential diagnosis too, you need to rule out any medical condition that could explain the presentation or if substances are contributing to the presentation. Our medical knowledge then allows us to take a deeper dive into the psychosocial and environmental factors of the child's presenting issue.

As an example, I have a girl with a developmental issue. She has presented to the hospital here 12 times, and I was asked to do an Emergency Department consult (which I rarely do these days). I read up on her history in her chart, and when I saw her, she looked dysmorphic. To me, that changed my entire overview of what everybody else says, of what was put in her chart. So instead of just starting her on something for impulse-control or mood lability, I wrote for a workup that included genetic and neuropsychiatric testing. We found out that the child's IQ is 56, and she does have a heritable genetic disease. Her behavior was getting her referred to delinquency court, and this comprehensive work up I did with her changed her placement options. She could go for treatment, as opposed to being shipped off to a juvenile correctional facility. Some of her externalizing behaviors were related to her emotional and intellectual maturity. So as a psychiatrist, I may take on more of the biological aspects than a psychologist, and I have more psychological insight than a pediatrician because of my training. I focus a lot of my time making sure that the other domains are cared for, like education, physical health, physical health things. So, for those physical health things, I'll call their pediatricians, because I want their thyroid function to be followed by an endocrinologist and the pediatrician can help with monitoring other things.

I think also with that lens comes trying to understand if you're really, really with pharmacology. You have to think about what's medical and what's not. If you're talking about ODD, sure a medication could help with comorbid impulsivity, but your treatment plans should really be thinking about parent management training. So yes, in an evaluation, a psychiatrist can act as the gatekeeper of what is actually under the purview of medication versus what is more of a behavioral or psychosocial intervention that is indicated.

Snyder: Of course, we can't medicate a parent-child interaction or a family systems issue! The relationships need work.

Floyd: For sure, and I do take "guardianship" of the physical part of it. So, in my formulation, I will note that they live in a food desert, I know that the neighborhood is dangerous, and they cannot exercise. That there are so many things that need to be considered to support the health and development of this child. And considering the presentation, I have to then reconcile what can be done in twice-weekly therapy for a month and what needs to happen outside of therapy to see if I can get more traction. Do I introduce a mentor? How do I take care of the welfare of a child knowing that all of these things influence their physical, emotional, and spiritual development?

Snyder: What you're describing is really looking at the child in a positive way, meaning less about pathology and more from the lens of just health and wellness. Right. Sure, maybe there is some neuroconnectivity issue that medication can assist with, but what about health promotion, looking at, physical health and wellness, social health and wellness, emotional health and wellness. So, it sounds like from your perspective, it's asking, "How can I look through this lens of wellness for this child and touch on all these domains of their life?"

Floyd: Of course, that's why we become physicians, to help people live healthier lives across the different parts of their life; domains of health and wellness are all connected to each other. And some of those questions we have to ask are along the lines like "Are you going to the dentist? Do you eat lunch? Are you going to bed on time?" For me, there are so many other pillars of health that have to be there, whether you think about a pillars of health approach, or whether you think of Maslow's hierarchy. Wherever you conceptualize it, you can't just take your piece of the child and go with it. You can't shortchange a family by being a lone wolf in caring for them; there are plenty of other factors in this child's life.

Snyder: That's the developmental systems approach in a nutshell. There are multiple systems at play that produce the presenting problem, and they occur within a particular developmental window. The response to such problems requires systems of care and systems of wellness, the pillars of health you mention.

Floyd: Right, don't feel you have to manage it yourself. I made it a part of my practice just to work with pediatricians, and some out there actually enjoy working with different populations. That peer network is an amazing resource. I have somebody I can call if something doesn't look right, so I don't just ignore something or overlook it because it makes me uncomfortable.

Snyder: At the end of the day, it's always about patient care and considering what's the best thing for this patient.

Across all of what we talked about, you touched at times about intervention and a lot of different ways you address things like considering different domains and what to do. So now, I want to target intervention in the more pointed way that you do in your evaluation. What's running through your mind as you do your formulation? You get to your diagnosis, then you think, what treatment recommendations do I make? Are there common things that you recommend or approaches you take to recommendations?

Floyd: There can be two camps with recommendations. So, when I was a resident, I had my treatment recommendations like this is what I'm doing for depression: we're hitting sleep, we're looking at food logs. In my mind, I would check yes, this is what we're doing, an antecedent consequence logic, an if/then. So, in some ways, yes, you should always have your standard of care things, and you should always have ways to track what you're doing, like if it's the CPSS-5 for trauma symptoms or something simple like the PHQ9. Or do something like the CRAFFT. Track if there's adherence or therapy interfering behaviors.

Then on the other side, there is a bit more of an open approach. It recognizes that if we start with something, we need to be open to feedback. There's another part of an intervention that tries to figure out how this time can be different for this child. It's really just thinking about what is going to get this on a developmental trajectory that can promote health and wellness.

Snyder: So, on one end, it's pushing the trajectory in one direction with the intervention, then the other approach is trying to re-integrate aspects of the child's life that were thrown into discontinuity before or after the onset of illness. It's organizing it so it can be self-corrective, as opposed to the physician-directed correction.

Floyd: And when I talk to families about interventions, I take their temperature and ask them, is our meeting today as you expected? Did you get all your questions answered? I'm very honest with them again. Some of the kids may have been seen by other people, and I tell them that I have to learn about their family. I have to catch up on it. So, it's acknowledging that I'm not up to speed because this was our first visit, and I need to bring you back. And it's setting up a few appointments out because I really need to know what I'm treating to actually treat it. I can't usually get it in one visit; otherwise, I would be relying solely on biases like case history or biases about what has worked for me as a provider. And I try to see them within two weeks and check in with them between visits to see if they have a therapist. And when I have follow-up appointments, it's good to have your battery of inventories to help track things so you can have an honest conversation. So, on this Ohio scale, you presented initially as really high, and now it's actually in the middle, we're actually moving. And sometimes that's enough to change the parent's lens of therapy and lens of the child. I don't want to set up the expectation that if you do this, all of your problems will go away. I It's holding up the idea that behavior change takes time and that a lot of outside things can influence change, for instance, a pandemic, parent stress, the change in the marking period where the child gets a new teacher.

Snyder: It's transparency and collaboration. It's having the working hypothesis, sharing it with the family, working through potential treatments. Like you said, this isn't just a matter of doing an EKG where there's a firm reading and there's a corresponding treatment. When we treat emotional and behavioral problems, we are seeing that kids change across time, seeing the presentation change across time as it is influenced by the environment.

Floyd: Yeah, so I think being honest about what we're working toward after the first visit. Again, my lens is I'm trying to get you back on to your "psychological growth chart" and that is an evolving process. This didn't happen overnight, nor is it going to be fixed overnight or after one visit. I also remind them that our meeting is one aspect of getting them back on the right track. I'll recommend school supports, or mentorship, or prosocial activities, and therapy, and oh yeah, medication if that is appropriate.

Snyder: Considering environmental influence and developmental time, a child won't be frozen in time until the next visit; they are continuously developing day after day. I've referenced this elsewhere, with newborns, they grow so rapidly on a physical level, and so they have to adjust to walking or crawling every day because their body is different from the day before. Emotionally, too, when we look at children, the way they were yesterday is different than today, and there can be some general growing pains, and sometimes, there are cumulative effects of those pains. This kid is having an ongoing narrative being written in real-time.

Floyd: Of course, like say you have a very depressed kid, and they come in, they think you're going to fix it in one day because that's the narrative, the depression has to be corrected so that child doesn't leave feeling hopeless. But what I can do when I close that session out with a family is that there is the possibility of the future being different. That's where I end with the family, it's thinking: how can I help this child and family to open possibilities for a narrative of health and wellness, in which they feel empowered, energized, and content with their quality of life? No feeling is final, so we need to be open to the idea that things could be different. And to go back to the beginning of this interview, that condition of possibility needs a clinician that listens, that has a sense of boundaries, transparency, a spirit of collaboration. We are the instrument and the intervention, so we need to make sure we are calibrated to make the best impact that we can.

Things Clinicians Should Know

Psychiatric assessment: Much of this assessment mirrors a biopsychosocial evaluation, and there are a few key areas that only apply to physicians: the physical evaluation (including a review of systems), the assessment of health and wellness via diagnostic tests, and pharmacological recommendations.

Physiological considerations: Children's body composition and body development play a vital role in the selection of medications. The way a medication is absorbed and processed in a child differs greatly from that with adults.

Recommendations: The key aspect of treatment planning is treating the syndrome and not the symptoms with medication intervention.

Consent/assent: Consent involves the client having capacity to make an informed decision based on the available information provided to them by the physician regarding risks, benefits, side effects, and alternatives to treatment. Assent is the child's indication for agreement to engage in a treatment.

Cultural competence: Patient-centered care involves understanding the family's view about medication, how psychopathology is viewed within their culture, and consideration of complementary approaches that can engage patients in care.

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PART II

THERAPEUTIC APPROACHES FOR SPECIFIC DISORDERS

6

Chapter

Intellectual Disabilities/Intellectual Developmental Disorders (IDD)

Donovan Richardson, MA; Sean E. Snyder, MSW; Jessica Reinhardt, PhD

Javier is a 20-year-old, Latinx, first-generation, cis-gender male from an urban city, identified with an Intellectual Developmental Disorder. He enjoys video games and helping people. He has a warm and supportive family and is the oldest of his 3 siblings. Javier receives post-secondary special education support. He began receiving special education services in kindergarten. He also attends coursework at a local college that provides a specialized instruction program which provides a college experience among his chronologically aged peers and with others with similar academic performance needs.

As we will see throughout this chapter, Javier represents the reality that intellectual disabilities have implications across the lifespan, from early childhood through transition to adulthood.

Our goals in this chapter are the following:

- Understand Intellectual Disability/Intellectual Developmental Disorder as a health condition

- Apply a developmental systems theoretical perspective used in healthcare to provide appropriate environmental support for those living with Intellectual Disabilities
- Consider the Lived Experiences of those living with Intellectual Disabilities
- Provide a framework for understanding the importance of autonomy, motivation, self-determination, and collaboration can provide an opportunity for favorable outcomes upon service delivery

Overview of Intellectual Disabilities

Names matter. In disability services, the proper identification and naming of a disability provides the gateway to remove physical and social barriers that prevent individuals from expressing their capabilities (Melrose et al., 2015). Naming empowers individuals, but it also can have negative consequences. As described in the disability work by Melrose et al. (2015), history has had its share of discrimination towards those with disability. They note that before the 1900s, the word idiot was used throughout much of the world to describe a generally vague class of individuals who were not considered to be “normal.” Membership in this class was often assigned simply because individuals were thought to deviate from “normative” abilities.

Terminology shifted over the years, highlighting a social construction of the notion of intellectual disability. The term “feeble minded” became common and then divided into three categories: moron, imbecile, and idiot (Melrose et al., 2015). These predated the categories of mild, moderate, and severe/profound mental retardation, and, after the development of IQ, became the categories of disability in that system (Kastner & Walsh, 2009; Melrose et al., 2015). This term fell out of favor as the field began to view these challenges through a developmental lens, specifically that those with intellectual disabilities were developmentally arrested or had a slow developmental rate (Melrose et al., 2015). The idea of “slowness” then gave way to the term mental retardation.

The American Association on Mental Deficiency (now the American Association on Intellectual and Developmental Disabilities or AAIDD) issued its new diagnostic and classification manual in 1961 (Melrose et al., 2015), and this manual replaced the terms moron, imbecile, and idiot with mild, moderate, severe, and profound mental retardation (Melrose et al., 2015). Additionally, the manual included the category borderline mental retardation for those whose IQ test scores lay between one and two standard deviations below the average

IQ of 100 (Melrose et al., 2015). IQ standards changed 20 years later to articulate that people with IQs from 70 to 85 were no longer considered to have mental retardation (Melrose et al., 2015). These changes of criteria and categorization further demonstrate that intellectual disability is largely influenced by social constructs of ableism.

The term mental retardation is no longer used because of the pejorative nature of that label and because it does not capture the real phenomena experienced by the individual. Current terminology that attempts to be more representative include developmental disability, which is an umbrella term to include physical disability like epilepsy, cerebral palsy, autism and intellectual disability (Melrose et al., 2015); however, this term can be confusing because it lacks specificity. Mental disability is another term; however, it can lead to confusion between the ideas of mental illness and intellectual impairment (Melrose et al., 2015). Learning disability refers to the specific learning disabilities that impact learning but do not denote intellectual impairment (e.g., dyslexia) (Melrose et al., 2015). The term developmental delay has been used when discussing intellectual impairment. However, while individuals with intellectual impairment commonly experience developmental delays, not all individuals with developmental delays experience intellectual impairment. In summary, naming the experiences of the child should be specific and support their self-determination. (Melrose et al., 2015).

For the behavioral health practitioner, the DSM-5/DSM-5-TR (APA, 2013; APA 2022) can pose to be a stumbling block. This diagnostic manual requires deficits in intellectual functioning and limitations in adapting to environmental demands prior to age 18. According to the DSM-5-TR, a person with an Intellectual Developmental Disorder must be determined to have deficits in intellectual functions confirmed by both clinical assessment and individualized standardized intelligence testing with onset of intellectual and adaptive deficits occurring during the developmental period before the chronological age of 18. There are several well-known cognitive assessments which are discussed later in this chapter. IQ score alone is not sufficient to make the diagnosis of IDD. The youth must also have significant deficits in adaptive functioning that result in failure to meet developmental and sociocultural standards for personal independence and social responsibility. Ideally, adaptive functioning should be formally tested, and there are several well-known standardized measures of adaptive functioning that are discussed later in this chapter. Considerations of cultural and community or environmental context must also be part of a valid assessment.

For behavioral health practitioners in school settings, the Individuals with Disabilities Education Act (2004) is a federal law that provides funding to local educational agencies to educate students with disabilities. Intellectual Disability is one of 13 disability categories recognized by this law. “Child Find” is a component of the law that requires states to have a comprehensive system to *locate, identify,* and *refer* as early as possible all children (birth to 21) with disabilities, for early intervention or special education services. Part C of IDEA pertains to children birth to two years of age. Part B of IDEA pertains to children through age 21. The criteria for Intellectual Disability under IDEA is nearly identical to the DSM-5-TR criteria. To be eligible as a child with an Intellectual Disability, there must be evidence of each of the following criteria (Individuals with Disabilities Education Act, 2004): “means significantly subaverage functioning, existing concurrently with deficits in adaptive behavior and manifested during the developmental period that adversely affects a child’s educational performance.” According to the ECEA 2.08 (4), a child with an Intellectual Disability “shall have reduced general intellectual functioning, existing concurrently with deficits in adaptive behavior and manifested during the developmental period, which prevents the child from receiving reasonable educational benefit from general education.”

State regulations further specify the process of identifying IDEA. For example, the Colorado Department of Education (2013) specifies the following criteria:

> To be eligible as a child with an Intellectual Disability, there must be evidence of each of the following criteria: (1) A full-scale score of 2.0 or more standard deviations (SD) below the mean on individually administered measures of cognition; and (2) A comprehensive adaptive skills assessment based on a body of evidence that reflects the child’s social, linguistic and cultural background. The level of independent adaptive behavior is significantly below the culturally imposed expectations of personal and social responsibility. The body of evidence shall include results from each of the following: a. A full-scale score of 2.0 or more SD below the mean on a standard or nationally normed assessment of adaptive behavior; b. An interview of parents; and c. Observations of the child’s adaptive behavior that must occur in more than one educational setting. A discrepancy must occur in two or more domains related to adaptive behavior in more than one educational setting. (3) An Intellectual Disability as described above, prevents the child from receiving reasonable educational benefit from general education, as evidenced by the following criteria: a. A deficiency in academic achievement, either as indicated by scores of 2.0 or more SD below the mean in a formal measure of language, reading, and math, or a body of evidence on informal measures when it is determined that reliable and valid assessment results are not possible due to the student’s functioning level.

An Intellectual Disability as described above, prevents the child from receiving reasonable educational benefit from general education due to the student’s functioning level (Individuals with Disabilities Education Act, 2004).

At times individuals with IDD may be served under other special education categories, with Multiple Disabilities being most often:

> Multiple disabilities means concomitant impairments (such as intellectual disability-blindness or intellectual disability-orthopedic impairment), the combination of which causes such severe educational needs that they cannot be accommodated in special education programs solely for one of the impairments. Multiple disabilities does not include deaf-blindness (Individuals with Disabilities Education Act, 2004).

Prevalence of Intellectual Disabilities

Consistent with the bell curve, about 2% of the population falls into this category. Of those who do meet criteria for IDD, the vast majority (85%) would fall into the mild severity level for each domain (Alim et al., 2014; Emerson & Hatton, 2007; Wallender, Dekker & Koot, 2006): have the potential to reach 3rd to 6th grade skill level in reading, writing, and math and may be employed and live independently. About 10% would be considered to have a moderate intellectual disability, being able to master basic reading, writing and self-care with some supervision (Alim et al., 2014; Emerson & Hatton, 2007; Wallender, Dekker & Koot, 2006). About 5% would be considered at the severe level of IDD, with limited functional self-care skills and requiring oversight of daily environment and activities. Less than 1% are profoundly disabled, needing intensive support (Alim et al., 2014; Emerson & Hatton, 2007; Wallender, Dekker & Koot, 2006).

Although the majority of children and adolescents who meet criteria for IDD do not meet criteria for another mental health disorder, a disproportionate percentage (35 to 49%) of children with IDD do (Emerson & Hatton, 2007; Wallender, Dekker & Koot, 2006). Emerson and Hatton (2007) found in a large sample of British children a higher likelihood of autism spectrum disorder, ADHD and conduct disorders occurring among children with IDD compared to those not diagnosed with IDD. This is similar to what has been found in other studies.

Prevalence of co-occurring mental health disorders is significantly higher than among children without IDD. Several studies have shown that the prevalence rate of other mental health disorders is about 40% among children and adolescents with an IDD diagnosis. Emerson and Hatton (2007) found a 36% prevalence rate among a large sample (N= 7977) of British children and adolescents with IDD compared to those without an IDD diagnosis. Any conduct disorder was at 20% compared to 4% for children with no IDD diagnosis in the sample. Any anxiety disorder was at 11% among the children with IDD compared to 3% among children with no IDD diagnosis.

How Intellectual Disability Develops in Youth

Intellectual Developmental Disorder/Intellectual Disability is not a single or isolated disorder; the overall causes of intellectual disability are most often attributed to genetic or chromosomal conditions or prenatal teratogens or other insults. There are several hundred genetic causes of IDD. IDD is noted in a wide range of neurodevelopmental conditions including autism spectrum disorders (ASD), Fragile X syndrome (FXS), Rett syndrome, tuberous sclerosis, and a spectrum of non-identified etiologies (idiopathic IDD), as is the case for Javier. The most common single gene cause of IDD is FXS; the most common chromosomally caused disorder is Down Syndrome. Fetal Alcohol Spectrum accounts for the most cases of IDD due to prenatal exposure (Siegal et al., 2020; Toth et al., 2021). A review of etiology of intellectual disability by Toth et al (2021) present genetic and chromosomal influence numbers: Down Syndrome (1 in 800 newborns); Fragile X syndrome (1 per 4000 males; 1 per 8,000 females); phenylketonuria PKU (1 in 13,500 to 1 in 19,000 newborns). They also note environmental influences such as exposure to teratogens during fetal development; Fetal Alcohol Spectrum Disorders (1% of live births); FAS (.5 to 2 per 1000 births); prenatal and perinatal infections such as toxoplasmosis, herpes; difficulty during labor and delivery, asphyxia are the most common causes of IDD. Postnatal up through adolescence including accidents that result in head injury or loss of consciousness and illnesses such as meningitis (Toth et al., 2021). The primary risk factor was equally distributed across prenatal (including genetic), perinatal, and postnatal causes, although it was unknown in almost half of the cases (Siegel et al., 2020, p. 471).

Javier's Early Childhood Development

Javier was not identified with any birth complications. Javier's parents, who immigrated to the United States, prior to his birth, received support from their Latinx community. In his early years, Javier's parents noticed some significant delays in his developmental milestones. He spoke first words at 2.5 years old and was delayed in acquisition of both English and Spanish words; at times, he demonstrated echolalia. He also experienced some challenges with word formation and developed a stutter. Javier pronounced words differently than other children at his age. His major point of communication was pointing and making sounds that were not fully formed words. His parents describe that they understood what he needed. He received speech therapy from age 2-3.

Navigating medical support for Javier presented challenges; he was frequently sick and required tubes in his ears. His parents were committed and responsive to Javier's medical needs. However, his parents initially experienced language barriers when they were initially seeking community health resources.

Developmental Systems Considerations for These Disorders

Children with IDD are often identified as having delays in core areas of functioning and receive support services through local agencies between birth and age two. Indeed, early identification of IDD offers the opportunity for intervention. Funding for early intervention is provided by IDEA Part C, which covers Early Intervention to Infants and Toddlers with Disabilities. Part C requires states to establish "A comprehensive child find system . . . including a system for making referrals to service providers . . . that ensures rigorous standards for appropriately identifying infants and toddlers with disabilities for services…"(IDEA, 2004). Research suggests a relationship between motor skills in early childhood and cognitive development (Piek, Dawson, Smith, & Gasson, 2008) and a relationship between motor and language skills in early childhood and cognitive development among children with typical and atypical development (Houwen et al., 2016).

Children with IDD often experience delays in the acquisition of language abilities in early childhood; such delays are heterogenous. Some researchers posit that language and motor differences in early childhood often contribute to social challenges of children with IDD (Piek et al.; Houwen et al.). With consideration to Javier's childhood history, he began getting support with his speech and language development needs at age two when his parents noticed that he did not speak much and rarely used words to communicate, outside of calling for his mother or father. Javier's parents did notice that his development was slower than the children in their family. After speaking with his pediatrician, Javier's parents explored early intervention services to support his developmental delays, centered on support from a speech and language pathologist.

Javier's parents noticed progress in his speech and language development. Javier entered pre-K with his neighborhood public school. Javier's teachers noticed that he often stayed to himself and had some difficulties with gripping pencils and crayons. Javier's teachers noticed that he got upset often when taken away from an interest activity. The educators in his school noticed that it took him longer than many other students to gather himself during these episodes. At age 6, Javier was able to show some mastery of toileting. Javier entered kindergarten at age 6. He enjoyed being at school with other students. In kindergarten, his social interaction with his peers did not significantly change from his time in pre-K. His kindergarten teacher recommended that he seek additional support at a local outpatient mental health provider due to his anger outburst. He was later identified, by an outpatient mental health provider, with Intermittent Explosive Disorder (IED). This was based on his home life and his frequency of fighting with his younger siblings or breaking his toys when he was upset. At age 9, Javier was given his diagnosis of IDD based on the continued delays in milestones when compared to his peers, like his inability to tie his shoes, his naïveté towards social engagement with peers and adults, challenges with task completion at home, and difficulties completing classwork and homework assignments at school. His diagnosis was given by his pediatrician.

Javier's parents faced communication challenges in his care with both school and medical professionals, due to the language barrier and the fact that the family was still trying to navigate living in an urban environment in the mainland part of the United States. Support for family members is critical throughout this process. Raising a child is not easy, let alone those with more adaptive needs in a world that may not be as accessible as it needs to be. As Javier progressed through middle school and high school, he showed uneven learning patterns, limited problem-solving skills orthopedic impairments (hand formation and fine motor skills) and sensory preferences for tight clothing and dim lighting.

Javier's School Life (K-12)

Javier was able to enter public schools once he mastered toileting. Therefore, he was one year older than most of his peers when he started kindergarten. Javier liked school and interacting with others. At times, he demonstrated behaviors which concerned his teachers; he externalized moments of frustration by throwing things, screaming, and yelling. He received services as an English Language Learner (ELL) but made minimal academic progress and had challenges with socialization, communication, and activities of daily academics such as organization and following directions. In kindergarten, he was identified with a primary disability of Speech and Language Impairment (SLI) and secondary disability with a Specific Learning Disability (SLD). He was provided with special education services. In third grade, Javier was re-evaluated for special education; his overall cognitive functioning was estimated to fall within the Moderately Impaired range. His receptive and expressive language skills were his areas of greatest weakness. He was reported to have very significant deficits in his adaptive skills. Based on the evaluation data, he was identified with an Intellectual Disability in school. Javier's pediatrician confirmed a diagnosis of IDD around this time.

In addition to a developmental understanding of IDD it is prudent for practitioners and researchers to consider intersecting identities. A complete review is beyond the scope of this chapter. That said, a brief introduction to experiences across race and ethnicity and LGBTQIA+ youth is considered. Regarding experiences across race and ethnicity, health disparities in BIPOC individuals with IDD exist, as well as an oppressive history of weaponizing IQ tests for the purposes of segregating BIPOC youth in schools. Health disparities are particularly apparent when youth transition to adult service systems (Lotstein et al., 2010), and this holds true with youth with IDD. Scott & Havercamp (2014) report that racial/ethnic minority adults experience disparities in healthcare utilization. In particular, Hispanic American adults with IDD are most underserved in health care. Lotsein et al., (2010) suggest that these disparities emerge as a result of insurance-related problems, living in low-income/low-resource communities, or other sociocultural factors. Additionally, considerations of sexuality and provision of sex education is often missing in discussions and services for youth with IDD. A common myth about youth with IDD is that they are "asexual" or do not have a sexuality. This is a harmful assumption for all youth with IDD, and especially so for LGBTQ youth with IDD. This oversight can lead to exclusion from sex education or HIV prevention programs, placing these youth at greater risk for contracting HIV (Duke, 2011; Wilson et al., 2016).

Assessment of Intellectual Disabilities

The American Association of Intellectual Disability (2021) defines intellectual disability as a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 22 (AAID, 2021). The following guidelines are presented to identify intellectual disability:

1. **Intellectual functioning**, also called intelligence, refers to general mental capacity, such as learning, reasoning, problem solving, planning, judgment, and academic and experiential learning. One way to measure intellectual

functioning is an IQ test. Generally, an IQ test score of around 70 to 75 indicates a limitation in intellectual functioning.

2. **Adaptive behavior** is the collection of conceptual, social, and practical skills that are learned and performed by people in their everyday lives.
3. **Conceptual skills** include language and literacy; money, time, and number concepts; and self-direction.
4. **Social skills** include interpersonal skills, social responsibility, self-esteem, gullibility, naïveté (i.e., wariness), social problem solving, the ability to follow rules/obey laws, and the ability to avoid being victimized.
5. **Practical skills** include activities of daily living (personal care), occupational skills, healthcare, travel/transportation, schedules/routines, safety, use of money, and use of the telephone.

Standardized tests can also determine limitations in adaptive behavior. But in defining and assessing intellectual disability, the AAIDD stresses that additional factors must be taken into account, such as the community environment typical of the individual's peers and culture. Professionals should also consider linguistic diversity and cultural differences in the way people communicate, move, and behave. Finally, assessments must also assume that limitations in individuals often coexist with strengths and that a person's level of life functioning will improve if appropriate personalized supports are provided over a sustained period.

AAIDD (2021) has created a four-tier level of need that should match what the person needs to live most independently. The level of need suggests the level of support needed to function fully. Levels of need range from intermittent assistance only during transitions or larger stressful events to pervasive. Some research exists suggesting that with appropriately matched and sustainable personalized supports, the life function of the persons with intellectual disability generally will improve (Luckasson et al., 2002, as cited in Schalock, Luckasson, & Shogren, 2007, p. 118). This moves us from a deficit understanding of disability to a normative understanding that disability is part of the human condition, and every human being needs support. See Table 5-1 for AAID definitions of each level.

The present authors advocate for a comprehensive review of records, multiple interviews, observations, and standardized testing when assessing for intellectual disabilities. Assessment of intellectual disabilities relies on formal testing for intelligence and adaptive functioning. Common symptoms of IDD include presentation of language, problem solving, decision making and reasoning abilities that are well below other children of the same chronological age. Alim and Hearn (2014) point out that there is a wide range of cognitive profiles and etiologies presented among children who meet criteria for IDD. Traditionally, a formal IQ score below 70 had been considered a threshold score that resulted in the diagnosis of earlier DSM labels of mental retardation. This cutoff score is no longer listed in the criteria of DSM-5, which also changed the name to intellectual disability disorder. DSM-5 places more emphasis on the child's adaptive functioning in addition to IQ scores and a more comprehensive assessment (American Psychiatric Association, 2013).

Three specific criteria must be met for a DSM diagnosis of intellectual disability: 1) deficits in intellectual functioning, 2) deficits of adaptive functioning, and 3) onset before age 18. The DSM-5 no longer specifies a specific IQ score as in the past, although diagnosis requires clinical assessment and individualized standardized intelligence testing that demonstrates "deficits in intellectual functions, such as reasoning, problem solving, planning, abstract thinking, judgment, academic learning and learning from experience…[and] deficits in adaptive functioning that result in failure to meet developmental and sociocultural standards for personal independence and social responsibility" (APA, 2013) The criteria further specify that limits in adaptive functioning must exist in one or more daily activity.

Child/Client Interview Questions

Practitioners are encouraged to modify and adjust questions in culturally responsive and developmentally appropriate ways.

- What are your strengths? What do you do well?
- What do you do for fun?
- Passions?
- Tell me about your friends.
- Tell me about things that are easy at school?
- Tell me about things that are hard?
- Tell me about things that are hard at school?
- What do you like to do with your friends/siblings?
- What do you like to do alone?
- How can you tell if you feel happy? Mad? Sad?
- How can you tell if someone else is mad? Happy?
- What are your mornings like before you go to school?
- What is your favorite thing about school? Least favorite?

Family/Caregiver Interview Questions

This interview is designed to obtain a comprehensive history of development and current functioning. When exploring adaptive functioning, the focus should be on what the client can do independently.

- Child strengths/challenges?
- Developmental history? (emphasis on developmental milestones and pre-natal, birth, and post-natal info)
- Social skills ages 2-4?
- Family history of disabilities?
- Medications?
- Interactions with others, such as siblings, caregivers, family members, friends?
- Feeding/Eating?
- Sleeping?
- Toileting?
- Navigating the community?
- Extra-curriculars?
- Group activities vs. individual?
- Can your child follow social conversation and/or directions?
- Are there any aspects of daily living that your child requires more support with compared to others?
- What’s a typical morning like for your family?
- What’s a typical afternoon/night like for your family?
- What are your hopes for your child?

School Personnel Interview

Information about the child’s physical problems, peer interactions, social skills, and emotional state can be productively used in conjunction with more formal assessment methods.

- Student strengths in conceptual, practical, and social domains?
- Student weaknesses in conceptual, practical, and social domains?
- Academic performance
- Student interests? Passions?
- How do they interact with peers in specials and on the playground?
- Does the child behave differently in group work than in individual work?
- Can the child follow social conversation and/or directions?
- How independent is the child in different situations compared to their peers? (Snack-time/lunch, toileting, in-class tasks)

Suggested Observations in Naturalistic Settings

The focus of observations is to determine how the client navigates their world and what they can do independently and what requires support. It is recommended to complete observations across multiple settings, including home, school, and community environments, looking for the presence or absence of age-appropriate adaptive behaviors:

- **3-5 years:** communication, self-care, social skills, and physical development
- **6-13 years:** communication, self-care, social skills, home living, community use, self-direction, health and safety, functional academics, and leisure
- **14-21 years:** communication, self-care, social skills, home living, community use, self-direction, health and safety, functional academics, leisure, and work

Suggested Rating Scales and Measurement

A comprehensive adaptive skills assessment is based on a body of evidence that reflects the child's social, linguistic, and cultural background. The measurement of adaptive behavior typically includes surveys of the child's behavior and skills by trained personnel in a variety of settings, including his or her classroom, school, home, and neighborhood or community. Because it is not possible for one person to observe a child in all of the key environments, measurement of adaptive behavior should depend on feedback from a number of people. Areas of focus include the following:

- **Communication:** Interacting with others, using expressive and receptive language, writing, and listening, etc.
- **Self-Care:** Eating, dressing, hygiene, toileting, grooming, etc.
- **Home Living:** Caring for clothes, housekeeping, performing property maintenance, preparing food, cooking, budgeting, etc.
- **Social:** Getting along with others, being aware of other people's feelings, forming relationships.
- **Motor:** Fine motor, gross motor, sensory motor, etc.
- **Practical Academics:** Literacy and numeracy, etc.
- **Community:** Accessing the community, transportation, shopping, safety, medical, etc.

Parents have many chances to observe their child in a variety of settings; thus, they are usually the best sources of information about adaptive behavior. In addition to parents, teachers and other educators are well poised to provide valuable information on activities of daily living. The most common method for gathering information about a child's adaptive behavior skills in the home environment is to have a school social worker, psychologist, counselor, or someone trained to use the assessment interview the parent using a formal adaptive behavior assessment rating scale.

Adaptive Skills. The follow are common assessments of adaptive skills, all with different requirements and specifications for administration:

- **Adaptive Behavior Assessment System®-Second Edition (ABAS®-Second Edition)** is a complete assessment of adaptive skills functioning and assesses all 10 specific adaptive skills areas specified in the DSM-IV (ages 0-89).
- **Adaptive Behavior Evaluation Scale-Revised-Second Edition (ABES-R2)** provides a measure of adaptive behaviors that are necessary for success **Diagnostic Adaptive Behavior Scale** released (2013) and provides a comprehensive standardized assessment of adaptive behavior (ages 4-21).
- **Scales of Independent Behavior-Revised (SIB-R)** is a comprehensive, norm-referenced assessment of adaptive and maladaptive behavior (ages infancy-80+).
- **Vineland Adaptive Behavior Scales-Third Edition (Vineland-III)** is a

measure of personal and social skills needed for everyday living (ages birth-90+).

Cognitive Abilities. Cognitive abilities are generally measured using standardized intelligence tests or cognitive ability tests. Although the use and misuse of intelligence tests has come under scrutiny over the years (Gould, 1996), intelligence or that said, “IQ tests” are thought to be predictive of IQ stable around ages 7 to 8. There are many different concerns about how intelligence tests, also known as cognitive abilities tests, obtain participants used for normative data. Historically, we know that IQ tests exclude people with intellectual disabilities among the participants; thus, the representation among the participants can be a concern (Sansone et al., 2014). Despite the limitations, IQ tests among those with IDD do present a significant floor effect of the scores. This stratification of IQ testing is used to the exclusion of those with intellectual disabilities for the standardization of IQ test. It can be argued that generalizability of the IQ test is not present since all members of the population are not representative. For this reason, the assessment of IQ among those with IDD is constantly an area of exploration for researchers. Mungkhetklang et al. (2016) explored the non-verbal cognitive abilities of those with IDD along with typically abled (TA) people, where there were not any significant differences among in test scores on non-verbal cognitive abilities in the areas of working memory when verbal language is not required. Mungkhetkland et al. (2016) found that there are clear differences between IDD and TA individuals in task completion in the test where IDD individuals relied on visual memory and TD individuals relied on their vocabulary knowledge. This finding is important as we consider the design of an IQ test, specifically if test administration relies on verbal instructions. The goal of an IQ test is to measure cognitive abilities among participants; if the test does not account for the disparities between verbal instructions and non-verbal instructions, it can be argued the test cannot be representative of the true cognitive abilities.

Common assessments of cognitive skills include the following:

- **Bayley Scales of Infant and Toddler Development, 4th Edition (Bayley-4)** is a comprehensive assessment tool for determining developmental delays in children. The test may be administered to young children across a broad range of developmental levels (ages 16 days to 42 months).
- **Comprehensive Test of Nonverbal Intelligence, 2nd Edition (CTONI-II)** is a nonverbal measure of general intelligence among children and adults. The test is designed to evaluate a full range of cognitive abilities without the use of verbal language and is used for those who may have significantly lowered scores on other tests that rely on oral and written language. It also accounts for any impairment of language or motor abilities (ages 6 years to 89 years, 11 months).

- **Differential Ability Scales, 2nd Edition–Early Years Form (DAS-II)** is a comprehensive, individually administered, clinical instrument for assessing the cognitive abilities that are important to learning (ages 2 years, 6 months to 17 years, 11 months).

- **Kaufman Assessment Battery for Children, 2nd Edition (KABC-II)** is a norm-referenced, individually administered measure of cognitive ability, appropriate for children and adolescents (ages 3 to 18 years).

- **Mullen Scales of Early Learning (Mullens)** provides a complete picture of motor development and cognitive ability in infants and toddlers. This assessment pinpoints strengths and weaknesses, assessing school readiness and understanding overall abilities (ages birth to 68 months).

- **National Institutes of Health Toolbox Cognitive Battery (NIH-TCB)** is a battery of validated computer-administered cognitive tests with utility across childhood, adolescence, and adulthood.

- **Stanford Binet, 5th Edition (SB-5)** is a standardized assessment of cognitive abilities across the life span (ages 2 to 85+ years).

- **Wechsler Intelligence Scale for Children®, 5th Edition (WISC-V)** identifies key cognitive strengths and weaknesses related to learning disabilities, executive function, attention disorders, TBI, intellectual disabilities, and giftedness (ages 6 years -16 years, 11 months).

- **Wechsler Preschool and Primary Scale of Intelligence, 4th Edition (WPPSI-IV)** is a measure of cognitive development for preschoolers and young children (ages 2 years, 6 months to 7 years, 7 months).

- **Wechsler Adult Intelligence Scale, 4th Edition (WAIS-IV)** is an individually administered and standardized measure of cognitive ability for adults (ages 16 years to 90 years, 11 months).

- **Universal Nonverbal Intelligence Test, 2nd Edition (UNIT-II)** is a norm-referenced, individually administered, non-verbal test of intelligence for individuals who have speech, language, or hearing impairments; have different cultural or language backgrounds; or are verbally uncommunicative (ages 5 to 21 years).

- **Woodcock-Johnson Tests of Cognitive Abilities, 4th Edition (WJ IV, COG)** is an individually administered, norm-referenced assessment of intellectual ability (ages 2 to 90+ years).

There is a lack of consensus in both clinical and research practices on which assessment of cognitive abilities is best for identifying and progress monitoring children with IDD. There are well known issues with many of these tests in differentiating in the lower ability ranges. These are commonly known as "flooring effects." Recent efforts have been made to utilize a transformation of z-scores termed "deviation scores" on the SB-5 to provide clinically meaningful information about variations in cognitive abilities of individuals with significant IDD (Sansone et al., 2016). The ongoing research on the NIH Toolkit is in validation phases and is designed to improve its utility for progress monitoring (Hessl et al., 2016). The severity of the DSM IDD diagnosis is to be specified as mild, moderate, severe, or profound for each of three domains: conceptual, social, and practical. The DSM-5 lists narrative criteria for each domain and a clinical determination of which level for conceptual, social, and practical functioning is to be specified as part of the diagnosis.

Assessing Javier with Transition to Adult Care

Javier continued to college and is actively taking classes, despite some environmental changes due to the COVID-19 pandemic. Javier transitions from his outpatient mental health services in the children's department to the adult mental health services department. As Javier's mental health provider, I first explored many of his goals for treatment based on his personal interest. Javier loves video games and wants to find a job in that field when he finishes school. Javier talked about one day leaving his current home, where he lives with his parents and siblings, with the intention to live away from home in a more suburban neighborhood. Javier mentioned that he doesn't like the noise in his current neighborhood and wants to move outside of the urban environment.

At the initial assessment session, I knew of the previous diagnosis of Intellectual Disability Disorder (mild), and there was a previous working diagnosis of Intermittent Explosive Disorder. After further assessment, we determined the outbursts were a result of Javier being placed in situations when he was scared to do something, as he does have phobias of things, like heights. Little was known about his medical history due to the language barrier between the parents and the previous therapist. After reviewing previous treatment plans and obtaining a copy of the Individualized Education Plan (IEP), I was able to understand more of Javier's needs when it came to setting his goals.

Intervention

Early and ongoing intervention is critical in relation to the severity of IDD. There is consensus that intervention that is intensive and multi-dimensional in the first five years increases the potential intellectual developmental trajectory over the lifetime of the individual. In addition, continued intensive intervention working directly with clients with IDD has the best outcomes for continued independent functioning and productivity over the lifetime of persons with IDD. There is great disparity in who receives effective interventions with low-income families less likely to receive early and ongoing intervention. Clinical work with children with an intellectual disability and another disorder should be similar to clinical work with any child or adolescent with this disorder. As always, we will need to match our evidence-based approach to the additional disorder (e.g., anxiety or depressive disorders or disruptive behavior disorder) with the needs and capacities of the child or adolescent. A functional behavioral analysis can be very useful as it will reveal the antecedents and existing reinforcers or negative consequences that the child experiences in relation to the behaviors and emotions associated with the mental health issue. If we scaffold desired behaviors that we wish to teach, we can help our client learn more complex skills.

An integrative approach is most helpful when working with children and adolescents who meet criteria for IDD and another mental health disorder. Including the family and school or other service contexts in ensuring that positive behaviors get reinforced consistently across contexts will increase the likelihood that newly acquired desirable behaviors will be maintained. A simplified approach to psychoeducation and skill building associated with cognitive behavioral approaches to anxiety, depression, PTSD, or disruptive behavior disorders will allow us to use the same techniques with the child or adolescent in a way that accommodates their level of intellectual and adaptive functioning.

Lawton and Aman (2014) point out that Labov's research during the 1970s on effectiveness of intensive early intervention using Applied Behavioral Analysis demonstrated an increase in IQ scores, and, for some children, IQ and adaptive functioning moved into the normal range. Witwer, et al. observe that this degree of change has not been shown among children with IDD who are not on the autism spectrum. Limited research exists on the effectiveness of clinical practice, with 30 to 40% of children with IDD also meeting criteria for another mental health disorder (Soltau et al., 2015; Toth et al., 2021). One study of a large sample of parents found that only a small percentage got helpful treatment. Parents found clinicians not well prepared to work with their children (Soltau et al., 2015). Werner and Stawski (2012) conducted a comprehensive literature review of research from 1995 that examined training of professionals including social workers and counselors in regard to working with children and adolescents who are dually diagnosed with both IDD and another mental health disorder. Their review revealed that little specific attention to this population is given in the education of professionals who work with children in behavioral health. In the UK, mental health services for individuals with IDD are chiefly provided through specialist IDD services; this is not true in the U.S.

Due to the heterogenous nature of IDD treatments, interventions are best selected to match the unique needs of the individual. The authors encourage a focus on self-determination in all aspects of intervention. Ryan and Deci (2017) coined self-determination theory, an idea that explores motivation, autonomy, rewards for oneself, and interpersonal and intrapersonal interactions among families, schools, and societal groups and cultures. Differences among social norms, cultural beliefs, and access to resources based on societal constructs are considerations when taking a self-determination theory approach, especially with those who live with intellectual disabilities. Shogren et al. (2017) explore the value of using self-determination theory for those living with intellectual and developmental disabilities, related to the basic psychological needs of autonomy, competence, and relatedness as applied to educational, vocational, and social interactions. Below is a non-exhaustive list of common interventions and practices:

- Center-based educational programming
- Alternate educational assessments
- Functional academics
- Adaptive skill instruction
- Safety skill instruction
- Social skill instruction
- Mental health services
- Comprehensive sexual education
- Speech therapy
- Occupational therapy
- Physical therapy
- Reverse inclusion
- Transition services
- Vocational training

Interventions for Javier

Throughout elementary schools Javier received speech, language, and occupational therapy, as well as assistive technology, and mental health support services. He was also exempt from taking standardized testing. Javier experiences some writing challenges due to the formation of his hands and gripping writing instruments can be a little challenging.

Beginning in middle school, Javier joined a Level 1 self-contained classroom. His peers included other students with IDD and many with ASD. He also continued to receive special education services including speech, language, and occupational therapy, as well as assistive technology and mental health and academic support services

Javier does experience moments of frustration and is referred to outpatient mental health services by his school at age 14 due to significant outbursts. Javier continues to work hard in his schoolwork and eventually graduates from high school at age 19. He plans to go to college and likes computers. Javier had scoliosis as a child and received surgery at about age 15 years old to address this condition.

Intellectual Disabilities are a heterogonous group of conditions characterized by challenges in adaptive functioning and IQ two standard deviations below the mean. Individuals with ID benefit from school and community supports and can and do live happy and fulfilled lives. Assessment and intervention practices should center self-determination.

Clinical Dialogues: Intellectual Disability and Self-Determination in Practice

Jessica Reinhardt, PhD is a licensed psychologist and nationally certified school psychologist. She is an Associate Professor of Practice and is the director of the school psych program at Temple University in which she oversees the university's psychoeducational clinic and I'm an associate professor of practice.

Katey Burke, PhD is an Assistant Professor of Research in special education at Temple University. She also serves as a senior research associate at the Institute on Disabilities at Temple. She was formerly a K-6 classroom special education teacher in Philadelphia, and she now does research and teacher preparation in those areas.

Pete Gladstone, PhD currently works at the Colorado Center for Assessment and Counseling, focusing on diagnostic evaluations. His research focuses on facilitating improved postsecondary goal attainment for all students, and especially those with intellectual and developmental disabilities.

Sean E. Snyder, LCSW: We have three psychologists who work in different capacities related to intellectual disability service. Considering our topic of intellectual disability, what is it like to engage with families, who oftentimes come in with some concerns about school performance or activities of daily living? How do they even get to you?

Jessica Reinhardt, PhD: Lots to unpack in that question. To start, I think when we're talking about any psychopathology, in particular developmental psychopathology, there is an element of grief that comes with the process for families, to have a child being identified for getting services. And for parents, very often there's a shift in the entire life expectancy for their child, not the vision they had during pregnancy or during their adoption process or however they came to be parents. I think one of the first things that comes to mind on engagement is really the importance of family-school partnership or family condition partnership. Let the parents and caregivers and guardians have spaces to have a voice in the process. Equally of importance is having the individual with IDD have a voice, and that is something that we know historically has been taken away from that population, more so often than other populations. For me, one of the biggest themes with engagement would be absolutely honoring the lived experience of the client and the family.

Pete Gladstone, PhD: By the time we're seeing a lot of children with concerns of intellectual disability in our clinic, it's often because other answers haven't worked out, or attempts with intervention haven't really been successful. So, parents are really wondering what's going on and by the time they get to us, we're seeing parents who are kind of hoping for intellectual disability diagnosis. It might actually provide some answers and help them out. So, on the one hand, we might be seeing them changing their expectations and feeling very disappointed, and on the other hand, we also have to remember that a lot of times these kinds of diagnoses can be really helpful for them in providing answers. That's something that I've been really trying to balance, not trying to sugarcoat anything for them and really helping them understand exactly what's going on, so that they can get the best services possible.

Katey Burke, PhD: I always try to start from a place, especially when considering education, that disability is a natural part of the human experience. That's what's written into the Individuals with Disabilities Education Act and really that's what underpins my view on special education, support and disability as a whole. Most, if not all of us, will experience some form of disability at some point in our lives. And we recognize that often there have been and continue to be stigmas and lower expectations placed for people with disabilities, especially those who have more significant support needs. It's an understanding to not approach from a deficit-based model, but instead focusing on a strength-based model that is focused on individualized supports. From the beginning that would be my biggest piece with engagement: really valuing the input of the family and the person themselves. Understand, too, that as a partner, you're there to look at the whole child and support the whole child, and that support is natural.

> *Disability is a natural part of the human experience. Most, if not all of us, will experience some form of disability at some point in our lives.*

Snyder: I love that, going beyond the ableism bias. Children get to providers via different ways. It could be through primary care, it can be through the school, or, as Pete said, sometimes they've been through so much already, and they're looking for answers. So how do you prepare families for this process where there can be a lot of evaluation that might go on, a lot of school observation?

Burke: Always take ourselves back to a place of plain language and communicating like humans, instead of in our practitioner or clinician speak. We've developed all of these acronyms; we talk about a lot of terminology and categorization. Understand that when you start throwing all of these terms at families, that can already put up a wall and a barrier, and it can also create a power dynamic where the family then feels less comfortable communicating and sharing openly. With that aside, I would say, starting with plain language is a core tenet that we should all be sure to focus on. Two other pieces I would add. One would be an overview of the process, deciding what detail is necessary to go into at the time, because the reality is that there is going to be a lot of detail. There's going to be a lot of paperwork, and that can be overwhelming. Start with what's the high-level overview that will help them understand the process as a whole, before going into the nuances that will be part of each step. The second piece, I would say, would be to consider connecting them with people who are trained to support families, especially parents and guardians, as they go through this process. So, IDEA (there I go with my acronyms!) provides funding for parent training and a technical assistance center. It would be possible to connect families and parents or guardians either virtually or in person at a place that they can talk with people who have materials and resources on exactly this stage in the process of a potential disability identification.

Reinhardt: When I think about having initial conversations with families, I believe that your feedback begins with your first conversation, so use counseling micro skills. When a parent says something, I will reflect it back to them using some of the clinical language, connecting to plain language. Perhaps they're describing some things where the child's having trouble with some self-care and orienting in the neighborhood, and I'd say "I'm hearing you talk about that some of the bedtime routine around hygiene is really hard, and it's different than your other kid. And you worry about them waiting for the bus. We refer to those things as adaptive skills or activities of daily living."

Snyder: A lot of clinical practice is reminding yourself that you have these micro skills, and they are so powerful. I love that, about getting feedback and making sure our biases aren't coming in and that we're actually accurately representing what they're saying.

Ok, now the technical stuff. How do you prepare yourself for doing assessments and meeting the family where they are?

Reinhardt: So, I'm going to start with a controversial statement on this topic. Sometimes depending how old the child and purpose of the evaluation, I change what I'm going to do a little bit. Sometimes I will choose something that potentially could be harder for the child with testing, so the worse their scores look, the more services and funding their family gets to support their life. That's a controversial statement, but that's a reality. Even though I'm all about strengths-based work, and I care about that

> *I would encourage folks to continually challenge themselves and their clients to aim higher because the higher the expectations that we have for the clients with IDD, the more likely they are to reach them.*

so much, sometimes we're really trying to highlight deficits to get services that the child needs. Normally, though, I want to get a very robust whole picture, where there's a profile of strengths and challenges.

Burke: There's a difference of the evaluation and the opportunities for a child. The student's interests and preferences may not always be evident through more standardized assessments; interviewing the child about specific topics or those who are close to the child is an important piece. It can be a powerful tool when planning what's the appropriate path to take with supports and interventions and those types of things.

Snyder: So, let's say I've picked up an evaluation report. How do I even start to read it?

Reinhardt: My first recommendation is to look to see if there were any strengths in the standardized scores and connecting those with interests because you're going to use those to springboard those areas of challenge. I keep an eye out for weaknesses around toileting, eating, sleeping, and eloping because they present safety risks. Those are more adaptive skills, and the adaptive skills can be most salient for day-to-day activities. I would look to see if the report has had multiple informants, does it have the teacher, family, other influential folks. This gives a broad understanding across domains and then getting a multidimensional picture of their preferences.

The people on the report are people that I'm going to want to keep in touch with, that I'm going to want to check in with to make sure we were taking a team approach. Family school partnership is so important. Knowing the providers in the child's world is helpful because you probably have crossover in what you are working on, and if all those people have a shared vocabulary, think about what that does for reinforcement if they hear the same thing in two places. The other part that underscores this: cultural humility and cultural relevance is essential. Whatever you are reading and planning for intervention, view through the lens of culture.

Snyder: What would you say are foundational approaches you take with intervention then, knowing that you are going to get lots of feedback along the way?

Burke: Pete and I both have interest in research on self-determination, and we know that supporting self-determination has strong impacts on a student's experience and their academic outcomes, while they're in school. It also has enormous impacts on post school outcomes, and that includes both likelihood of enrolling in higher education, employment, and living in their desired location in the community. The self-determined learning model of instruction is one of the few areas that has been promoted as an evidence-based practice for supporting self-determination, and we've seen these huge impacts on outcomes especially with students with intellectual disability.

I would say the two areas that I would strongly encourage clinicians to have in mind as they think about how this process goes from engagement to assessment to intervention and support would be 1) strengths-based approach and 2) an inclusive approach. I think we're seeing that shift happen more across education; we see it in psychology with the emergence of positive psychology. I think coming from that place and seeing disability as something that's a natural part of the human experience is an approach that will have an enormous impact on what this child's life looks like in terms of the support they receive. The opportunities that they have to live the life of their choosing is going to look different at different ages, so I think that strengths based and inclusive approach has to adapt with the child's development. While we don't include self-determination as part of diagnostic testing, it is a wonderful consideration because of that strong correlation we've seen between self-determination and outcomes across someone's quality of life.

Snyder: Right, how do we empower folks to show self-determination? Pete, any last thoughts?

Gladstone: I would say to remind everyone that we're all susceptible to socialization and we've all been socialized to believe that every person with intellectual disability has a profound intellectual disability. We think that they can't do anything right, and so I would encourage folks to continually challenge themselves and their clients to aim higher because the higher expectations that we have for clients that we have with IDD, the more likely they are to reach them. If we have low expectations that's where they're going to settle at. So have a growth mindset: it will break their stereotypes and surprise the people that you are working with.

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Appendix: Lived Experiences

Finding community is a significant part of the lived experience for us all; it connects us, helps us, and shapes our experiences, especially when we find common experiences. Verdonschot et al. (2009) relate social domain theory to how people with intellectual disabilities connect to domestic life, interpersonal life, major life activities, and community, civic and social life and found that people with IDD who live in community settings versus institutional settings engage more in social domains. However, in research we find a limitation in the inclusion of people living with IDD in general social settings. Understanding this, we can explore the ways that people living with IDD continue to fight for inclusion in our general community—as our society continues to recognize the value of inclusion to reduce social exclusivity and shifting the narrative for those living with disabilities in education (Moriña et al., 2020; Naraian (2019) Sauer & Lalvani (2017). We do see that education does take the lead with inclusion for those with disabilities; however, we do understand that community and social life activities are valuable to the human experience. Kampert & Goreczny (2002) defined the desire of those who live with intellectual disabilities to have a variety of community inclusion, based on the voices gathered in IM4Q program, which uses a 98-question interview to assess quality of life experiences for those living with intellectual disabilities. We know that people living with IDD experience this world beyond their medical condition, as we have examples of lived experiences that can support and guide our ability to better support the needs of people who do have voice despite adversities our society can place to people living with IDD. We see that people with IDD can develop their own narrative and have voice beyond the expectations of medical providers, as seen by the lives of Roland Johnson, Lia Lee, and several others now leading the charge in lived experience in social media.

Lost in a Desert World: An autobiography (Johnson & Williams, 1994)

Roland Johnson, born in Philadelphia, PA in 1945, is well-known for the changes to "deinstitutionalize" the lives of those who live with disabilities, specifically those living with neuroatypical conditions. When entering school, Roland received notes from teachers concerned with his academic performance and was identified by the family physician with mental retardation (what we now call intellectual disability). Roland grew up in the 1950's, before legislation like the Developmental Disabilities Assistance and Bill of Rights of 1984 and the Americans with Disabilities Act of 1990, were created to protect people living with disabilities and provide equitable rights to those living with all disabilities. Johnson was removed from his family home in South Philadelphia and placed at Pennhurst State School and Hospital, a residential facility in suburban Philadelphia, created to house and educated people living with mental and physical disabilities. Roland's account of his abuse and the abuse of others in the facility, along with his opportunity to fight to live outside of this facility in boarding homes, to his work to promote community living for those living with intellectual disabilities, as a political activist. Johnson's own lived experiences and self-determination lead to several invitations as a public speaker, numerous awards for social activism for those living with disabilities, and leading the charge to change how people living with intellectual disabilities (even his platform helped society use this term, instead of mental retardation). This account of his life shows that people living with intellectual disabilities can have a voice; aptly the social ice organization Johnson was affiliated within Philadelphia is called "Speaking for Ourselves". This story shows that people living with intellectual disabilities can live independently with supports, have meaningful work experiences (Johnson worked as a janitor, when he first left Pennhurst), have a sexual identity and desires, and participate in society as any of us are able to despite our challenges.

The Spirit Catches You and You Fall Down (Fadiman, 1997; Fadiman 2012)

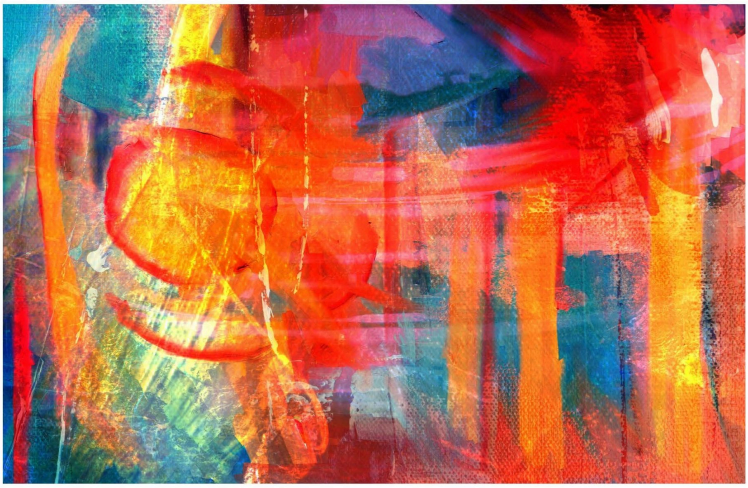
Although not an auto-ethnographic account, *The Spirit Catches You and You Fall Down* provides an excellent account of the challenges faced by families of individuals with low incidence disabilities and co-occurring intellectual abilities. Journalist, Anne Fadiman accounts the life of Lia Lee and her Laotian family- of Hmong decent, forced from their home in Thailand to the U.S. during the Vietnam War. Upon arrival, Lia is diagnosed in her early life with epilepsy, and one of her seizures leads her to have an intellectual disability. Faidman chronicles the many obstacles that are created by significant cultural difference between Hmong and American culture and how the use of cultural awareness with quality of life care for a person living with an intellectual disability does not fit into the definitions of Western traditions and the lived experiences of the Hmong people, who do not even identify epilepsy or intellectual disability as disease in their culture, are able to support and give care using their own traditions in accordance to their belief system. This biographical account of the care for a person with an intellectual disability shows the value of social supports, especially in domestic life, as Lia's family are her sole providers and most of her abilities are set to the domestic domain of socialization. Lia values her family, as the story accounts, and this support is integral in her continued defiance of medical odds and becomes a significant factor with her living beyond the expectations of her medical providers.

Studies that speak about the limitations of social skills development, like deBildt et al., (2005) and Djordjevica et al., (2020) often miss the value of social media in the realm of socialization. As we continue to see the influence of social media and birth of micro-celebrity (Marwich and Boyd, 2010; Page, 2012; Khamis et al., 2017), having representation from those living with intellectual disabilities is an important step to an inclusive society. As we see in a World Today News (2021) article about five influencers in social media living with disabilities, each use social media platforms like Instagram, TikTok and YouTube, along with their own personal blogs and vlogs, to give representation to people with intellectual disabilities and their families, access to social domains that historically lack representation of people with disabilities, like fashion and beauty. Their lived experiences can help those who give services to those with intellectual disabilities as lens to understand that an intellectual disability cannot limit a person's ability to participate in society.

Popular Social Media accounts of individuals with IDD:

- SuperChloe
- Tank Schottle (Special Olympics Athlete)
- Madeline Stuart (Model with DS)
- Patrifashion (Fashion influencer with DS)
- Marian Avila (Model with DS)
- Zack Gottsagen (Actor with DS)
- Working with an intellectual disability (2019)
- We Have Choices (2018)

Understanding more young people living with intellectual disabilities are engaging in social media platforms Borgstrom et al. (2019) pointed out, that young people living with intellectual disabilities can use social media to connect with others and develop their identity, however, they are as vulnerable to the negative aspects of social media, such as communication barriers, cyberbullying, sexual exploitation, safety, and security risk. To address communication barriers, Martins et al. (2021) suggested a solution to make the experience of social media for those living with intellectual disabilities an easier platform.



7

Chapter

Autism Spectrum Disorder in Children and Adolescents

Sean E. Snyder, MSW; Samiha Islam, MA; Meghan Kane, MSEd, BCBA

Leo is an 11-year-old Latinx, cis-male, diagnosed with ASD. He was referred for behavior support services while enrolled in a residential treatment program. Leo's caregivers were interviewed as part of the referral process. Some stated that he was "always an odd child," and he had a fixation on animals. Their impressions were that he actually thought he was an animal at times, like a wolf or a bear. Leo had difficulties with boundaries. He would observe other children raising their voices in play, and he would start screaming in an attempt to match their behavior. The other children would become upset at him for yelling, and Leo would become angry and confused. He had difficulty regulating himself. He would scream at night constantly because of this. The other kids didn't like that he kept them up all night. Leo knew that the other kids were mad, and this caused him a lot of anxiety. He would stay by himself in his room, not wanting to see the other kids. He was afraid that they wouldn't like him and would "say mean things or make threats to my family."

Overview of the Disorder

Autism spectrum disorder (ASD) is a biologically based, neurodevelopmental disorder. It is identified in the DSM-5 (2014) as “persistent deficits in social communication and social interaction” and “restricted, repetitive patterns of behavior, interests, and activities.” Autism is viewed on a spectrum because of its neurodiversity; it can be said that no two cases of autism are alike. How we have approached our understanding of autism has had recent shifts, and innovative research continues to push the boundaries of this understanding.

Autism spectrum disorder has had a unique history in its development and articulation as a disorder. Earliest mentions of autism come from the child psychiatrist Leo Kanner, who in 1943 published a paper with “autistic” in the title; in it, he wrote his observation of a unique, unarticulated condition in children (Kanner, 1943; Tanguay & Lohr, 2016). This condition was named early infantile autism (Spielman et al., 2020), and it was characterized mainly by an inability to form close emotional ties with others, speech and language abnormalities, repetitive behaviors, and an intolerance of minor changes in the environment and in normal routines (Bregman, 2005). The current iteration of autism spectrum disorder was grounded in Kanner’s and Hans Asperberg’s work (Asperger, 1991; Spielman et al., 2020, Tanguay & Lohr, 2016).

Autism did not become an official diagnosis until the DSM-III was published in 1980 (Tanguay & Lohr, 2016), and it came to its current rendering of autism spectrum disorder with the publication of the DSM-5 in 2013. Where there were previously three separate disorders— autism, Asperger’s syndrome, and pervasive development disorder—the DSM-5 merged these into the current diagnosis. The rationale points to reasons such as the lack of literature that speaks to differential responses to treatment or differences in cause between the previous categories of autism and Asperger’s (Happe, 2011; King et al., 2014), and the lack of successful genetic studies that could identify differences between the behaviorally defined subtypes of autism (Harris et al, 2008; Happe, 2011; King et al., 2014). Some people who were diagnosed with Asperger’s may still be attached to that label rather than autism.

Prevalence of Autism Spectrum Disorder

Autism’s prevalence has steadily increased, likely due to the changes in case definition, more awareness about the disorder, earlier detection, as well as more availability of specialized services related to autism (Kogan et al., 2018; Xu et al., 2019; Maenner et al., 2020; Lai, Lombardo, & Baron-Cohen, 2014) with research indicating a 10% increase in prevalence since 2014 (Maenner et al., 2020). The prevalence rates in the US vary from 1 in 54 overall (Maenner et al., 2020), to approximately 1 in 40 children overall (Kogan et al., 2018); with sex variants ranging from 1 in 26 boys, and 1 in 93 girls (Kogan et al., 2018) to 1 in 34 boys, and 1 in 145 girls (Maenner et al., 2020).

There are known neurodevelopmental comorbidities with ASD, with studies indicating that approximately 33 to 45% of children with ASD have an intellectual disability, learning disability, and language/communication disorders (Simonoff et al., 2008), and that 50% have attention deficit hyperactivity disorder (Leitner, 2014; Simonoff et al., 2008). Other comorbid psychiatric conditions include anxiety disorders (like generalized anxiety disorder), panic disorder, separation anxiety, and social anxiety disorder (Zaboski & Storch, 2018); as well as other disorders such as obsessive-compulsive disorder (Postorino et al., 2017), depression, and oppositional defiant disorder (Romero et al., 2016; Simonoff et al., 2008).

Repetitive patterns of behavior or interests can be exhibited in a number of ways. The child might engage in stereotyped, repetitive movements (rocking, head-banging, or repeatedly dropping an object and then picking it up), or she might show great distress at small changes in routine or the environment.

How Autism Spectrum Disorder Develops in Youth

Autism has various etiological factors that are still being understood. While distinct mechanisms may not have been agreed upon (Gardener et al., 2011; Lai et al., 2014), the prevailing theory is the epigenetic theory, in which an abnormal gene is expressed early in the development of the child, which then alters the expression of other genes (Muhle et al., 2018; Samaco, 2004). It is a highly heritable disorder, with research indicating a heritability rate of 81% (Bai et al., 2019).

Autism appears highly heritable and influenced by genetics, as identical twins show concordance rates of 60%–90%, whereas concordance rates for fraternal twins and siblings are 5%–10% (Autism Genome Project Consortium, 2007; Spielman et al., 2020). Genetics influence the neural development of a child, so it follows that genetics would play a role with this neurodevelopmental disorder.

Developmental Systems Considerations for Autism Spectrum Disorder

Considering the above scenario with Leo, his team did know that his parents had a history of psychiatric disorders, as well as concerns about intellectual disability. His parents were deceased at the time of treatment. This leaves one to wonder if his parents had undiagnosed autism, especially since Leo's parents would have been children themselves in the 1980s. Considering the developmental systems perspective, we could see this potential biological vulnerability, coupled with the social vulnerability due to parental stress and difficulty with caring for Leo, and the environmental influences on behavior (e.g., school not being the place to best meet therapeutic needs, transitions to learning new social rules and children in a residential facility).

Experiences Across Race and Ethnicity. Diagnosis of ASD had been previously known to have higher prevalence in White youth, with researchers indicating that there were significant racial/ethnic disparities in the recognition of ASD (Mandell et al., 2009). ASD has been shown to be more commonly identified in Asian than White youth (Sullivan, 2013). This often occurred because of the presence of intellectual disability which complicates further developmental assessments (Mandell et al., 2009) or because mild levels of symptoms presented by Black and Hispanic/Latinx youth go unnoticed (Nevison & Zahorodny, 2019), or are even more so mistaken for ODD/ADHD/other disruptive disorders (Mandell et al., 2009). Current trends of ASD diagnosis show that rates of ASD diagnosis for Black and Hispanic/Latinx children are exceeding rates for White children; this appears to indicate that provider barriers to identification of ASD in minority youth are beginning to diminish.

Experiences of LGBTQ Youth. One study about gender identity and sexual orientation in autism spectrum disorder (George & Stokes, 2018) offers the recommendation for clinicians to be aware of gender diversity within the ASD population, as it will influence the necessary supports for the child. George & Stokes (2018) found in their study sample that sexual orientation in some youth with ASD relates to their gender experience, specifically that the relationship between autistic traits and sexual orientation were mediated by gender-dysphoric traits. This information is critical to understand, as affective distress is common with ASD and gender dysphoria respectively, and a nuanced approach to working with ASD youth is necessary to distinguish challenges with anxiety, social skills, or sexuality-related worry. It is also important to keep in mind challenges youth with ASD may have communicating their experiences with gender diversity, as well as their sensitivity to bias/harassment due to their movement away from "typical" being further highlighted if they come out as gender diverse (Strang et al., 2018).

Assessment of Autism Spectrum Disorder

Autism spectrum disorder is probably the most misunderstood and puzzling of neurodevelopmental disorders. As pointed out in the Spielman et al. (2020) chapter that discusses autism, children with this disorder show signs of significant challenges in all three main areas: (a) deficits in social interaction, (b) deficits in communication, and (c) repetitive patterns of behavior or interests. Autism manifests early in life and introduces serious impairments in functioning (APA, 2013)(Spielman et al., 2020). There are also three severity levels, spanning from “Requiring support” to “Requiring substantial support” to “Requiring very substantial support.” The Autism Speaks website offers an open-access outline of the diagnostic criteria for autism and the related disorders, as well as the severity levels recently mentioned.

The child with autism spectrum disorder might exhibit deficits in social interaction by not initiating conversations with other children or turning their head away when spoken to (Spielman et al., 2020). These children tend to struggle to make or maintain eye contact with others and seem to prefer playing alone rather than with others. In a certain sense, it is almost as though these individuals live in a personal and isolated social world that others are simply not privy to or able to penetrate. Communication deficits can range from a complete lack of speech, to one word responses (e.g., saying “Yes” or “No” when replying to questions or statements that require additional elaboration), to echoed speech (e.g., parroting what another person says, either immediately or several hours or even days later), to difficulty maintaining a conversation because of an inability to reciprocate others’ comments (Spielman et al., 2020). These deficits can also include problems in using and understanding nonverbal cues (e.g., facial expressions, gestures, and postures) that facilitate normal communication. (Spielman et al., 2020).

As we saw with Leo, he had difficulty with modulation of the volume and tone of his speech. He also had difficulty with maintaining appropriate space when he did engage with others. These characteristics lead to further social isolation as he was not able to connect with peers or learn in a social context. His unique and heightened interest in animals tended to make for interesting starts to conversations, but he often would spout facts about these animals without concern for the interest of who was listening. His conversation skills were much more limited when the topic wasn’t focused on his interests. When he would go into “animal-mode,” he seemed to be in a world to himself that other people cannot understand. This leads to the next core feature of autism spectrum disorder, repetitive interests.

There are known neurodevelopmental comorbidities with ASD, with studies indicating that approximately 33 to 45 percent of children with ASD have an intellectual disability, learning disability, and language/ communication disorders.

Repetitive patterns of behavior or interests can be exhibited in a number of ways. The child might engage in stereotyped, repetitive movements (rocking, head-banging, or repeatedly dropping an object and then picking it up), or she might show great distress at small changes in routine or the environment (Spielman et al., 2020). For example, the child might throw a temper tantrum if an object is not in its perceived proper place or if there are disruptions to the daily schedule (Spielman et al., 2020). In some cases, the person with autism spectrum disorder might show highly restricted and fixated interests that appear to be abnormal in their intensity. For instance, the person might learn and memorize every detail about something even though doing so serves no apparent purpose (Spielman et al., 2020). Finally, individuals on the spectrum often experience sensory issues such that they are excessively sensitive to certain stimuli or not very sensitive at all. Each person with autism may be sensitive to different kinds of stimuli, which can include sounds, textures/touch/ temperature, sights, smells, and tastes. Hypersensitivity to sensory stimuli is a common source of distress for individuals on the spectrum, and hyposensitivity may lead to fixation on certain stimuli (e.g., shiny objects) or seeking out sensory experiences (e.g., rubbing a textured carpet). Importantly, autism spectrum disorder is not the same thing as intellectual disability, although these two conditions are often comorbid. The DSM-5 specifies that the symptoms of autism spectrum disorder are not caused or explained by intellectual disability (Spielman et al., 2020).

Assessment Tools

Diagnosis of autism should employ a multidisciplinary approach that should include multiple informants, consideration and potential observation of the child in multiple settings, and psychological testing that can evaluate cognitive skills, language skills, adaptive function, executive function (Blijd-Hoogewys et al., 2014), and academic function (Tanguay & Lohr, 2016). Parents may be able to observe restrictive patterns, but not all autistic children behave in this way as infants or toddlers. Depending on the context, the child may have a different presentation; for instance, they may be less restrictive with their mother, or they may be more interactive with siblings. Lastly, the neural diversity of autism creates an imperative to understand this particular presentation of autism; one of the common clinical mantras with autism is “when you meet one person with autism, you have met one person with autism”

Interview Questions for Client, Family Member, or Teacher. Autism does require specific assessment approaches, but for those not in specialty clinics, you can do brief screening questions to then see if further evaluation is needed. Tanguay and Lohr (2016) offer these common screening questions:

- Does your child talk to you or make sounds to you, just to be friendly?
- Is it difficult to catch your child’s eye?
- How has your child responded to others in distress?

You may even hear these questions asked of parents in their child pediatrician visits, especially during the first few months after birth.

Observation in Naturalistic Settings. Autism assessment will include direct observations of the client for diagnostic purposes. This is especially critical considering the core deficits of ASD according to the DSM-5 Autism Diagnostic Criteria are behaviors or patterns of behavior. Kroncke (2016) identifies key areas to be included for observation as part of a comprehensive evaluation: behavior, appearance, eye contact and gestures, play and interests, social reciprocity, attention, motor skills, mood and affect, and naturalistic. Naturalistic observations give the assessor more information about behavior and presentation across multiple settings and within naturally occurring contexts such as at home, school, or a clinic. This can be useful for complex presentations and for directly observing social abilities and social reciprocity within the child’s natural environment.

When a problem or challenging behavior is a concern, a functional behavior assessment (FBA) will be conducted. The FBA requires direct observation of the impact of environmental variables on behavior, consistent with methodology from applied behavior analysis. During a functional behavior assessment, the assessor will collect data on observations of antecedents, behavior, and consequences (ABCs) in order to hypothesize the function or the purpose the behavior is serving for the individual. This is the first step to developing an effective behavior intervention based on teaching functional replacement skills.

Measurement and Rating Tools. Common assessment tools for ASD include the Modified Checklist for Autism in Toddlers (M-CHAT) (Robbins et al., 2001), Autism Diagnostic Interview-Revised (ADI-R) (Lord et al., 1994), the Social Communication Questionnaire (SCQ) (Rutter et al., 2003), Autism Diagnostic Observation Schedule, 2nd edition (ADOS-2) (Lord et al., 2012), and the Childhood Autism Rating Scale (CARS-2) (Schopler et al., 2010).

Intervention with autism focuses on improving quality of life and reducing functional problems; unlike some other disorders, there will be no remission of symptoms or cure with intervention for autism.

The CARS-2 (Schopler et al., 2010) measures 15 core deficit behaviors associated with autism spectrum disorders, including relationship to people, imitation, adaptation to change, and emotional expression. The standard form (CARS-2-ST) is appropriate for youth younger than age 6 or youth aged 6 and older who have a notable communication deficit or an IQ of 70 or lower. The high-functioning form (CARS-2-HF) is appropriate for youth aged 6 and older with verbal fluency and an IQ of 80 or higher, which allows the assessor to differentiate comorbid challenges.

The ADOS-2 (Lord et al., 2012) has five modules, and each module is appropriate for children at different developmental and language levels. The assessor will choose which module to use based on the relative fluency and complexity of language used by the child, ranging from no expressive use or receptivity of words to fluent language. The modules assess the child in planned social occasions or social situations that typically produce a social response in someone. These occasions are referred to as presses from the assessor, and they are attempts to engage the child in imaginative activities, social role plays, or other social-communicative behaviors.

Differential Diagnosis Considerations with Autism Spectrum Disorder

ASD shares features with several other psychiatric conditions, including (but not limited to) generalized anxiety disorder (GAD), social anxiety disorder (SAD), obsessive compulsive disorder (OCD), depression, and social (pragmatic) communication disorder (SCD). This can complicate diagnostic decisions, as symptoms of ASD may be misdiagnosed as another condition, symptoms of another condition may be misdiagnosed as ASD, or once a diagnosis of ASD is established, a comorbid diagnosis may be missed (or vice versa).

Many youths with ASD experience a significant amount of anxiety in their daily lives, and this is particularly true for youth with autism requiring little support (Gilliot et al., 2001). Youth with ASD may become anxious when their routines are disrupted, when they are overwhelmed by sensory stimuli, or when they are in unfamiliar environments and social situations (Wood & Gadow, 2010). A diagnosis of GAD, however, requires that anxiety is present more days than not across a wider variety of settings and situations due to pervasive worry, as well as the presence of physical symptoms of anxiety such as fatigue, muscle tension, and sleep disturbance (APA, 2013). In order to differentiate between anxiety stemming from ASD symptoms and a formal GAD diagnosis, it is necessary to assess the triggers and underlying content of anxious thoughts.

Both individuals with SAD and ASD may present with anxiety in (and leading up to) social situations (Spain et al., 2018). As a result of this anxiety, both categories of individuals are likely to avoid social situations and may also show social skills deficits (Spain et al., 2018). However, the source of the anxiety can differentiate the two; individuals with SAD experience anxiety in social situations due to fear of judgment and negative evaluation from others (APA, 2013). On the other hand, individuals with ASD may become anxious in social situations because they have a hard time interpreting nonverbal social cues, engaging in nonverbal communication (e.g., eye contact or gestures), and engaging in joint attention with others, thus reducing the overall quality of social interactions and making it difficult for youth on the spectrum to navigate (Tyson & Cruess, 2012). Of note, not all individuals with ASD feel anxious in social situations, as some may have low motivation or interest for social interaction to begin with (Tyson & Cruess, 2012). Conversely, many individuals with ASD are motivated to make social connections but lack the social skills to do so; if these individuals also experience much anticipatory anxiety leading up to social situations due to a fear of negative evaluation from others, they may also meet criteria for SAD (Bellini, 2006). Youth with high-functioning ASD who are more self-aware about their social skills deficits are more likely to experience comorbid SAD (Tyson & Cruess, 2012).

> *Three core intervention models emerge to address core autism or general symptoms: behavioral model, social-communication focused model, and multimodal developmental model.*

Restricted and repetitive behaviors are hallmark symptoms of both ASD and OCD (Ruzzano et al., 2015). Both youth with ASD and OCD may adhere to strict routines, have a need for sameness in their everyday environments, and have perseverative thoughts or intense preoccupations (Griffiths et al., 2017). However, feelings elicited by these behaviors and thoughts may help differentiate between ASD and OCD symptoms. While obsessions and compulsions in OCD are ego-dystonic (i.e., regarded as intrusive and distressing), preoccupation with special interests and adherence to routines in ASD are generally ego-syntonic (i.e., pleasurable or rewarding) (Griffiths et al., 2017). Of note, features of ASD and OCD are highly comorbid, and comorbid ASD/OCD is associated with greater functional impairment across domains and poorer treatment response (Griffiths et al., 2017).

Depressive disorders and ASD are both characterized by notable social withdrawal and flat affect; other shared features may include irritability, low motivation, executive function challenges, problems with eating/appetite, sleep disturbances, and perseverative thinking (Pezzimenti et al., 2019). However, clinicians must keep in mind that symptoms of depression are a departure from an individual's "typical" functioning; this may be harder to assess for more enduring depressive symptoms lasting over the course of several years, as is the case for persistent depressive disorder (also referred to as dysthymia) (APA, 2013). In any case, clinicians should assess when symptoms began to elucidate whether they may be transitory, which may be more indicative of depression; furthermore, if symptoms have become more severe over time relative to baseline functioning, this may also be indicative of depression (Pezzimenti et al., 2019). Additional considerations should include individuals' unique symptom etiology. For example, the reason for social withdrawal may help clarify whether it stems from depression and/or ASD, as youth on the spectrum are less likely to be socially motivated or may want to avoid sensory overload in social settings. Similarly, changes in eating patterns may be attributed to depression and/or ASD, depending on the underlying issue; depressed youth may eat less due to reduced appetite, while youth on the spectrum may eat less due to tactile sensitivity to various food textures, resulting in a limited range of tolerable foods.

The social communication deficits that must be present for individuals to be diagnosed with ASD are not always accompanied by restricted and repetitive behaviors (Gibson et al., 2013). In these cases, a diagnosis of SCD may be more appropriate. Individuals with SCD present with many of the same social skills deficits, including difficulty communicating in a manner appropriate to the social context, deficits in changing communication to match the needs of the listener, difficulty with reciprocal conversation, and impairments in interpreting nonverbal cues and figurative speech (APA, 2013). Note that SCD should not be diagnosed alongside ASD; if a child shows social communication impairments, diagnosis will hinge on the presence of restricted and repetitive behaviors and interests (Gibson et al., 2013).

Intervention

Intervention with autism focuses on improving quality of life and reducing functional problems; unlike some other disorders, there will be no remission of symptoms or cure with intervention for autism. Considering the variance in presentation of youth with ASD, an expert panel (Maglione et al., 2012) identified core aspects of care that include aims to improve social functioning and play skills, improve communication skills (both functional and spontaneous), improve adaptive skills, decrease nonfunctional or negative behaviors, and promote academic functioning and cognition. Three core intervention models emerge to address core autism or general symptoms: behavioral model, social-communication focused model, and multimodal developmental model (Tachibana et al., 2017). The Center for Disease Control and Prevention (2019) highlight other specific therapies, including applied behavior analysis, social skills training, occupational therapy, physical therapy, and the use of assistive technology (e.g., use of communication boards or tablets to assist with communication with others).

An intervention approach that addresses the core deficits of ASD is applied behavior analysis (ABA) (Warren et al., 2011). Literature reviews (Seida et al., 2009) indicate behavioral approaches in general, with the understanding that some form of treatment is better than no treatment at all. Psychopharmacology evidence is limited, with a trial of risperidone showing success for the core symptoms of autism; however, because of its neural diversity, it is difficult to generalize to all presentations. (McDougle et al., 2005). More often than not, pharmacological interventions will focus on treating the comorbidity associated with the child's presentation.

Clinician Exercise

Read the rest of the vignette below. How would your approach change if we found Leo also had anxiety?

We worked on adding some contingencies and teaching replacement skills. The plan was to teach Leo how to use the proper tone of voice and volume. We role played different scenarios and practiced different voice volumes. Each time Leo was observed using his conversation voice, or his outside play voice in the correct context, he would access reinforcement. Aside from social reinforcement from his friends, he also received praise from staff and a sticker on the sticker chart. The stickers were a token economy; once he earned ten stickers, he could trade them to listen to a song in the therapy office on YouTube. This strategy worked to replace the yelling behavior. He started to play with the other kids during free time without disruptions and was more engaged in group. A new issue developed: Leo could not keep appropriate personal space. The children were reporting he was too close for comfort and, at times, touching his peers as they were sitting in group. A similar program and reinforcement schedule was created for maintaining personal space. This is a common scenario for children with ASD. Subtle social skills and boundaries may have to be explicitly taught. It is common for multiple interventions to be used and adapted over time as the context and social rules evolve.

As we see with Leo, a behavioral schedule was created; this is a common antecedent management strategy in ABA and incorporates the use of visual cues. There were specific behaviors being targeted for increase. He would access his highly preferred YouTube songs for demonstrating 3 out of 6 school hours with appropriate tone of voice, and the aim of this intervention was to positively reinforce a behavior. It is important to consider where Leo's developmental age and chronological age may diverge; he may still operate in the realm of fantasy due to his developmental age and may have cognitive barriers to engaging in cognitive oriented treatments. With the developmental systems perspective in mind, it is critical to consider the personal factors such as these, the caregiving relationships and the environmental contexts that could serve as a holding environment. Lastly, it is important to consider sensory-based activities to supplement the ABA style interventions (e.g., holding kinetic sand during a social skills training).

It is worth noting that working with autistic youth can be challenging and there are potential harmful behaviors to contend with such as biting, hair pulling, slapping. crisis intervention approaches such as Handle with Care should be considered given the potential for physically unsafe scenarios. Our interventions are meant to address these problematic behaviors, but the spirit of our intervention matters.

Clinical Dialogues: Autism Spectrum Disorder with Richard Weyler, MD

Richard Weyler, MD is a board-certified child and adolescent psychiatrist who has extensive history in working with neurodevelopmental disorders such as autism spectrum disorder. He completed medical school at Jefferson Medical College and completed a child and adolescent psychiatry fellowship at the Children's Hospital of Pennsylvania. His experience spans leading a neurodevelopment unit at a children's acute psychiatric hospital to working at the Center for Autism in Philadelphia.

Sean E. Snyder, LCSW: Dr. Weyler, could you start us off from the beginning? What is it like for you with engagement of families that come to you for evaluation or for other autism related services?

Richard Weyler, MD: Engagement depends on where the child actually falls functionally. As to the techniques, lower functioning children who have intellectual disability would be a much different approach than a kid who maybe is having some social issues but does meet criteria for autism.

Snyder: You're touching on the whole nature of autism being a spectrum. So, engagement is dictated by an assessment to see what kind of comorbid challenges or pathologies are present, and many times, it's the comorbidities that tend to dictate how you interact with them?

Weyler: Yes, exactly.

> *Diagnoses have leveled off, although it has increased somewhat from 2010 until now… I think it's because we're getting better at diagnosing it, and we're getting better at screening kids and differentiating diagnoses in our assessments.*

Snyder: What about with parents? How can you work with parents who really are experts in their children's lives?

Weyler: From my practice, I have seen two common trends with parents. One set are those who are very invested in having an autism diagnosis, and the other set who are kind of hard by the diagnosis. And then there are those who fall between those poles. When engaging the parents, you really have to take the temperature and read where they're at and approach them in a way that's going to make them comfortable with treatment.

For example, for parents who don't accept the diagnosis, I like to try to still keep a provisional diagnosis to keep the kids in treatment because I want to keep the patient engaged. I don't want to chase anybody out of treatment while trying to get my point across that their kid has a certain diagnosis. So, I'll try to keep them engaged as best I can, and that allows me to get them into the same treatment that they would be getting, whether or not they had a diagnosis. So I'll give a provisional, like unspecified developmental disorder. That could ease the parents into it a little bit more, but in giving that diagnosis, it doesn't stop me from being able to implement treatment.

Snyder: Do you get the sense with parents of children being evaluated for autism, that there's secondary gains that are common with other diagnoses like ADHD or ODD? In practice, I've seen parents almost hoping for a diagnosis in hopes of getting services or other kinds of gains. Do you see that happening?

Weyler: I would say the answer to that question is nuanced because malingering exists in the DSM for a reason, but anecdotally, I don't tend to see it. I feel like most of the parents are, by the time they get to me, invested in the child because they've already gone through their pediatrician, and things are really serious by the time I see kids. Usually these families are struggling.

Snyder: At that point, they've already kind of put in all that effort and investment because of their child's functioning. On the opposite end, with the parents that are not overly invested, is it because they are in disbelief of the diagnosis? Is it something where they have self-blaming behaviors? Is it a problem of a lack of education about autism?

Weyler: What I see from those on the opposite end of the investment spectrum, are a lot of people who are overwhelmed. It requires a lot of time and energy with the initial evaluation phase, and for follow-up appointments, sometimes the family has to take off an entire day to get that kid to that appointment. A lot of what I see here is people struggling to be able to still be employed and get their children to have a bunch of appointments and just manage. I'm usually pretty empathetic when people are having trouble following through with recommendations.

On the other hand, you do have to be firm because if nothing changes, nothing changes. It can be a delicate balance in keeping people engaged and engaging in treatment. And then, I always like to say, "if you don't have a patient, you don't have a patient." Keep people engaged and be as empathetic as possible because I see lack of engagement as a function of some barriers to treatment that we need to address that maybe we're not able to see right away. So, I don't believe that anybody who's gone to the trouble of getting their kid all those evaluations is then not serious about treatment and that maybe a lot of other things going on.

When I get the sense of a lot of barriers, I usually will start increasing the levels of care and increase frequency that I see people. The psychotherapy part of me would say that your countertransference is that you're annoyed with people that they're not following through, and that's probably the person you need to see more frequently.

Snyder: And not less frequently. Yes, we need to consider our own countertransference in all of this process, which can be a barrier to engagement and treatment. So one last thing with barriers. What about caregiver support? How do you bolster support systems with caregivers, for instance, with respite services?

Weyler: To start, respite is where caregivers and people who take care of people who need a lot of care whether it be an older, sick relative or a child with developmental disabilities. There are programs out there where they can get a break or have an extra personal care assistant or nurse to come to your house on Saturday afternoon, so the parent can go and have a cup of tea without somebody needing something from you or, worst case scenario, some of the children are aggressive. The life of parenting can turn into trying to keep the child from hurting themselves and others at certain moments in time. It's nice for a parent to take a break and not have to referee fights between siblings for four or five hours. Some programs will take kids who are eligible, financially and behaviorally (usually the ones with more severe behavior). There are a lot of references therein Autism Speaks.

One question I hear from students a lot is about parents being invested in the idea that the children will always have to live with them. So, I do come across that scenario from time to time. You have to read between the lines of that statement and take a developmental approach for both the child and the adults. A place where a lot of parents are at developmentally when they're child age is the big concern is that you're going to die, and no one's going to be around to take care of your children. When I hear parents say, "They're never going to leave my home," I think the message is really "Who's going to take care of this kid after I die?" That can open up another conversation of motivation to getting the youth adaptive support, getting them working and getting them linked up to transitioning into adult services, or, for my intense cases, get them into an assisted living facility while the parent is still alive. One of the things you want to see as a parent is that your children are able to take care of themselves in the world. Consider it an extension of generativity. And this is really about engaging the family across the lifespan.

> *These are children with developmental disorders. In general, there are programs under the name of life skills, but with these youth, they're enhanced life skills programs where they'll spend part of their day outside of the school learning how to work as a customer associate in a deli, learning how to take vital signs at the doctor's office, doing circulation duties at a library.*

Snyder: Okay, great. So, last thing with the engagement piece, we need to look at different domains, specifically school or the workplace for kids. What's the best approach when working with teachers and the school system to give students support in the least restrictive environment?

Weyler: My response isn't only autistic kids per se. These are children with developmental disorders. In general, there are programs under the name of life skills, but with these youth, there are enhanced life skills programs where they'll spend part of their day outside of the school learning how to work as a customer associate in a deli, learning how to take vital signs at the doctor's office, or doing circulation duties at a library. They'll rotate through different fields where they can figure out how they can be fully included within the fabric of society. They get the reward of being able to take care of themselves and contribute and get a paycheck at the end of the week.

Snyder: Why does it seem like we are seeing more ASD diagnoses? Are there still gaps with subpopulations like males vs females still?

Weyler: Diagnoses have leveled off, although it has increased somewhat from 2010 until now. Now, it's like one in 58 kids. The gender gap is starting to close and same with racial/ethnicity gaps. I think it's because we're getting better at diagnosing it, and we're getting better at screening kids and differentiating diagnoses in our assessments. For instance, kids who would have been written off as having schizophrenia or kids who have been written off as intellectually disabled are now being more accurately diagnosed with ASD.

Snyder: That makes sense. On one hand, we're being more precise with our measurements and standard ways of looking at it. I'm sure awareness campaigns like Autism Speaks have made an impact, now with schools and pediatricians becoming more aware. So maybe this is a matter of better dissemination practices. And I'm sure there is still more advanced research that is being disseminated and waiting uptake from the general clinician population.

Weyler: I have a personal anecdote that may address some of this. When I was deciding what field to go into, I considered neurology. I found that my problem with going into neurology is that they're really great at diagnostics, but there aren't a lot of cures for anything neurological at this point. I don't think there will be until we get into some pretty heavy trials with stem cell research that can start repairing the central nervous system. We could start diagnosing and repairing the central nervous system to rewire itself.

I don't think that there's going to be any advances in treating the core of autism. There are no medications that directly treat autism. We treat autistic kids' symptoms, and this gets tricky when trying to advocate for advanced levels of care. I can't get somebody hospitalized with an autism diagnosis, so there has to be something else going on that caused them to be hospitalized. Their neurological baseline isn't enough for intensive care.

Early intervention is key because the brain is a lot more plastic than we initially thought, but it's still considered to be a neurological baseline. From that baseline, you have to think in a parallel way with assessment and treatment. For instance, we could have kids with ASD as a baseline but also demonstrate hyperactivity and impulsivity, which falls under ADHD criteria. In a large percentage of ASD youth, that phenomenon mirrors the general population. These kids have different options with treatment, and some will respond to ADHD meds.

With assessment, consider other transdiagnostic features. For instance, OCD has some overlap with the core features of Autism, like ritualistic and repetitive thoughts and pattern of behaviors. ASD youth whose symptoms resemble OCD could be much more refractory to meds because OCD is refractory to medication treatment in typically developing children. Another diagnostic example: it's important to separate out ASD and psychotic symptoms, too. You have to be careful because autistic kids will believe stuff. I have an autistic child who believes that he is a werewolf, and it's more of around a very firmly held belief. For him, he could get really aggressive when it's time to be a werewolf.

Snyder: Right. Our class discussed how it's important to consider developmental age, especially with a concept like magical thinking, in folks with intellectual disabilities. A person that is chronologically 30 years old but developmentally five years old will have thoughts that might seem like they are psychotic, but really, it's magical thinking, like "I'm a werewolf." This was from a youth I came in contact with at our clinic, and he was inspiration for our case vignette Leo.

Part of the crux of ABA is that there's a function to behavior. With autistic kids, the function might not be as clear because sometimes the function can be sensory or physiological.

Weyler: Right and a lot of folks won't see the magical thinking if they don't know they're looking at. They're thinking, "Oh, somebody who thinks they're a werewolf, and they talk to themselves, they must be schizophrenic," and I think, that perspective changes the course of treatment. Giving him or her high doses of medications that they don't need and really not getting at the root of the problem. There's no medication for an overall belief that you're a werewolf.

And on the subject of medications, it's important that students know that some medications have benefits that don't outweigh the risk. And for some, like antipsychotics, you have to get really good benefits from it because these medications can lead to high blood pressure, weight gain, diabetes, and high cholesterol. Diabetes and high cholesterol down the line lead to really bad complications, and we're talking about really young people here! You really have to be sure about what you're diagnosing and how you are weighing long term risks and benefits of particular treatments.

Snyder: I think you bring up a good point about long term care. So, an indirectly related point, when you bring up diabetes. There is no real cure for type one diabetes. Similarly, there is no cure for autism per se. We should think of it in terms of chronic illness or disease. We have to really treat it with the same perspective of treating chronic illness like type one diabetes. With diabetes, it's something patients manage with ongoing professional support and lifestyle changes or adaptations. With ASD, it's really about management of certain symptoms, creating a support infrastructure for the family, and considering any lifestyle changes that support their overall quality of life.

Assessment led us to talk about medication treatment, so let's stay on intervention. What about behavioral interventions? What are some of the interventions, then, that you typically recommend after you do your assessment?

Weyler: I tried to decide what kind of level of care they need; e.g., is this kid dangerous or can this child go home where they have busted out every window in their house and their parents have locked themselves in the bathroom and called 911? First, you must determine safety risk, which determines level of care and subsequent intervention.

After considering safety, I like to see if there is a family structure problem. There could be a family hierarchical problem where the parents have difficulty with disciplining the kids, and I might recommend family-based services. The treatment team goes to the home to provide services and considers the ecological and family systems within the home. Then there are lower levels of care like outpatient, and this really depends on the level of adaptive functioning the child presents.

So there is the level of care to consider, but within these modalities, I would generally start off with Applied Behavior Analysis (ABA) approaches. Part of the crux of ABA is that there's a function to behavior. With autistic kids, the function might not be as clear because sometimes the function can be sensory or physiological. I've had many examples where a kid came in with a rotten tooth or an earache, and they ended up in a psychiatric hospital because he was being so aggressive, but the function wasn't evident.

Snyder: To summarize, determine safety risk, determine level of care, consider the surrounding support. When treatment initiates, ABA is the starting point in order to look at functions of behavior. A clinician should consider sensory issues or less visible functions.

Weyler: And consider this is a spectrum, so there are so many ways to meet a child's needs. There's data that autistic kids respond to CBT, sometimes with treating comorbid anxiety and OCD. Behavioral treatments grounded in conditioning principles are key. Keep in mind that ABA is something people get their masters in, where they are basic principles, but there is a lot of nuance with translating it to practice.

For someone not trained with ABA or advanced behavioral technique, the idea of an extinction burst may throw off treatment. For those not familiar with the extinction burst, I will use the hungry puppy analogy. If feeding your puppy food off the table and the puppy starts getting sick, the vet says, "you have to stop feeding the puppy food from the table." When you try to implement that strategy with the puppy and set boundaries, what does the puppy do the first night you say no? The puppy might fight, scratch, or even try to jump up on the table at first. Kids do the same thing when you try to implement a behavioral strategy and set limits. They will try to up the ante, and for kids with behavioral health challenges, an extinction burst can cause drapes to be ripped down in your house. The extinction burst actually means what you're doing is working. Consistency is essential to behavioral conditions because even if you give-in one in 10 times, the give-in can reinforce the behavior you're trying to lessen. That's how the casinos make money; they give random reinforcement to keep people spending their money.

It's important to think about parents in treatment with their kids because it's going to increase their stress as well. They may see the burst and question the treatment team, saying "What are you guys doing; he's getting worse!" So, it's important to view this developmentally and within the family systems context.

Snyder: Students have asked me (and this is representative of our field during a pandemic), "What's your take on the pandemic lockdowns and the needs of youth with ASD?" I feel like a lot of these kids kind of thrive in the school settings with learning life skills and having support like that. Now they're kind of home. What would you say to families during the COVID-19 quarantine?

Weyler: This time is the opportunity for reengagement. This conversation would come with giving limits to people, and it is important when people can hear limits, that they feel like they're being heard. So first, I would make sure that they were being heard. But I would go over what the recommendations are, and I would frame it as "you're not stuck at home, you're safe at home." Education about the importance of following the CDC recommendations is critical for anyone engaged in patient care.

Like with anything, consistency with the intervention, even the platform of intervention delivery, will serve clients best.

From a behavioral focus, I would also recommend that they make a schedule and they put the schedule and a big piece of poster board or cardboard, whatever, and that they continue to evolve that schedule throughout the day every day. Autistic children especially thrive on sameness. All the techniques that they use in elementary schools and preschools for transitioning kids and keeping them moving throughout the day, you can do all the same stuff at home. For example, 9:30, we're doing spelling; 9:30 to 10, we are going to color; 11:30 to 12:30, we're going to break and have lunch. It also keeps the parents engaged and working through the schedule throughout the day, even though they think it's for the kids. And it's also going to help them. And because they can even schedule time in like, okay, this is the time that you're going to color, and I'm going to go do what I need to do.

I would recommend people get through your day without too much negative emotion and everybody getting along. If it gets to the point where implementing a class schedule in your home is causing meltdowns, I would trust peoples' parent instincts.

Snyder: With schedules, it's good for the anxiety that people have in general! Also, you may need to coach parents on distinguishing what are new behaviors popping up in this environment that weren't at school. There may be a need for home-based behavior scheduling and behavior reinforcements to see what behaviors need to be reinforced or extinguished at home.

Weyler: And they will need some start up support with any telehealth platforms out there! The youth will need to adjust, and it could be the case that they are more comfortable in the privacy of their own home versus in my office. Like with anything, consistency with the intervention, even the platform of intervention delivery, will serve clients best.

To sum up everything, a good working relationship will help with developing safety, the appropriate level of care, and the best treatment that focuses on promoting the well-being of the family.

Things Clinicians Should Know

Antecedent: what occurs prior to or sets the stage for the exhibited behavior

Behavior: what someone does, including something internal and external; external behaviors are easily observable

Consequence: what happens following a behavior and can affect the likelihood of the behavior happening again

Scripting/Camouflaging: behavioral adaptations used to mask symptoms during social situations

Common Elements Approaches

Psychoeducation: about the diagnosis, education about functional adjustments and interventions, options for supports in schools and other domains

Tangible rewards: can be used in a schedule to increase a desired behavior; can be used in chaining, or prompting error correction

Relaxation: can take the form of sensory soothing techniques, especially when the child is in an undesired sensory state

Social skills training: providing information and training in social situations, may use modeling or role play to simulate common social scenarios like ordering food

Open Access Screening Tools

Modified Checklist for Autism in Toddlers (M-CHAT)

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8

Chapter

Attention Deficit Hyperactivity Disorder in Children and Adolescents

Sean E. Snyder, MSW; Victor Pereira-Sanchez, MD, PhD

Diego is always active, from the time he wakes up in the morning until the time he goes to bed at night. His mother reports that "he came out the womb kicking and screaming, and he has not stopped moving since." He has a kind disposition but always seems to be in trouble with his teachers, parents, and after-school program counselors. He seems to accidentally break things; he lost his jacket three times last winter, and he never seems to sit still. His teachers believe he is a smart child, but he never finishes anything he starts and is so impulsive that he does not seem to learn much in school.

Overview of Attention Deficit Hyperactivity Disorder (ADHD)*

Diego likely has attention deficit/hyperactivity disorder (ADHD). Spielman et al. (2020) note in their chapter on ADHD that the symptoms of this disorder were first described by Hans Hoffman in the 1920s. Hoffman was taking care of his son while his wife was giving birth to a second child, when he noticed that the boy had trouble concentrating on his homework, had a short attention span, and had to repeatedly go over easy homework to learn the material (Jellinek & Herzog, 1999 as noted in Spielman et al., 2020). Later, it was discovered that many hyperactive children—those who are fidgety, restless, socially disruptive, and impulsive—also display short attention spans, problems with concentration, and distractibility. Spielman et al., (2020) describe more about the history of ADHD, reporting that by the 1970s, it had become clear that many children who display attention problems often also exhibit signs of hyperactivity. In recognition of such findings, the third edition of the Diagnostic and Statistical Manual of the American Psychiatric Association (DSM-III, 1980) included a new disorder named "attention deficit disorder with and without hyperactivity," which in later DSM editions would be renamed as "attention-deficit/hyperactivity disorder" (ADHD).

Prevalence of ADHD

ADHD occurs in about 5% of children worldwide (APA, 2013), and on average, boys are three times more likely to be diagnosed with ADHD than girls. When girls are diagnosed, they still have the same level of severity as boys (Barkley, 2006). The diagnostic rate differences between boys and girls might be due to biology, but it could also be due in part to underdiagnosis of girls, who typically are more inattentive and less hyperactive and thus stand out less than boys (Barkley, 2006). Children with ADHD face significant academic and social challenges. Compared to their non-ADHD counterparts, children with ADHD tend to have lower grades and standardized test scores, as well as higher rates of expulsion, grade retention, and dropping out (Loe & Feldman, 2007). They also are less well-liked and more often rejected by their peers (Hoza et al., 2005).

ADHD can persist into adolescence and adulthood, with a longitudinal study finding that 29.3% of adults who had been diagnosed with ADHD decades earlier still showed symptoms (Barbaresi et al., 2013). Nearly 81% of those whose ADHD persists into adulthood had experienced at least one other comorbid disorder (Barbaresi et al., 2013). Longitudinal studies have also shown that children diagnosed with ADHD are at higher risk for substance abuse (Molina

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& Pelham, 2003), and this risk increases for those with ADHD who also exhibit antisocial tendencies (Marshal & Molina, 2006).

How ADHD Develops in Youth

Genetics play a significant role in the development of ADHD (Burt, 2009), which is highly heritable (Nikolas & Burt, 2010). Studies show that regulation of dopamine could play a role in ADHD, hence why first-line stimulant treatments enhance dopamine transmission between neurons (Gizer et al., 2009, Volkow et al., 2009). From a neuropsychological point of view, ADHD can be described as a condition that affects executive functions, which are responsible for complex cognitive tasks such as reasoning, planning, and impulse control, as well as other cognitive systems (Gizer et al., 2009, Volkow et al., 2009).

Research, clinical practice, and lived experience have supported the conceptualization of ADHD as a neurodevelopmental disorder; claims that it is caused by bad parenting, ‘unhealthy’ nutrition, excessive video gaming or other factors are unsubstantiated. Supportive parenting can indeed help children with ADHD thrive, maintain good behaviors, and develop skills, mitigating the impact of the disorder, but the absence of these parental behaviors does not by itself cause ADHD; the environment is more a modulating rather than an etiological factor, while genetics and neurodevelopment are etiological factors, on the other hand (Burt, 2009).

> *ADHD is characterized by evidence of the existence of symptoms of inattention and/or hyperactivity and impulsivity in a frequency and intensity beyond what is expected for age and developmental stage, having started during childhood, being present in more than one area of the client’s life, and being impairing and/or distresing.*

Developmental Systems Considerations with ADHD

With Diego, it is interesting to note that his mother recalls that he “came out the womb kicking and screaming,” which seems to indicate the early neurobiological underpinnings of the disorder. In this example, we are seeing it across domains. As mentioned in an earlier question, is ADHD about poor parenting? We can see that the disruption caused in the educational domain points to something apart from parenting. If the child was only having problems at home, we could more clearly see the link between family interactions and the behavior. The developmental systems perspective would look at these ecological variants: what contributes to his presentation in different settings? If it was defiance to adults, we are thinking about a totally different disorder cluster. Time matters here, too. We sometimes see development as a way for problematic behavior to resolve but not in this case. Despite interaction with many adults who most likely gave him feedback about his behavior, the ADHD seemed to stick.

As you will read at the end of the treatment section, the ripple effects of ADHD can infiltrate academics, socialization and developing a peer circle, the development of self-concept. So while the etiology of ADHD may appear to be heavily neurobiological, the perpetuating factors are clearly systemic, often predicted by access to treatment. So what happens when children don't get access to ADHD treatment, or are misdiagnosed all together?

Experiences Across Race and Ethnicity. Scientific literature points to racial and ethnic disparities in ADHD (Morgan et al., 2013), and a recent report from the National Center for Health Statistics presents a similar picture (Zablotsky & Alford, 2020). Analysis of national data indicates that non-Hispanic Black children ages 3-10 years old were more likely to be diagnosed with ADHD or a learning disability than non-Hispanic white or Hispanic children (Zablotsky & Alford, 2020). Family income across all racial and ethnic groups was a predictor of these rates, with the percentage of children diagnosed with ADHD or a learning disability decreasing for families with higher incomes (Zablotsky & Alford, 2020). Consider the cultural factors with diagnostics. How much of the diagnoses are a result of clinician bias? How much is it a result of parental stress due to structural factors?

Experiences of LGBTQ+ Youth. There is scarce data regarding prevalence rates specific to LGBTQ+ children. There is data to suggest that, compared to cisgender individuals, transgender and gender-diverse individuals have elevated rates of ADHD (Warrier et al., 2020). Considering victimization rates with LGTBQ+ youth, a clinician should bear in mind how the presence of ADHD can affect coping and socialization; ADHD can create an added vulnerability for these youth.

Assessment of ADHD

A child with ADHD shows a constant pattern of inattention and/or hyperactive and impulsive behavior that interferes with normal functioning (APA, 2013). Some of the signs of inattention include great difficulty with and avoidance of tasks that require sustained attention (such as conversations or reading), failure to follow instructions (often resulting in failure to complete school work and other duties), disorganization (difficulty keeping things in order, poor time management, sloppy and messy work), lack of attention to detail, becoming easily distracted, and forgetfulness (Spielman et al., 2020). Hyperactivity is characterized by excessive movement, and includes fidgeting or squirming, leaving one's seat in situations when remaining seated is expected, having trouble sitting still (e.g., in a restaurant), running about and climbing on things, blurting out responses before another person's question or statement has been completed, difficulty waiting one's turn for something, and interrupting and intruding on others (Spielman et al., 2020).

Timing is an important consideration for the onset of these symptoms. In the DSM-5, time is a critical component. It states that "Several inattentive or hyperactive-impulsive symptoms were present prior to age 12 years" (DSM-5, 2013), which leads us to believe that if there were no symptoms prior to 12 years, there must have been some activating event like traumatic exposure, a medical condition, or onset of a mood disorder that would lead to the symptomatology. While there can be youth that "fall through the cracks" with assessment, typically those who have severe symptoms will catch the eye of school staff, pediatricians, and the caregivers who are with the child daily (Spielman et al., 2020).

Assessment Tools for ADHD

The diagnosis of ADHD is clinical; that is, it is a judgment from a competent clinician, and currently no tool (questionnaire, test, medical workup, or imaging) has diagnostic ability per se, nor is strictly needed to support a diagnosis. Such clinical judgement is based on the information gathered through interviewing and observing the client and obtaining collateral information from people close to them. In children, diagnosis relays mainly on reports from main caregivers, usually parents, while information provided from other caregivers, and, especially, from schoolteachers, is often valuable. This information should provide evidence of symptoms of inattention and/or hyperactivity and impulsivity in a frequency and intensity beyond what is expected for age and developmental stage, having started during childhood, being present in more than one area of the client's life, and being impairing and/or distressing, according to DSM-5-TR criteria (American Psychiatric Association, 2022).

When a clinician is assessing a client for ADHD, the interview with the client and their caregivers should include questions about current problems, timing, and their context, as well as other educational, social, mental health, and medical problems in the present or past, a history of the client's development, with particular interest in possible problems during pregnancy and labor and the fulfillment of developmental milestones. The strategies for interviewing and observation of clients would depend on the child's developmental stage. In younger kids, more valuable information could be obtained through observation, play, and projection through artwork, while formal conversations would be more valuable in adolescents. Especially with young children, behavior at the clinician's office during assessment might not be representative of their usual; they might be very excited about missing class or meeting new people and receiving attention, or they might be very shy and scared in a novel situation, or upset due to the disruption of their routines, or hungry or sleepy at the moment. Another concern is that information obtained from their interviews might be biased by lack of insight, agreeableness, or concealing. That is why collateral information is essential, especially if coming from different informants and reporting on observations over a long period of time.

> *Medication often lays the basis over which parents, teachers, and if needed, non-physician mental health professionals can support the children's skill development. Psychosocial and behavior interventions are also pillars of the children's treatment.*

A number of assessment tools have been developed over the years to aid clinicians in obtaining, characterizing, and quantifying information to support their clinical judgment (Weiss & Stein, 2022). Structured clinical interview guidelines exist, which might be of value for research but mostly impractical in regular clinical settings, where time is limited, and the context and purpose of the visits go beyond diagnosing or ruling out a specific disorder such as ADHD. Several rating scales have been developed to identify and quantify symptoms and impact, as well as other features of ADHD beyond diagnostic criteria. Some of these hold promise of becoming useful for screening; they could be used outside of clinical settings and reliably rule out ADHD in children who do not have it while identifying children at high risk who require clinical assessment. Some of these questionnaires are to be completed by the client, others by the caregivers, and others by teachers. These tools have been categorized into those in the Achenbach System of Empirically Based Assessments (ASEBA), which includes the Child Behavior Checklist (CBCL), which inquires for problems and symptoms related to ADHD and other mental health conditions; those within the Conners family, which focus on ADHD, oppositional defiant disorder, and related problems; those following the DSM diagnostic criteria, such as the ADHD Rating Scale and the Swanson, Nolan, and Pelham (SNAP), and Vanderbilt questionnaires, which focus on the symptomatic areas of inattention, hyperactivity, and impulsivity listed in the DSM; the Strengths and Difficulties Questionnaire (SDQ); and others. While the use of any of those questionnaires, separately or in combination with others, cannot replace the clinical diagnosis, incorporating information from some of them, especially when including different informants (client, caregivers, and teachers) and dimensions (DSM criteria for ADHD plus features related to other possible problems and conditions) can provide a comprehensive overview of the child's struggles, and the rating scores in some of those tools can be used to monitor changes with time and treatment (Mulraney et al., 2022).

A large set of paper-and-pencil and computerized neuropsychological tests have been designed, tested, and incorporated into clinical practice; some of the most used include Weschler and Kaufman Intelligence Quotients (IQ), the Trail Making Test, and the Continuous Performance Test. Such tests, which usually require experts to assist in data collection and interpretation of results, are not validated nor required for diagnosis but can provide insight into the client's strengths and deficiencies in specific cognitive areas such as general, verbal, and spatial intelligence, executive functions, attention, memory, and more. This might inform individualized educational support strategies (Lange et al., 2014). Finally, to date, no medical workup or imaging tool (such as electroencephalography or magnetic resonance imaging) have demonstrated diagnostic value, although some of those might be warranted if there is reasonable clinical suspicion to rule out conditions that could be coexisting with ADHD or be an alternative cause of the observed ADHD symptoms (conditions such as brain trauma or tumor, nutritional or hormonal deficiencies, etc.).

Intervention

Where would we start with Diego? Scientific literature indicates that the first-line treatment for ADHD is medication (Caye et al., 2019), despite common public perceptions that children are overmedicated. The landmark study – the Multimodal Treatment of ADHD (MTA), indicated that medication treatment was superior to other modalities (The MTA Cooperative Group, 1999), and alternative outcome analyses indicate that the sharpest rate of improvement for youth with ADHD was highest with combined high-intensity behavioral and medication management approaches, then medication management only, then high-intensity behavioral treatment only, and finally standard community care (Conners et al., 2001).

For Diego, stimulant medication does seem indicated. Imagine what that would be like for him, to have that type of support; what would he look like in the classroom? What would it be like to get him out the door to school? I'm sure that there would be fewer arguments related to corralling him to the bus or fewer incidents at school with his teachers or peers. Consider what that would mean for his self-concept. We often see comorbidity with ODD and conduct disorder. Let's say he doesn't get the medication intervention and problems persist. Would he internalize these problems and label himself a bad kid?

With stimulants, the important thing to remember is that the most common side effects (decrease in appetite and wakefulness) are usually mild and only present while the medication is in the bloodstream. This makes it important to understand the different pharmacokinetic (the way medications are absorbed, metabolized, distributed, and eliminated in the body) profiles of each of the available brands. For instance, methylphenidate and dextroamphetamines are the most used stimulant molecules, but depending on their brand, they will have different profiles of onset and waning of their effect. Physicians prescribing those medications would usually discuss with parents the best medication formulation (brand) for their kids to make sure they get high blood levels of the molecules during the time of the day they need it most and that the medication gets cleared from the body before bedtime. It is important for parents to note that their children will have less appetite while the medication is in high levels in their bloodstream, so it may be advisable to supplement breakfast and dinner if it is expected that the child would tend to eat less at lunch. Other less frequent side effects are changes in mood and irritability. Prescribing clinicians would sometimes recommend suspending medication during the weekends, on holidays, or after a year since the start of treatment to assess how the child does without them and evaluate the need for continuation.

Medication often lays the basis over which parents, teachers, and, if needed, non-physician mental health professionals can support the children's skill development. Psychosocial and behavior interventions are also pillars of children's treatment. Some interventions may be ecological; think about necessary school supports if there really is a learning disorder. Maybe a 504 plan is warranted to provide scaffolding to support adaptive behavior.

So, imagine that Diego is in your office, there has been medication, and there has been educational support. What do we do with the behavior? Common behavioral approaches for ADHD include behavioral parent training, behavioral classroom management, behavioral peer interventions, cognitive training, and organization training (Evans et al., 2014). The common elements within these interventions tend to focus on reinforcement techniques such as time-out, token economies, and response cost techniques that remove rewards or privileges (Floet et al., 2010).

All in all, children with ADHD do best when all actors implicated in their care and support are on the same page. Parents that have been thoroughly and compassionately listened to and educated about the disorder and the available treatments and interventions, and made active participants of the decision-making will be more likely to understand and engage in treatment. Physicians, other mental health professionals such as social workers and teachers should feel an important part of the supportive team for children, listening to one another, being coordinated, and acknowledging and respecting the specific responsibilities and limitations of their own role.

Interventions should aim at increasing executive functioning capacity, namely those skills and processes that help with organization, impulse control, and affect management. A practical exercise to do with these youth is the book bag organization activity. You can instruct parents on how to guide a child through organizing their backpack so they know where their folders and books are and where they can easily find assignments. If the child has siblings, you can organize a game to see who can get a particular item first from their backpack, like a math worksheet. This can preview some organizational skills that can be taught related to school. If children can be organized, it can make doing schoolwork easier.

To take a broader approach, let's consider what Hinshaw and colleagues (2015) observed in their study about ADHD intervention. They recognize that there are many factors at play in ADHD, such as biological vulnerability, discordant family interactions, peer rejection, and classroom struggles (Hinshaw et al., 2015) which leads to the recognition that ADHD requires a multi-faceted approach, something that would ultimately be grounded in the developmental systems perspective. Consider the ripple effects ADHD could cause; for instance, what about parent support and managing their stress? What about the academic effects of being held back or suspended? Or the loss of friendships and difficulty in making new friends? ADHD treatment should consider these factors as they pertain to developmental continuity and adaptations required to recover.

Clinical Dialogues: ADHD in Children and Adolescents with Dr. Stephon Proctor, PhD

Dr. Stephon Proctor is a Child and Adolescent psychologist at the Children's Hospital of Philadelphia. He attended graduate school at Pennsylvania State University and completed an internship and postdoc at Geisinger Medical Center in Danville. He started working at the Children's Hospital of Philadelphia in 2013 within the Center for the Management of ADHD. Dr. Proctor specializes in ADHD treatment and assessment in the center, where they treat children between the ages of five and 18, doing individual and group treatment, and conduct diagnostic assessments as well as psychoeducational evaluations. Dr. Proctor is board-certified in Child Adolescent Psychology, and he has a subspecialty in anxiety disorders.

Sean E. Snyder, LCSW: Thank you for joining us Dr. Proctor. Our conversation is going to cover a few sets of questions: engagement, assessment, and intervention. By engagement, we mean the multidimensional commitment to treatment from initial outreach to the ongoing involvement of the family in the treatment episode. With that in mind, what is the typical process for engagement with families?

Stephon Proctor, PhD: Families are usually self-referred, so they call our intake, and at that time, we send out information for the caregivers and the teachers to fill out so that we can have a comprehensive view of the child's functioning across the home and school domains. Once the information is collected, we will set up an initial evaluation with the family to understand a little bit more what concerns they have about ADHD and/or other behavior problems, because those are sometimes comorbid concerns that come along with it. During the course of evaluation, if we determine that a child does meet criteria for ADHD, we give them options about treatment whether that is internally at CHOP or, if it is outside, with another community care provider.

Options can come in a couple of forms. We do offer parenting groups for parents with children with ADHD, and these are really focused on teaching parents behavior management skills in a group-based format led by one of our clinicians in the ADHD center. We also offer options of individual family-based therapy focused on working with children and their parents on behavior management; this also helps them to navigate things like accommodations in the school. For some children, we have discussions about medication management and facilitating medication management, either inside or outside of CHOP.

Snyder: That sounds like you are really meeting them where they're at and seeing what's the best fit for them, given the many contexts of the family.

When I reviewed information on the Center for Management of ADHD, some materials mentioned two groups of youth seen at the center: youth with ADHD and youth at risk for ADHD. What would constitute a child being at risk for ADHD? I wonder if that affects engagement at all.

Proctor: With youth at risk for ADHD, usually early signs come from teachers and/or parents that a child is struggling with academics or behavior. A typical complaint may be that this child is very forgetful and disorganized or zones out a lot. So, there's concerns about whether there is something like ADHD or something else. If they are younger (and we're seeing that), then there's a little bit more concern, and usually what someone is observing are a lot of failures and unexpected behaviors through home or school routines.

Snyder: It's starting to get flags of what could be a more formal diagnosis. So, it seems there, it would follow normal outreach and engagement. I'm thinking now about the parents and caregivers that may be feeling really overwhelmed before they engage with your center. With that in mind, do you do a lot of psychoeducation on the front end, or do you wait until after the assessment? How do you balance intervention and assessment in that way, considering that families may be feeling a little overwhelmed?

Proctor: We try to do some psychoeducation during the evaluation and then after the evaluation. So, at the outset, it's really clarifying what's involved with an ADHD assessment. There's a lot of misconceptions that families have about how the condition is diagnosed. A lot of times they may ask "Will we have to do a brain scan or an MRI?" Or they may have thoughts about hours of neuropsychological testing. So we try to pause and help them realize that in terms of best practices, it's really based on clinical interviews and ratings from teachers and parents about a child's behavior across home and school.

Once a child is diagnosed with ADHD, or even when they're not, there is psychoeducation about the development of it; that is, how your child comes to have these symptoms. And there is consideration of what is the parent's role in that. So, we may discuss the different domains of interventions, including things that parents can do at home and school or in terms of medication.

The provider is giving a context for understanding the source of the potential disorder as well as thinking of the potential solutions because a lot of parents are looking for solutions to these challenges. Once they have a label and they know what they're dealing with, you'll usually see that a lot of the stress about what the problems are tends to go down. They now know that there's a clear path for them to be on, as opposed to the potential confusion or lack of information they had prior to coming to our center. Before that, they may have an inkling, and some are just completely confused. It makes it hard for them to know which direction to take because they don't know what kind of problem it is.

Snyder: It's almost the "name it to tame it" approach; once they have an understanding of the issue, there is a clearer pathway to approach the issue. It sounds like there's a lot of prep work that goes into them even getting into the assessments, and by prep work, its overviewing what's going to happen with the care episode, the general contexts, the rating scales or pre-assessment forms and observations.

Let's fast forward to the initial meeting with the family. Let's say the child is in your office, and it's clear that they're hyperactive. You see that they may be touching things and are kind of moving around the room a lot. It can be tough for those kids to sit through an evaluation, so how do you engage them in the moment when you are seeing them displaying that hyperactivity?

Proctor: I've really tried to help get the child to be involved in the evaluation. I know it may be easier for me to just talk with the parent because I know that they're going to be a lot more attentive and motivated, but early on, during the beginning of the interview, I actually will start part of my evaluation asking the child about who they are, what school do they go to, who is in their family, what are their hobbies, just so that would they know that I think that their experience is helpful and valid for me. At some point, though, I will have to transition to obtaining more information from the caregivers. I usually will not give any instruction about how I want the child to behave, because I want to get a naturalistic observation of just the child without any structure. There's data in observation of how the parent responds to the child who is flipping on the couch; that gives me some data for what the child's behavior is in a public setting, but also gives me some data on how a parent may handle that in a public setting.

At some point, depending on how distracting the behaviors are, I will provide some modeling for the parents, where I may give the child some instructions about how I'd like them to behave, how I'd like them to sit if they're able to do it. I may offer an incentive in terms of getting to play with some toys in the office. For some kids, we may even use things like stickers and say "if you do a really good job of staying in your seat for the next 10 minutes, I'll give you a sticker from the sticker book." The reason I do that goes back to engagement. I want to show parents that this is the exact same type of strategy that I would be coaching you to do, and giving your child clear instructions, observing how they perform, then having some sort of positive reinforcement for that.

I am very big on modeling that from the outset, because it helps me get my evaluation done without too many distractions. It also primes the parent for when we start talking about behavioral treatment. They can remember when I asked their son to sit for five minutes, and I was going to observe how long they could do that. I may say "You could do that when you're at the Olive Garden," and I coach the strategies before and during evaluation.

Snyder: This is the classic case where the assessment is an intervention itself but also how intervention can be built into the assessment.

Proctor: I think sometimes, too, I'm thinking with parents where a lot of times they think it's going to take a complex strategy to get their kids to do whatever they are requesting the child to do. Sometimes, it's just a simple thing and being structured and intentional with it.

Snyder: So, you get a lot of observational data based on small interactions. How do you balance all the data you get from an interview with all of the collateral reports? I'm thinking of a scenario where the child isn't hyperactive in the office and maintains focus. The caregivers are clearly distressed by the symptoms at home. What happens if what you see in the office doesn't match the rating scales and the classroom data. How do you deal with all this information, especially when there could be variance?

Proctor: Oftentimes, I'll let parents know that my observation is only a data point in this larger view of your child, and I tell them that it actually is pretty common that children will not behave in the same way in our office than they do at home or at school. That is usually because they do not know who we are, and there's a completely different structure. They can't really be their full selves, and so I don't want parents to think that because I didn't see the behavior that I'm going to negate that parents experience. I do think there is sometimes that fear.

Thankfully, because we know that what the child does in our office is actually not a criterion for the diagnosis, I'm going to rely more on what parents report and the ratings that we get from home and school. And if I have any other data from previous evaluations or previous therapists, all of that is going to weigh a lot more heavily than what I see.

And if I do see the behaviors, I will note it and ask, "Hey mom or dad, is this kind of an example of what you see at home?" And they may reply "Completely, he interrupts us all the time!" Again, I reinforce that my observation is not a make or break for the diagnosis.

Snyder: I'm sure that will give parents some relief as well, right, because they have some expectations coming in, and it wasn't invalidated by the clinician focusing on one tiny detail among this constellation of data points.

So, let's get into the nuance of assessment itself. The Vanderbilt can be the go-to measure, maybe because it is freely accessible. What are your thoughts about this measure or using measures like the Vanderbilt?

Proctor: I really enjoy the Vanderbilt. One reason is because it aligns very closely almost item by item with the DSM-5, and so you don't really have that huge gap between what the diagnostic criteria are and the items in the actual measure that you have. You may see with other conditions, there is kind of a description of the behaviors in the ratings for instance, like with anxiety, where the items on the measure match up exactly with the criteria for generalized anxiety disorder. So 1) the Vanderbilt matches up well, and 2) it's freely available. You don't have to worry about licensing and fees and things like that. It's quick and easy to score, if you were to compare with other measures like the Connors where you have to have scoring software or you have to hand-score, and that takes time. In clinical practice, you want to think about these questions: What's the most efficient way to get this data? What's the most efficient way for me to get good data? And I think the Vanderbilt strikes a good balance with that.

> *I am very big on modeling from the outset in evaluation, because it helps me get my evaluation done without too many distractions, but it also primes the parent for when we start talking about behavioral treatment.*

It also does a really good job of screening for things like oppositional defiant disorder, anxiety, and depressed mood, which often are comorbid with conditions. Then, it does a good sense of getting us impairment in terms of academics, social and family functioning. It's also great because when you are collaborating with physicians, pediatricians are more likely familiar with the Vanderbilt if they've got some psychiatry training. It's the most widely used, widely available measure for pediatricians. If you were to switch to something like the Conners, they may not know how to interpret those scores, but most physicians who have some exposure to ADHD are more familiar with something like the Vanderbilt.

Snyder: And with your thoughts about the comorbidity that comes with ADHD, you touch on something so important. Understanding if a child has inattention because of ADHD or because of racing thoughts related to anxiety completely changes the treatment for a child. I'm thinking beyond the Vanderbilt now; there can be misdiagnosis of ADHD as it pertains to trauma or anxiety related disorders. How do you account for the possibility of a trauma related disorder or an anxiety disorder as influencing the client presentation?

Proctor: We do that during the course of the clinical interview. We do a safety screen where we're asking about trauma, and we're asking about suicide symptoms like ideation and about suicide attempts. That's really the best way that we get that information. Some of it may come up when a parent writes it on an intake form. But there again, we're trying to balance the parsimony of the information that we asked on paper versus what we can gather in person with a lot more nuance.

Snyder: I think maybe even coming at it from that idea of client safety is more relevant to the clinical interview because there are a lot more follow up questions to that. So, you briefly touched on comorbidities in that last response. In that same mindset of thinking of multiple aspects of a child presentation, we also know that domains matter; for a formal diagnosis, there needs to be impairment in a couple domains. What do you do with data that shows impairment in only one domain? What does that tell you?

Proctor: What you must account for is this question: is there a reason that you're not seeing it? So, for instance, does the teacher have great classroom management, and as a result, the child actually looks relatively impaired because the teacher really knows how to prepare the environment for this child? They may use a lot of positive reinforcement and so on.

The flip side is true with the home. Parents may be able to handle the behavior really well, but the teachers are saying they're really seeing a lot of challenges. With that, I often ask the parent or the teacher, "If you were not to provide all the structure that you do, which is successful, how do you think the child would perform?" They'll say, "Oh yeah, well, he will forget his jacket and his lunch every day if I didn't stay on top of them." So, I do treat that as an indicator of what would happen without all the extra support there, if that makes sense. What would happen if this child didn't have a 504 plan and extra reminders?

Often the biggest comorbid condition with ADHD tends to be oppositional defiant disorder. A parent may say, "Well, my child doesn't listen to anything I say," and in the clinical interview, you may find that the child hears the parent perfectly fine but refuses to follow through with the command. They may even have very overt ways of letting the parent know that they didn't want to do that, through things like hitting, screaming, kicking, or laying on the floor. And so, another consideration is this: is there actually a different disorder that explains or describes what is happening in this interaction, so to speak with one parent and the child versus a child and the teacher?

Snyder: That makes sense because it's like the idea of what's really driving the symptoms that you're seeing. Is it in relation to inattentiveness or is it something with relating authority figures? Diagnostic clarity is huge.

Last questions with assessment before moving more specifically to interventions. What do you make of what seems to be the increased prevalence of ADHD? There's some sociological theories out there that say high stakes testing has contributed to this rise in ADHD diagnoses, or clinical theories may say we're measuring it better. I see a lot of ADHD in my practice and I wonder often, what's happening with this increased prevalence or at least what seems to be an increased prevalence?

Proctor: That's an important question: is it what it seems like versus is it what's actually happening in nature? And I think the answer is complex. There's just more awareness and acceptance of it, but you can find this with any condition, that society becomes a lot more comfortable with mental health over the long term, and so people are more willing to report having histories of it or concerns of it. So, I think that's one part; it's going to just be more accepted as a diagnosis, not seen as stigmatizing as some other conditions.

I do think there may be the chance for it to be overly diagnosed because not everyone who received the diagnosis receives the comprehensive evaluation. A lot of providers in the mental health field will tell you that they've received a report from another therapist or a doctor that has given a diagnosis of ADHD, but there doesn't really seem to be a strong basis for that diagnosis. Maybe they only got information from the parent and nothing ever about the teacher, but it seems like ADHD, so they gave a diagnosis and that can inflate the official statistics about the rates of ADHD.

Usually what I've seen in the past is that most concerns about mental illness don't come straight to a mental health provider. It usually comes to medical providers like a pediatrician, and some pediatricians do feel comfortable with identifying and even managing some of these child areas. However, they're not always as skilled or trained in the assessment of these conditions. Someone who is not so skilled with ADHD diagnosis and identification maybe does not do much of a comprehensive assessment, so their diagnosis of that child is kind of a "plus one" in that category of the prevalence of ADHD.

Snyder: Yes, I think I see that a lot in evaluations. ADHD, by history, somebody gave the diagnosis, and it gets continued, or, like you said, sometimes it's based more on heuristics like case examples versus doing a thorough assessment.

We know that any good assessment needs a formulation to tell the context of the interview, and a good assessment links treatment outcomes with recommendations. So, let's get to intervention. "ADHD and medication" is a recurring story. There are studies that indicate that medication is the frontline treatment, which sometimes gets a negative reaction from mental health clinicians, and sometimes medication can carry stigma for families. So, what are treatment planning conversations like with families, knowing that this is the frontline intervention? Are families receptive or resistant for the most part?

You might see how well a child can do with just behavioral accommodations in school and at home. If you're finding that you've done behavioral treatments either individually or in group, but they are hitting a plateau, and we're not really getting much more extra benefit, then I might say, let's try medication.

Proctor: So this is definitely a conversation most families are already prepped for, with different avenues about how to respond. Some families are receptive, some resistant, some are curious, and everything in between. I first start with the research, like the MTA studies that show children who have a combination method of ADHD behavioral treatment and medication tend to have better outcomes than children who have a singular treatment. I start off by saying in general what's helpful for a kid.

I do of course spend a lot of time talking about behavioral treatments, because I think they should always be present, regardless of whether you choose to medicate your child. When I talk about medication treatment, I discuss the benefits and the side effects because, I think, of course, most families are concerned about the side effects. In terms of the benefits, I often talk about it addressing a lot of core symptoms of ADHD, like inattention, hyperactivity, and things like that. But I also talk about how medication has come a long way since a lot of parents first learned about it. Most parents have kind of a view of Ritalin and Adderall, because those were the two medications that were really the dominant ones for the past 20 to 30 years. And now we have maybe 10 to 12, or maybe even more, with different formulations in terms of whether they're short or long acting, and different routes, whether it's a pill, sprinkles, liquid, or transdermal patch.

And so, I bring that up, and I also give them an example of kinds of stimulants that they may be using that they're not even aware of. I say, "Mom or Dad, do you guys drink coffee? They're like, oh yeah, we drink coffee." And I said, "well, I don't know if you know that that's actually a stimulant, and it stimulates your brain. You take that in the morning, and it helps kind of shake the fog off, and it helps you concentrate." And then I would go on to explain that throughout the day, your body metabolizes it, and you may get another cup of coffee, or you may be done for the day. I want you to think about that with ADHD medication. The same way that a child takes this medication in the morning. It's a lot more targeted than your coffees, so please don't give them Starbucks every morning. But I do want you to think about that. This stimulant is formulated differently. It does help your child focus through the school hours. Some children may need only something that lasts six hours, and some children may need something that lasts throughout the day depending on the severity or their symptoms. And the good thing is that just like your coffee the ADHD medication gets metabolized throughout the day, and so, by the time the child goes to bed, it's pretty much out of their system. And then the next day they take it again.

So, the benefit of ADHD medication is short acting. The benefits, as well as the side effects, only affect the child during the duration that they're actively on the medication. So, if their child has a side effect, let's say appetite suppression, you can stop taking the medication, inform the prescribing provider, and you won't have to worry about that symptom until the medication is adjusted. I think that relieves a lot of the initial stress on families because there is this perception that the child may have to be on it for a while and that you really have to accept the side effects. With the benefits, I have to say, we actually have a lot more fine tuning than we did with previous medications, where for some kids their first medication is a home run, and with other kids, there is a little bit of a trial and error approach. It's hard for me to know at the outset which one is going to be right for your child. But because it's so short acting, you can still feel cautious about the side effects and also dip your toe in, so to speak, and see what happens. I say most families are more receptive if your conversation takes that approach.

Finally, if a parent asks, "How would I decide whether to use a certain medication? Do I do it sooner or later?" I say it's based on the severity of the presentation and what interventions are present. If we can divide up ADHD severity, in terms of one, two, and three, a level three is a more severe child and is maybe even to the point where they're being disciplined in school, made to repeat a grade, or being expelled. It's causing a lot of issues in the classroom, and the child is getting daily reports home from the teacher about this disruption. That's more like a level three. Level one is the kind of child that really doesn't get noticed much, and there's symptoms here and there, but for the most part they're getting by. And then you have a level two who are those in the middle. I'd say if a child was a level three, where the ship is sinking, so to speak, I would have the discussion about medication sooner rather than later, because school is cumulative and whatever your first grader doesn't learn this year, they will miss for the second year as well because the teachers don't have the opportunity to go back and teach your son everything that he missed because of his ADHD. Now if your child is a level one, you might see how well a child can do with just behavioral accommodations in school and at home, and some children actually do pretty well with just behavioral interventions. If you find that your child is a level one or two, and you've done behavioral treatments either individually or in group, but they are hitting a plateau, and we're not really getting much more extra benefit, then I might say, let's try medication.

That approach tends to give parents a little bit more control, where they think "We don't have to decide today for medication for our child." They can actually take a more conservative approach, which is either start medication and behavioral treatment at the same time, or start behavioral treatment and wait to see later on if medication is warranted. I find that approach helps with the receptivity versus a statement like "Your child has to be on medication," because that's a one size fits all approach, and as we know, every child with ADHD and their family situation is unique. I think we need to tailor our interventions and recommendations based on those factors.

Snyder: That point touches on neurodiversity and also ecological diversity with these youth. We need to think about where our treatments are happening, with whom, and in what contexts. With behavioral treatments and psychosocial interventions, are there any go-to treatments that you recommend, for instance, or specific protocols?

Proctor: Anything based on behavioral treatment is definitely my go to. Many people may be familiar with Barkley approaches in terms of therapist manuals, but also the parenting books which are highly accessible. Other treatments include things like Rex Forehand. At our center, we tend to default more towards the Barkley based treatment manuals, but I think that's just based on history. You'll find that there's other treatments that are not necessarily focused on ADHD, per se, but still have behavior management. Things like the Incredible Years are good for much younger children, and even PCIT for much younger children. They're not specifically focusing on ADHD symptoms, but behavioral treatments still do tend to generalize.

I would say Barkley's tends to focus more squarely on ADHD from the education piece but also kind of making your behavioral interventions focused on those core deficits that children with ADHD struggle with. We may find that children with ADHD also struggle with poor emotion regulation, and many ADHD treatments don't focus on the emotional aspects of inflexibility, per se. I'm finding that things like the Explosive Child book is really helpful for children who just really have this explosive reaction to the environment and use that as an adjunct on top of the behavioral treatments that you're doing for ADHD.

Snyder: What about alternative treatments? There have been some studies about neurofeedback for instance. What are your thoughts on those alternatives?

The most sustained benefit is going to be from what you teach the parents to teach the child when they go home. So, the real work happens in between sessions and not in your session.

Proctor: Yeah, those are popular alternatives right now. I think it's because sometimes parents who are cautious about medication treatments want to see what else there is, and it's valid to kind of wonder if they're missing something. Things like neurofeedback sound very scientifically legitimate, where you've got your child in an EEG cap, so it feels very official. But when we reviewed the literature on neurofeedback, it's not very strong. What you may find is that studies show positive results, but the positive results are only in the domain or the task as a child's being tested on, whether it is an interactive video game that the child is being tested on or a certain type of behavioral inhibition task. They may improve on that; however, it doesn't generalize to actual everyday behaviors. If you were to ask a parent, "Give me the top three behaviors that your child struggles with," it's going to be things that are happening in the real world, like he forgets to bring home his homework assignments. Well, neurofeedback isn't going to help with that.

What I often say to them is that the science currently says that the behavioral treatments and medication are the frontline interventions; these are currently the gold standards. You would want to start with a gold standard. And if you're finding that you're having trouble with accessing those treatments or having limited success with that, then you may want to consider complementary, alternative treatment. I would be cautious about starting with a complimentary or an alternative treatment because if your child doesn't succeed or get benefits with those, you've lost valuable time with the child's development because the child has been quite likely undertreated for more of the typical school year. If you spent half of the year doing neurofeedback well that's also half of the year that you weren't doing other things that could actually have benefited the child based on what the research says is most effective.

Snyder: Right, there's the difference here of lab conditions that show efficacy versus the effectiveness in real settings. So, to summarize what you just said, go with the gold standards, and if those aren't helping, then go to alternatives, as ADHD problems have a cumulative effect on child development.

We are reaching the end of our time with this interview, so I'd like to get some final words from you. What are some core pieces of advice you would provide trainees or folks with who want to improve their practice with working with children with ADHD?

Proctor: So, if I'm thinking of a trainee in mind, I think some tips that I would suggest to them are that sometimes there is this focus that a therapist needs to treat the child. And I want to underscore that whatever direct work you're doing with the child is going to be a drop in the bucket, because really the most sustained benefit is going to be from what you teach the parents to teach the child when they go home. So, the real work happens in between sessions and not in your session. I wanted to alleviate some of that kind of pressure that sometimes we either put on ourselves or that we feel like our supervisors put on us to "fix the child," and I would even sometimes say the parent puts that on us like, "Oh, well, I'm going to drop my child off, and you're going to rid them of like ADHD." And I say, "No, you're coming in, you're going to be part of the session to help me with that as well." So you'd find that if you were to watch me do therapy, I actually spend most of my sessions with the parent and the child in the room so that we're working collaboratively on the behaviors. But I'm not spending much time individually with the child unless they're kind of older, like a teenager, like a high schooler; then I can start to work more individually with them.

I'd say for early treatment, I find it is most effective to bring the family, because it delivers the message that we're all part of this and not that the therapist is magically fixing your child while you're in the waiting room. You may find that a lot of children with ADHD are not very engaged in the treatment, per se. They don't often see the same deficit that their parents or teachers do. Most kids, if you ask them "are you having problems in school?", they're like, "I'm fine." So, their insight into their ADHD tends to be kind of low, whereas everyone else may be kind of feeling like, "No, this child's really impaired." And that's okay. I think some of it is because everyone else picks up the pieces after this child, so the child doesn't really have to pick them up as well. Don't take it as a sign that the child doesn't have ADHD because they're not reporting symptoms of ADHD. It's very common for them to not endorse the same symptomatology as parents and teachers.

Snyder: You have contextualized ADHD into the developmental systems approach so well today, discussing that there are other contextual factors (e.g., risk/ protective factors) and proximal processes that can promote healing recovery and overall better quality of life for the child and family. It will greatly benefit our readers. Thank you, Dr. Proctor!

Things Clinicians Should Know

Executive functioning: the set of functions and abilities that affect the skills required for goal-directed behavior.

Inattention: a difficulty in sustaining attention and following instruction; disorganization, forgetfulness, and distractability.

Hyperactivity: excessive movement when not socially required, impulsivity, intruding in others spaces and interrupting others.

Stimulant: class of medications used to treat the neurobiological aspects of ADHD.

Common Elements of Intervention

Family engagement: helps family understand the nature of the disorder, how to monitor medications if indicated, and provide behavioral holding environment for the child.

Problem solving: assists the child with organizational skills, understanding how to complete tasks and seeing what supports are needed to complete tasks.

Tangible rewards: are given as behavioral reinforcement of executive functioning behaviors.

Open Access Assessment Tools

Vanderbilt Assessment Scales (NICHQ)

Strengths and Difficulties Questionaire (SDQ)

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9

Chapter

Depressive Disorders in Children and Adolescents

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Jamie (she/her/hers) is 16 and has described having a difficult year. She finished ninth grade with minimum passing grades, which is not consistent with her previous achievement of As and Bs. She thought that Jimmy (he/him/his), her boyfriend of three months, really liked her. Over the past few months, Jamie has been questioning her sexuality. When she told Jimmy that she did not want to engage in physical intimacy, he stopped texting and coming to see her. Jamie's parents work full time and her older sister is usually out with friends. Sometimes when Jamie is alone, she wonders if life is worth living and thinks about hurting herself. She has not tried to kill herself, but she is sometimes so sad that she wonders if she would be better off dead. Other times, she feels irritable or just OK and does not remember the last time she felt happy. She wants to be alone frequently, especially now that Jimmy doesn't want to see her. She has one best friend, Dennis (they/them). Dennis is someone she sometimes can talk about her feelings with, but most of the time together they drink alcoholic beverages, and sometimes they smoke weed. Jamie has been diagnosed with Major Depressive Disorder. Her mom says that Jamie was a happy child, but the depressive and irritable moodiness, isolation, and thoughts of suicide started when she was about 14.

Overview of Depression in Children and Adolescents

Depression is one of the most common mental health disorders in youth (Ghandour et al., 2019). In the case study above, Jamie is experiencing Major Depressive Disorder (MDD), which goes beyond the feeling of depression or sadness. With MDD, there is a distinct change and impairment in the functioning of a person, alongside a combination of symptoms. Specifically, for a Major Depressive Episode (MDE), the mood is sad (or irritable) or there is a loss of interest in activities for at least two weeks. In addition to one of these symptoms, youth experiencing depression will exhibit a combination of other symptoms, including changes in sleep patterns, levels of appetite, energy levels, motor activity, difficulty with concentration, feelings of excessive guilt or worthlessness, and/or suicidal ideation. In children and adolescents, the characteristics of these symptoms vary and emerge in various times across development.

There is also a lot of heterogeneity in depression, representing huge variability in how it can be experienced and expressed (Thapar et al., 2012). For example, youth can experience a single episode, while others might experience recurrent episodes. Youth with depression can also experience what is considered unipolar depression and bipolar depression (Kupfer et al., 2012). These terms are not in the current lexicon of the Diagnostic and Statistical Manual-5 (DSM-5; APA, 2013), although historically they have demonstrated a core concept. The old term of unipolar depression refers to the low side, such as low mood, anergia, and anhedonia (Kupfer et al., 2012). The opposite side (or pole) is the high side, such as elevated states of affect and energy, that can usually represent a manic or hypomanic state. It is during this elevated state of affect that a person may experience grandiose thoughts, increased energy, increased goal-directed activity, engage in high-risk behaviors, at times may lead to hospitalization.

How Depression Develops in Youth

There are various theories that help explain the etiology of depression, ranging from biological, stressful life events, interpersonal, and psychological explanations (see Bernaras and colleagues, 2019, for an overview). Biological theories view depression as being linked to genetics, serotonin dysfunction

(Kraus et al., 2017); endocrine or inflammatory issues (Clarke & Currie, 2009); and sleep disorders like insomnia (Sivertsen et al., 2014). Psychosocial theories explain depression as resulting from disrupted attachments (Reinecke & Simons, 2005); from learned negative behaviors (Antonuccio et al., 1989); and from learned helplessness (Abramson et al., 1978) and negative cognitions (Beck et al., 1979). Stressful life event theories argue that stress can influence the manifestation of depressive symptoms (Frank et al., 1994; Sokratous et al., 2013). Seeing multiple theories covering multiple domains fits within a developmental systems lens, there is no single causality with depression (Bernaras et al., 2019), with multiple individual and ecological factors influencing the development of depression. Individual children, adolescents and adults may each have their own unique constellation of influences on their depression. It can be useful to have a multifactorial understanding of the causes of depression as you try to understand each individual and family whom you work with.

> *Multiple theories covering multiple domains fit within a developmental systems lens; there is no single causality with depression (Bernaras et al., 2019), with multiple individual and ecological factors influencing the development of depression.*

Let's break down some of the indicators for Jamie. Her mom stated that most of Jamie's symptoms began to emerge around 14. What could fit a biological explanation? One factor could be physiological and hormonal changes due to puberty. Also, Jamie's mom expressed that she also experienced MDD, and so heritability and genetics could be another factor. With Jamie's grades, one can wonder if the depression influenced her school functioning, or if difficulties with school contributed to negative thought patterns, such as "I was always the top of my class in my middle school years, and now I am not that smart." We will talk more about perpetuating factors for Jamie's depression in later sections, but getting an overall sense of what could have precipitated her depressive episode can guide how we tailor our interventions for her.

There are several risk factors for depression. Some common ones include heritability, negative family relationships, stressful life events, peer victimization via bullying, and child maltreatment. Adolescent age and the female gender are associated with increased vulnerability for depression (Thapar et al., 2012). Adolescents who experience clinical depression are at higher risk for suicide and non-suicidal self-harm, substance use to self-medicate mood and lifelong depressive episodes (Clarke & DeBar, 2010). In a meta-analysis of risk factors across the lifespan, Köhler and colleagues (2018) identified the following risk factors as having convincing evidence: environmental stressors, exposure to childhood maltreatment, obesity, sedentary behavior, and sleep disturbances.

Köhler and colleagues (2018) also identified a study by Lu and colleagues (2012) that showed co-occurring asthma as a risk factor for pediatric depression. In reports about the ACTION study, a small-group CBT program for girls with depression or persistent depressive disorder, Stark et al. (2010) describe cognitive vulnerabilities for depression: the tendency toward rumination, a negative attribution bias, few problem-solving skills, and negative inferences about the self. Family level factors that can protect against depression include having a stable, attuned adult in the child's life and protective community factors include social support outside the family and safe neighborhoods (Van Voorhees et al., 2008). Cairns and colleagues (2014) reviewed risk factors that were modifiable during adolescence without professional intervention, and they found that substance use, dieting, negative coping strategies, and weight were modifiable, and related modifiable protective factors included healthy diet and sleep. As we will see in the intervention section, modifiable factors like healthy lifestyle changes will be incorporated into Jamie's treatment.

Developmental Systems Considerations for Depression

There is a variance in how and when depression emerges across the lifespan. Childhood depression is less prevalent and rates of depression for both boys and girls are similar. Depressive disorders in infants and very young children are considered relatively rare, and diagnosis takes specialized diagnostic training with an alternative diagnostic manual rather than the DSM which has poor reliability for younger children (Egger & Emde, 2011). The Zero to Five manual (2016) has specifically been developed to provide more valid and reliable criteria for diagnosis in children under five years old, in particular with zero- to three-year-old children, with an emphasis on changes in play, social interest, and sleep, factors that often times can be mischaracterized by caregivers as a behavioral issue (Luby, 2009).

Major Depressive Disorder requires a minimum of a two week period of depressed (or irritable) mood or loss of interest almost every day for most of the day.

Prevalence of depression has been estimated to be between 1% to 3% up to age 13 and closer to 6% percent in adolescents (National Institute of Mental Health [NIMH], 2019). By adolescence, prevalence increases, and girls are twice as likely than boys to be diagnosed with depression (NIMH, 2019). While depression could be underdiagnosed in males and similarly overdiagnosed in girls, the increased prevalence of depression is quite clear with research demonstrating that the risk of depression increases two to four times during adolescence (Hopkins et al., 2015).

Let's consider the case vignette, Jamie. It is important to note the role of her developmental tasks and her symptoms. During adolescence, a teen is typically trying to expand their worldview as they attempt to develop more autonomy. This involves learning new things in school and expanding social networks and engaging socially with the world around them. Jamie's social network appears small, so the support for positive reinforcers from her environment or providing social feedback could be limited. The isolation she desires and is engaging in is likely increasing and reinforcing her feelings of sadness. This is where we can pick up from our previous discussion of risk and resilience factors.

Jamie may have some biological vulnerabilities, but there appeared to be some stressful life events leading up to her start of high school. She had wavering support at home with her mom's new job that required overtime hours. From our vignette, it seems like the depression was maintained through a lot of interpersonal factors. Her then boyfriend became distant from her after she set some boundaries regarding physical intimacy. Her friend Dennis, while an emotional support, was an influence on her with drinking and occasional cannabis use. Her mom still works long hours, and her sister is out frequently. What do all these interpersonal factors mean for how we approach intervention? Hold this in your mind as we explore options.

Experiences Across Race and Ethnicity. Prevalence in rates of depression across race and ethnicity have varied across the years, at times suggesting that white youth have lower prevalence than non-white youth, yet studies have yielded mixed findings (Scott et al., 2015). According to a recent report by SAMHSA (2018), past year prevalence of Major Depressive Disorder for adolescents in the US were 16.9% for biracial youth, 16.3% for American Indian/ Alaska Native youth, 14% for white youth, 13.8% for Hispanic/Latinx youth, 11.3% for Asian youth, and 9.5% for Black youth. Not only are there disparities in diagnosis, but also racial and ethnic minority youth receive less adequate care than their white counterparts (e.g., Cummings, Ji, Lally, & Druss, 2018).

The experiences of exposure to risk factors for racial and ethnic minority youth are unique, and as a result, require intervention that is adapted to their needs. Scott and colleagues (2015) review such considerations, pointing to examples like the emphasis on family and relationships in Latinx adolescents and how family disruptions can be particularly detrimental to these youth. Zou and colleagues (2021) report on the unique experiences of Asian youth in North America, citing that there can be acculturative stress, discrimination, and immigration status. Depression was found with Asian American youth who had immigrant status, faced academic challenges, perceived parent-child conflict and maternal disconnectedness, and perceived negative peer relations (Zou et al., 2021). In a depression prevention trial, Asian American youth benefited from treatment at the same rate as other racial groups (Marchand et al., 2010).

As cited in other chapters, minority stress theory (Meyer, 1995) can be used a model for the development of depression, as discrimination and other racial prejudice can constitute stressful life events, a known risk factor for depression. Intervention therefore should target the unique protective factors of these youth. Scott and colleague's review (2015) identified protective mechanisms such as identity, self-esteem, religiosity, and maternal support as especially important for African American and Hispanic/Latinx adolescents at risk of depression. It is important to understand how culture and other minority identities play a role in the development, understanding, and maintenance of depression.

Experiences of LGBTQ+ Youth. Lesbian, Gay, Bisexual, Transgender, and Queer (among other identities) youth experience mental health concerns at higher rates than cis-heterosexual youth. According to a recent survey on LGBTQ+ youth mental health, 62% of LGBTQ+ youth had experienced symptoms consistent with a depressive disorder in the previous two weeks. Within the LGBTQ+ youth, those that are transgender or nonbinary, that number was 70%, compared to 53% of cisgender youth. (The Trevor Project, 2021). In addition, 42% of LGBTQ+ youth considered attempting suicide in the past year, and the number also increased to 52% for those that are transgender or nonbinary.

Russel and Fish (2016) note that LGBTQIA+ youth may have fewer intrapersonal skills to cope with minority stress from their experiences of discrimination. Difficulty with emotional regulation can lead to later symptoms of depression (Hatzenbuehler et al., 2008) and LGBTQ+ youth are more likely to experience rumination (Hatzenbuehler et al., 2008; Russel & Fish, 2016). It follows here that developing emotion regulation skills specific to coping with minority stress is crucial. Parental support of a youth's sexual orientation and gender experience can be protective against depression (Ryan et al., 2010), an important factor to consider as you work with the youth's caregivers.

After a few weeks of working with her clinician, Jamie shared that she might be attracted to other women. Jamie expressed that she has not let any of her friends or family know. She is worried that her mother might be too busy to care and is not sure if she would be supportive. She is planning on talking with Dennis in the near future. This situation is particularly stressful for Jamie and adds to the other stressors she has been experiencing in her relationships and school.

Assessment of Depressive Disorders

The disorders presented in this chapter all have in common a depressed or irritable mood. The amount of time spent being depressed, irritable, or both varies between each disorder. But once we can determine that the presentation has mostly to do with a depressed or irritable mood, then we have several decisions to make regarding what is being presented, for how long, and how the person experiences it. The presentation, duration, and severity of these disorders vary and provide the basis for differential diagnosis.

Clinical Features: Major Depressive and Persistent Depressive Disorders

Prevalence of MDD has been fairly well established, with an estimate of MDD at 3.2% in the age range from 3 to 17 (Ghandour et al., 2019). Similarly, Hopkins and her colleagues (2015) on behalf of the National Institute for Health and Care Excellence (NICE) Clinical Guidelines Update committee report that MDD affects around 2.8% of children under the age of 13 and 5.6% of 13- to 18-year-olds. Gender ratios of female to male are 1:1 until adolescence; however, risk of depression increases two to four times during adolescence with the prevalence ratio becoming 2:1 for female to male (Hyde et al., 2008). In terms of timeline, MDD requires a minimum of a two-week period of depressed (or irritable) mood or loss of interest, almost every day for most of the day. A community study of major depression in adolescents found a mean duration of depression episodes of 26 weeks, or around 6 months, with a median duration of 8 weeks (Lewinsohn et al., 1994), and these results are similar to adult cohort studies (Ten Have et al., 2017). Over a five-year follow-up study for adolescents with depression, about half of the sample reported a depressive disorder as a young adult (Lewinsohn et al., 2020). For full criteria for Major Depressive Disorder, consult the table provided by the Substance Abuse and Mental Health Services Administration (SAMHSA, 2016).

> *Minority stress theory (Meyer, 1995) can be used as a model for the development of depression, as discrimination and other racial prejudice can constitute stressful life events, a known risk factor for depression.*

Persistent Depressive Disorder (PDD) has been seen in about 0.6-4.6% of children and 1.6-8.0% of adolescents (Nobile et al., 2003). PDD for children and adolescents requires a minimum of one year of chronic low-level depression (or irritability) or loss of interest every day most days of the week, while a two-year length is required for adults (Nobile et al., 2003). With PDD, there is persistent and long-term depressed/irritable mood, and the mean episode duration is approximately 3 to 4 years (Nobile et al., 2003). A major depressive episode has been seen in children 2 to 3 years after the onset of PDD, and both MDD and PDD can be diagnosed concurrently. Consult the same SAMHSA (2016) resource for PDD criteria.

Jamie's mom says that her daughter had depressive and irritable mood nearly every day. Jamie has been losing interest in activities that she used to enjoy and isolating more. She reported having thoughts of suicide from time to time, but expressed no plan or means. Jamie has said that she has trouble falling asleep every night, and her appetite has decreased. She reported having a lot of negative thoughts, such as thinking she was no good and that no one liked her in school. Based on what Jamie and her mom report, she fits the criteria for a diagnosis of Major Depressive Disorder.

Clinical Features: Disruptive Mood Dysregulation Disorder

Disruptive Mood Dysregulation Disorder (DMDD) is a relatively new disorder, debuting in the fifth version of the DSM (APA, 2013). DMDD is characterized by extreme temper outbursts that are frequent and not proportional to the situation, as well as chronic irritability. For example, having a delay in receiving an ice cream cone becomes a travesty. The earliest studies of DMDD shows that it is relatively uncommon after early childhood, and it frequently accompanies both another emotional and/or behavioral disorder (Copeland et al., 2013).

The history of the development of the DMDD diagnoses stems from children and adolescents presenting with these symptoms and being diagnosed with bipolar disorder, a disorder characterized by mania or hypomania. Bipolar disorders present in youth by extreme irritability, happiness, or silliness, talking fast, having racing thoughts, grandiosity, and poor judgment (NIMH, 2020), and this disorder may often be misdiagnosed in children (NIMH, 2020). The Longitudinal Assessment of Manic Symptoms (LAMS) Study demonstrated how an initial bipolar diagnosis in children was not stable over time (Findling et al., 2010). In the study, a sample of children and adolescents diagnosed with a diagnosis of bipolar disorder were followed-up for reassessment every six months. Over the course of five years, the youth were reassessed every six-months, 75% of the participants did not meet criteria for bipolar disorder, even those who had elevated manic symptoms (Findling et al., 2010).

DMDD may be a more appropriate diagnosis for children where there is concern related to chronic irritability versus a specific bipolar disorder. The prevalence of DMDD is yet to be determined but in the last seven years, the data suggest rates of 0.8% to 3.3% (Bruno et al., 2019; Copeland et al., 2013;). For diagnostic criteria, consult the table included in the article by Baweja and colleagues (2019).

Assessment Tools for Depression in Youth

A recent review of freely available instruments (Becker-Haimes et al., 2019) reports four tools for measuring depression in youth that were tested among a representative sample. Psychometric properties of the measures included excellent internal consistency ($\alpha \geq 0.90$), and acceptable test–retest correlations ($r \geq 0.70$, among other criteria (for rubric, consult Becker-Haimes et al., 2019). Structured tools for measuring depressive symptoms include the Mood and Feelings Questionnaire (MFQ; Angold et al., 1995), the Patient Health Questionnaire-9 (PHQ-9; Johnson et al., 2002), the Positive and Negative Affect Scale for Children (PANAS-C; Laurent et al., 1999), and the Revised Children's

Anxiety and Depression Scale (RCADS; Chorpita et al., 2005). Treatment monitoring is even more essential for children with depression, whose maladaptive belief system may lend itself to thinking things are worse than they actually are. Any rating system needs to be contextualized but also serve as iterative feedback for the youth as they progress through treatment. With DMDD, the Kiddie Schedule for Affective Disorders and Schizophrenia for School-Aged Children has been used to diagnose DMDD by a NIMH research group (Copeland et al., 2013); however, these interviews have not been adapted for broad clinical use (Baweja et al., 2019).

At intake, Jamie was given the PHQ-9 by the intake clinician, and the treating clinician decided to continue using this to monitor treatment. Jamie and her mother's symptom reports mapped onto the items on the PHQ-9, with Jamie feeling like she can't have fun with people and therefore isolates (item #1); depressive and irritable moodiness (item #2); sleep difficulties (item #3); blaming thoughts (item #6); difficulty concentrating (item #7); and thoughts of suicide (item #9). She was in the moderate-severe range with a total score of 16. While she didn't endorse other items on the PHQ-9, this tool is helpful to monitor the manifestation of new symptoms, the intensification of symptoms, or, hopefully with ongoing treatment, the reduction or remission of symptoms.

Intervention for Depressive Disorders

Several interventions for youth depression have been developed. Weersing, et al. (2017) reviewed the most recent evidence base for interventions for youth depression and categorized their evidence based on Southam-Gerow and Prinstein (2014)'s criteria. The criteria take into account the evidence for the treatment and the methodological rigor of the studies; categories include the following designations: well-established, probably efficacious, possibly efficacious, experimental, or questionable efficacy. They found that the evidence for child interventions is weak, and no treatment obtained a well-established or probably efficacious status. The following interventions for children are possibly efficacious: overall CBT, group CBT, technology-assisted CBT, and behavior therapy. The experimental interventions for children were individual CBT, psychodynamic therapy, and family-based intervention. For adolescents, overall CBT, individual CBT, group CBT, overall IPT, and individual IPT are well-established interventions. Group IPT received a probably efficacious status while family-based interventions and bibliotherapy CBT are possibly efficacious. Lastly, technology-assisted CBT was experimental. A recent meta-analysis of youth depression psychotherapy effects concluded that effects are modest, with no changes in over a decade (Eckshtain et al., 2020).

Behavioral activation strategies like engaging in physical activities, increasing social engagement, taking up new activities or hobbies could break the negative behavioral loop that perpetuates depression.

The most widely disseminated intervention for youth depression has been CBT, as well as antidepressant medication. CBT involves understanding how youth interpret situations, and how they think about the world, others, and self. However, mood disorders have also been linked to neurological functioning, in particular the neurotransmitter serotonin. The Treatment of Adolescents with Depression Study (TADS) suggests that medication can be helpful as a standalone treatment or in combination with psychotherapy (March et al., 2004). The study found that CBT plus fluoxetine (Prozac) displayed a 71% response rate; fluoxetine alone displayed a 60.6% response rate; CBT alone was 43.2%; and placebo was 34.8% (March et al., 2004). It is important to note that Selective Serotonin Reuptake Inhibitors (SSRIs), such as fluoxetine, have rare side effects that include increased suicidal ideation, so monitoring by the caregiver and the treatment team is critical during the first few weeks of taking the medication.

How should we proceed with our case study, Jamie? As we see with treatment options above, CBT, IPT, and/or medication seem like good options. In the world of CBT, clinicians can focus on the behavioral side of the intervention first and then tackle cognitive aspects. Therefore, behavioral activation could be a good first step for Jamie. Behavioral activation strategies like engaging in physical activities, increasing social engagement, taking up new activities or hobbies could break the negative behavioral loop that perpetuates depression (i.e., Jamie feels sad, wants to withdraw, and then feels worse in the long-term). Sometimes thoughts can get in the way of this, like “what if people think I look stupid when I go for a run?” or “No one is going to want to hang out with me.” Sometimes, treating the behavioral activation strategy as an experiment can be the best way forward. You can collaborate with Jamie to decide what she would like to do and encourage her to give it a try to get some data or information on whether or not it worked for her. For instance, let’s say that we used the TRAILS behavioral activation worksheet to brainstorm ideas of activities that could boost her mood. She was able to identify some people that she could hang out with (e.g., her cousin), and activities she would enjoy doing like making a collage from her parent’s leftover magazines and going window shopping. She identified some rewards for herself if she was able to do those activities, like watch an episode of her favorite Netflix show. Afterwards, you can discuss how she felt before, during, and after the experiment, as well as what thoughts appeared for her and what she learned from the experience.

On the cognitive side, a clinician may need to consider what negative automatic thoughts are coming up for Jamie when she is faced with a difficult situation and identify the impact that those thoughts have on her mood. The clinician can talk about how truthful and/or helpful these thoughts are and discuss ways to increase cognitive flexibility. A clinician can use a thought record to discuss with Jamie how to evaluate her thinking, what cognitive errors she typically falls into, and come up with a more helpful and/or balanced thought that she would use and is helpful and believable to her. Consider this potential exchange when talking to Jamie about a situation in which her friends were talking about going to a movie:

> Jamie: “My friends haven’t invited me to the movies yet. And I don’t think they want me to be there.”
>
> Clinician: “Tell me more about why you think that they don’t want you there.”
>
> Jamie: “Well, why would they want me there? I don’t think they like me at all. Today, I walked into the cafeteria, and they were laughing at me.”
>
> Clinician: “Hmm, tell me the details of what happened. What are the facts?”
>
> Jamie: “Well, I walked into the cafeteria, went to our table, and when I got there, they looked at me and were laughing, so I just went and sat at another table”.
>
> Clinician: “Ok, let’s think through some possibilities. I wonder, last week we talked about cognitive errors, and you identified several that you typically fall into. Do you think one of those was present in this situation?”
>
> Jamie: “Well, now that you mention it, I think I might have jumped to conclusions. Amanda is usually telling jokes. You know what, they have gym together the period before, and the gym teacher is a bit silly. He probably did something goofy and were laughing at that. But it really felt like they were laughing at me, it just hurt.”
>
> Clinician: “Got it, so it sounds like there might be other things going on, but your immediate interpretation was assuming that they were laughing at you. What might be a coping thought that would be helpful for you to keep in mind for next time something similar happens?”

Jamie: “Maybe my friends are laughing at a joke, and I won’t know until I sit with them.”

Clinician Exercise

Take a look at the examples of automatic negative thoughts with this TRAILS resource:

- What types of thoughts is Jamie having? Could you think of potential other thoughts she may have based on her case history?
- Think about behavior activation for kids. What examples are feasible for your particular setting?

By challenging these thoughts and beliefs, we can attempt to open up some possibilities for Jamie. Jamie has been in treatment for 4 months now, and she is finding some improvements. Her PHQ-9 score is down to a 10 (moderate range). She states that she still feels down and still has some self-blaming thoughts, but she’s not really having the suicidal thoughts she had before. Her sleep has improved, and she thinks that is helping with her concentration in school. “I’m not as tired as I was when I first saw you; like I’m still tired, but not where I’m falling asleep in school or feel like too tired to deal with the thoughts in my head. I feel like I can just push back and move on, the thoughts are annoying but I’m dealing with it better.”

This type of mild symptom reduction can go a long way for the persistence of depression. Jamie does have more work to do, especially knowing that she will eventually disclose her sexual orientation to her mom. “I feel like I am in a better spot to actually bring it up, but I’m not ready just on a personal level, like nothing to deal with my depression. I’m just not there yet, but at least I know I don’t feel so guilty about myself and who I am.”

Clinical Dialogues: Child and Adolescent Depression with Guy Diamond, PhD

Guy Diamond is a Professor Emeritus at the University of Pennsylvania where he was for 20 years. He then moved to Drexel University, where he is a faculty member in the Couple and Family Therapy Program and the director of the Center for Family Intervention Science. He is one of the developers of Attachment Based Family Therapy.

Sean E. Snyder, LCSW: Thanks for joining us today. We know that you're one of the co-creators of Attachment-based Family Therapy, and it would be great to get your expertise on depressive disorders with children and adolescents. To start, we will talk about engagement.

Adolescents commonly feel guilt and self-blame with depression. Parents can also self-blame or feel like they're walking on eggshells with their child who may have depression or suicidal ideation, and these parents may feel like their child's depression is their fault. So how do you join with families, given these themes and the circumstances that bring them to treatment with you?

Guy Diamond, PhD: In a broad context, there's a couple strains of thought. First, we like to ask what is the source of depression in adolescence? We believe in a wide range of psychological science, and we certainly believe in temperament and genetics and biology, of course, but for a lot of kids, the depression seems to be more circumstantially driven: bad home environments, bullying, sexual identity issues. So, the driving questions are, "if depression is biological, what do you do about it? If it's psychosocial, what do you do about it?" My team tries to balance a nature/nurture attitude in intervention, because we believe in medication, and we believe in psychosocial intervention. Unfortunately, with medication, it's not always effective for adolescents. In this and other cases, we consider the nurture and contexts of psychosocial intervention.

Our primary strategy is centered on how we can improve the context of their life to be less depression promoting. As a team, we ask ourselves, "What can we do to improve their context?" For us, the basic stance is derived from attachment theory, where the assumption is that if a kid has a secure base relationship with their parents, they can turn to them for support when they are upset. The child can share difficult emotions without fearing rejection or humiliation or shaming, and they feel better about themselves. We know from attachment theory that kids internalize a sense of whether the world is a trustworthy place. They internalize questions like "am I'm worthy of love?" I think for Bowlby, that his theory of psychological development is if someone is treated well and attended to, and if their emotional needs are attended to, then they internalize a sense of the world as being comfortable and safe.

We capitalize on that attachment assumption in our therapy. The way we invite families into treatment is that we're worried as a care provider, particularly for a depressed suicidal adolescent. We are worried that they have lost their voice, that they feel things deeply and sometimes feel they've been treated unfairly and have things that they aren't happy about. But instead of saying something about it, these kids withdraw, or they get overwhelmed by difficult emotions, and at worst, they cut themselves or turn to suicide. So, we're interested in helping kids come back to the surface, figure out how to stand up for themselves, how to have a voice, and how to articulate their emotions better. So, rather than feeling overwhelmed by emotional distress, they can actually articulate it, talk about it, share it, and feel more able to understand it better. That's what we're interested in helping the teen do.

Our pitch to the parents is that they are the developmental cauldron. They are the foundation of what helps the child develop a sense of self, a sense of security, and the ability to talk about their feelings. So, we're trying to resuscitate or repair the attachment relationship in this therapy, so that kids can once again have a secure base to turn to for support as they go out and explore in the world. In general, that kind of stance is our basic invitation to families into therapy. It's not a blame model. It's not a pathology in the family model. Instead, it's one where families aren't the cause of the problem. They're the medicine to fix the problem. That's our phrase; we say it to the parents all the time. We think from an attachment point of view, that caregiving is as strong and instinctual an impulse as attachment.

> *Our primary strategy is centered on how we can improve the context of their life to be less depression promoting. As a team, we ask ourselves, "What can we do to improve their context?"*

Attachment is really the kids' need to go to their parents for comfort. Like in old times, the old saber tooth tigers outside the cave; as a child, they don't even think about it, they just run to mom and hide behind her skirt. In modern times, I fall off my bike and scrape my knee. I'm scared I'm anxious, and I run up the stoop jump in mom's lap, or in dad's lap. She rubs my head. He calms me down, regulates my emotions, and I go off and play. So, the attachment instinct is the kid's innate biologically wired-in survival tool.

Snyder: Right, attachment is a behavior system, and it's activated when fear is activated. The attachment system is definitely activated from both sides: child seeking protection and the parent's protection instinct.

Diamond: They don't think about it. They just run to mom and look for comfort, in the same way that parent's caregiving instinct is as biologically wired-in. We as parents, we don't sit there on the stoop watching him fall off the bike thinking, "He'll be fine with a scraped knee, big deal!" No, we drop what we are doing, we're down the street before he hits the ground. We're catching him and we didn't even think about it. It comes down to "my son's in trouble, go! My daughter's hungry, take my plate." That's the instinctual drive.

That caregiving instinct can get clouded with depression, with economic distress, with marital problems. The attachment instinct gets clouded with child thoughts of "they have failed me before, so I don't run up on the porch anymore because I know I'm just going to get laughed at and told to stop crying. I'm a boy." And so, things can happen that make the attachment instinct and the caregiving instinct not work so well. And our therapy with ABFT is about improving that instinct, on resuscitating it, revising it, and helping people feel that the instinct is trustworthy again.

Snyder: The clinician invites both the child and caregiver to come together and frames the encounter like you said, "the family is what's the medicine" or the family is what's going to foster healing. I am glad to hear that you reference various ecological processes like economic stress, marital issues, that can interfere with basic human drives, like the need to be comforted and the need to comfort the child. It's a get back to basics approach.

Diamond: Yeah, for a therapist, that mindset helps because the therapist is thinking, "Well, what should I focus on? There are 1000 things I could focus on in a family." It gives direction, where the therapist is going to focus on repairing trust, increasing emotional flexibility, helping the kid revise their internal working model of the parent to say, "it used to be that I couldn't trust my mom or dad, but boy, after Guy's work with her, he or she has kind of learned some skills, and she's back in the saddle, and maybe I could trust her next time."

Now, repairing attachment may not solve everything, but it is, we believe, a foundational pillar of strength that a kid feels the feeling that they have a secure base to turn to, whether they're 3 or whether they're 16. We know that in adolescence attachment is just as important as in earlier stages of childhood. It looks different, it manifests differently, but it's no less of a fixture of their psyche. So, we're trying to establish that so that then the family is a better team, and they can work on all the other problems like school failure, being bullied, or sexual identity.

Snyder: And when problems arise, if the attachment is disrupted, guilt and blaming can be a core family process. So, with intervention, the core of the matter is developing the trust between the family again.

Diamond: Yes, trust. If a child can say "I trust my mom," then they know they can talk to her about sexual identity or about bullying. The child can turn to her for support, can ask her to help them manage their medicine. A teen may think, "I'm not doing very well. But before I wouldn't let her manage my medicine.

Screw her, she's just controlling me. With treatment, that turns into "My mom is on my side, and I need help, because I keep forgetting to take the medicine. Mom, could you give it to me every day?" That's what we're trying to revitalize and get to.

> *That caregiving instinct can get clouded with depression, with economic distress, with marital problems. The attachment instinct gets clouded with kids… And our therapy with ABFT is about improving that instinct, on resuscitating it, revising it, and helping people feel that the instinct is trustworthy again.*

Snyder: It's like recalibrating and kind of getting things realigned and a lot of it, as you mentioned, is based on trust. That trust then can change how a child thinks or behaves.

So, my next question is something I get a lot with trainees and students that I've supervised. Trainees (and frankly, non-trainee clinicians as well) struggle with confidentiality and the therapeutic alliance. Considering that trust is so critical in this process for the family, but also in the therapeutic relationship, how does your team approach or explain confidentiality to a child without them feeling like they need to censor themselves or just keeping in mind the maintenance of trust within the therapeutic context?

Diamond: We definitely don't have the same philosophical constraints that, let's say, psychodynamic therapy has, which really thinks the clinician relationship with a patient is so sacred that if I were to even talk to their mother, they would feel violated. For a family therapist, they have always dealt with multiple alliances. It's just the nature of what we do. I think the way we do it, in part, has to do with transparency. We're very clear. I mean, what we say when we meet alone with the youth (because we split parents and youth into separate sessions before coming back together again in ABFT), we say, "Look, what we talk about between you and me is private. Obviously if you talk about hurting yourself or others, I'm obligated to report that, you need to know that. But stuff you tell me, I'm not going to go run and tell your mom or dad. My goal is that you tell your mom or dad anything's that's important, that is getting in the way of your relationship. I'm going to encourage you; I'm going to help you figure out how to talk to your parents about that. It doesn't mean you have to tell them that you're smoking pot or that you have a boyfriend already. Unless those are becoming dangerous things, my job is to help you help your mom to learn how to listen better so you can talk to her about things that are important. We'll go slow; we'll work it out together."

Snyder: Because I think as newer clinicians are developing skills, the fallback is always about the relationship. That makes a lot of sense. The therapeutic relationship is important, but it's not just for us as clinicians; that child needs a therapeutic relationship with their caregivers, where they feel supported enough to turn to them.

Diamond: It's partly also we see ourselves, as Winnicott said, as transitional objects. It's important for them to feel trusting of me as their therapist and connected with me, and I want that. You open up your heart in therapy, and then I'm going to try to transfer that over to the parent, because that has long-term implications, rather than a psychotherapy relationship that's short-term and once a week.

Snyder: Maybe we as clinicians over-value our role in the client's life. I mean obviously we are important in a therapy context, but we are not the ones that live with the child. Maybe this focus on the relationship with the clinician is part of a rescue fantasy or countertransference or our stuff. I appreciate you discussing this point, because the process is so important with all of this.

What about the other side of the family, how do you talk to the caregiver or parent around these issues of confidentiality?

Diamond: I could say the counterpart to what I just told you I say to the kid. There are two things we can say. On the one hand, our therapy in the beginning tilts a little bit more taking the adolescent side. We're not child-saving therapists though. In the beginning, we are trying to help the kid have a voice, which means having them identify what makes them mad, what makes them sad, and helping them say it. We've done a study where we interviewed parents after the first session and asked, "Does it feel like the therapist is taking the kid's side?" and the parents actually say, "I've never seen him talk so much in therapy, so I see why you're doing it! He usually sits here quietly, won't say anything. He's never talked to anyone the way he talked to you today."

And a lot of that comes because we just lean in and say, "of course, you're pissed off, of course you don't want to be close to her because it sounds like you've been hurt. I want to understand why." So, we try to understand their point of view, and every family therapist is struggling with walking a fine line of where it seems like blaming the parent when you're saying mom could have a role in what's happening with the child. You got to take her side too, recognize what they're doing, saying things like "You're a fantastic mom, I see how committed you are, and I see how much you love this kid. I do see there's a few things I could help you with that might make it easier for him to come to you." Generally, we are balancing alliances. I think we do say to parents, "Look if your kid feels like he can't trust me in private, he's not going to talk to me. So, don't ask me to reveal things to you. Anything that's important, we're going to talk about together. But please don't prod me because you're just going to undermine my credibility and handicap the process with your child talking in therapy."

Snyder: And I liken the idea to where sometimes it's like explaining to the parents like “Maybe it’s a little uncomfortable in the beginning, but there will be a long-term gain. You might feel a certain way about the process, like I’m siding with the child but it’s for the long-term goals we have.” There is a lot of relational assessment going on: the types, the quality of relationships. On a symptom and functioning level, are there standard assessments that you use, for instance standard screeners like the PHQ-9 or the RCADS or suicide screeners like the Columbia?

Diamond: A lot of our work is in the context of a clinical trial, so we’re trying to measure change over time. In clinical practice, we encourage our students or trainees to say, “Look, I gotta know how severe this depression is right now.” We do brief screeners that we repeat over time, so every couple of weeks we give it out again. Now, we happen to have our own assessment tool that we’ve developed over 15 years that’s a multi-dimensional web-based screening tool. We give the kid an iPad in the beginning, and he fills it out and it covers depression, suicide, substance use, psychosis, trauma, sexual identity, access to a gun, bullying, and family relationships. It gives us a full psychosocial assessment. It’s a screener, not a diagnostic tool, and we use that to inform our interview with the kid. For instance, we would say, “Hey, it looks like on the questionnaire, you said this, can you tell me more about it?”

And then we use that web-based tool at mid treatment with an abbreviated battery, with just a couple of the domains like depression, suicide, trauma and if its outpatient, we’re doing substance use. It helps us to show a kid, “In the beginning, you had a 45 on depression and now you have a 22. We’re going in the right direction.” Or by mid treatment, we say “Well, you started at a 45, and now you’re at a 62; what’s going on here?” Maybe it’s time we bring the psychiatrist in to augment some of what we’re doing with medication.

I think that the general best practice guidelines really is psychotherapy first, and in fact, in pediatrics, the recommendation is supportive therapy, about 2 to 4 weeks of supportive therapy, and if symptoms don’t change, then you start to ramp up to CBT or a family therapy. Generally, the recommendation is six weeks of psychotherapy, and if that doesn’t work, add medication. That is the general best practice guidelines, and most clinical folks will say, “If I get a severe enough kid, I’m doing medication, day one. I’m not going to wait for this kid to get way too depressed. I need something to

General best practice guidelines really is psychotherapy first, and in fact, in pediatrics, the recommendation is supportive therapy, about 2 to 4 weeks of supportive therapy, and if symptoms don’t change, then you start to ramp up to CBT or a family therapy.

turn down the volume a little bit so I can do engage them in therapy." Most studies suggest psychotherapy plus medicine is the best route for a more severely depressed kid.

We try to track symptom change over time as an additional viewpoint. We hand the assessment out, and then we discuss it with the kid. Look, you're still struggling with this. What's going on? Or you're sleeping better. You're not crying. Or you are still really having a negative view of yourself and hopelessness. Maybe when we're finished with a little bit of this family work, we should do a little CBT to try and target some of those negative cognitive processes. We always start with family because if we can get the family more supportive, it's easier to learn CBT skills. Consider the kid who lives in a family where their parents are screaming at them all the time, and they come to a therapist, and the therapist tries to tell them to challenge their automatic thoughts, and then they go home, and they are getting screamed at again. Not going to be effective there.

Snyder: I like how you have a multi-dimensional perspective because depression is one aspect of this kid's life. Clinicians have to take this broader focus because the presenting problem does not happen just in a vacuum. And the point about measurement is for it to be clinically relevant, so it provides context and the content for the sessions.

When suicide pops up on a screener, how do you triage? There's the SAFE-T model, but each agency has to determine how they use it depending on their screening and risk formulation strategies. What's your protocol like?

Diamond: We have a really robust, fully developed suicide protocol. If a kid says he's suicidal and we pull out a screen, we get some measure of the severity, and then we debate: can we manage this kid on an outpatient level? Is this severe enough where we need to send them to the emergency room? Way too many therapists get frightened and just send them to the emergency room when it's counter indicated. The emergency room is traumatic; a hospital is traumatic and not very treatment oriented. We like to think about "what do we have to do in order to keep this kid outpatient?" The hospital is never a positive experience in the American health system.

So, for a youth to stay outpatient, we evaluate warning signs. We do a safety plan. We do a family-based safety plan. We try to include the parents in the safety plan, then we use the safety plan to manage the situation. For instance, if he's feeling suicidal, he goes to his mom and his mom says, "Okay, let's look at the safety plan: going for a walk, playing with your dog." These little simple things on the safety plan are really a distraction to reduce the stress of a pending crisis. It's not a therapy, and it's based on the assumption that most kids who think about suicide or attempt suicide have thought about it for about 30 minutes and then the idea goes away. It's an impulsive act generally, and the safety plan is a distraction for 30 minutes. For instance, things like, go for a walk. That was 20 minutes and I have a little blood in my head now. Okay, I'm not thinking about it anymore. I'll go back to play with my dog and take a shower or listen to music or call a friend, go see my mom, go call Guy. The Safety Plan really is such an attempt to get someone through that short little stressor.

Snyder: It's flattening the suicide risk curve. Eventually the crisis will resolve, so the safety plan is intended to delay stress from peaking. And the family context is critical to support the use of the safety plan.

Diamond: And yes, there are definitely kids that need to go to the hospital. Plenty may need that, but most kids don't need to go. I don't want to be overly flippant here.

Snyder: It makes sense. The default clinical position shouldn't be hospitalization or the emergency room. We need to support people in their natural settings.

Now, going back to the multidimensional assessment and therapeutic approach. There's a lot of comorbidity with clients, especially in community mental health settings. So, do you see gains in other areas of the client presentation when you complete treatment?

Diamond: And we know comorbidity is the rule, not the exception. A lot of our kids are certainly struggling with anxiety. We see a lot of substance use. We have a lot of kids with trauma history, about a third of our kids have a sexual abuse history, and about a third of our kids are LGBTQ or questioning their sexuality. So, there are a number of domains that we think about and incorporate into the therapy as needed. My CBT friends, they always joke with me, and they say, "Guy, where's the suicide treatment in family therapy?" For us, we see suicide as a symptom of stress and we're trying to get to the stress: "My mom's an alcoholic, and I can't live with her. I get bullied at school because I'm gay. I'm in special ed learning classes, and I feel I'm not as smart as my brother." We're always trying to address these broader thematic things in the service of improving the parent-child relationship. We see reductions in anxiety in neuro studies; we see reductions in substance use. We've seen some reduction in post-traumatic stress symptoms. Our assumption is that as kids feel more protected and have a secure base, that the general level of psychopathology distress goes down.

Snyder: This reminds me of the active ingredients of CFTSI for trauma recovery, where the goal is we're getting a family on the same page, so the kid knows how to ask for help related to their trauma symptoms, and the parent knows when to offer assistance, as opposed to smothering the kid or avoiding them. The theme throughout your intervention is "if we can get that holding environment, if we can get that base security." It can set the stage to take care of a lot of other things.

Diamond: Bringing attachment theory in family therapy is one of our unique contributions, and it's a way of helping to think about what we do in family therapy work. But the other I think innovation of the model has been to put some system programmatic structure around family therapy. The way we have broken the model into tasks, into sequences of work helps the family therapy student feel like, “Oh, it’s not just, go in the room and see what happens, and debate about who’s going to talk first and…”

Snyder: “…am I going to set up an enactment?”

Diamond: With our structure, we lay out that there’s actually a progression of work, like “this week I’m working with the child on these types of emotions, and then next week I’m going to work on attachment narratives, and now I’m going to bring them back together.” And I think it’s given a structure to what can be a pretty amorphous experience for that room full of people. And I think a lot of people say to us, “I do exactly what you do in treatment, but where you just do it in 16 weeks, it takes me a year to do it.” There’s a roadmap to make these conversations happen in our training.

I’ll say one last thing. And I always say in the training to a room full of therapists, I say “You’ve come out of your therapy room and gone to the water cooler in your work on agency and said, ‘I just had the best session. We finally got to the real heart of it and the truth, and the kid was crying, and dad leaned over and hugged him. It was so satisfying.” And I say to my trainees with that scenario, “We make that session happen in every case around week 10.” The old model is engineered where we’re not going to get to that type of session early. In our work with ABFT, 90% of the cases by week 10 are having conversations that are at the heart of the matter. And I think for a family therapist that’s an innovation.

Snyder: With systems of care too, if we can be more efficient, even with our family therapies and individual treatments, we can increase our reach, so then maybe our wait lists might not be as long. There can be systemic spillover effects, just by sequencing and supporting the clinicians in that way.

Diamond: It’s a real plan. I think students find that when they follow the structure, it lets them really get interpersonal. Students who follow the structure find themselves having conversations they never thought they would have. The structure of the model gets them there. It’s not just their own intuition, but it’s the structure that allows the clinician to shine and help make some meaningful change.

For folks interested in the model, please look us up at our website at the Center for Family Intervention Science or ABFTtriаning.com at Drexel University, and we will help you get trained and supervised in ABFT.

Things Clinicians Should Know

Major depressive disorder (MDD): characterized by depressed mood for more than 2 weeks.

Disruptive mood dysregulation disorder (DMDD): a diagnosis that is characterized by chronic irritability and may be a more appropriate description of child presentation opposed to bipolar disorder.

Cognitive behavioral therapy (CBT): modality that attempts to examine automatic negative thoughts that promote depression and modify behaviors that sustain depression.

Attachment-based family therapy (ABFT): a family-based intervention that works on attachment narratives, expanding emotional experiences of the family.

Selective serotonin reuptake inhibitor (SSRI): class of medication used to treat depressive disorders. These medications are safe, though a rare side effect of suicidal ideation can appear in teens who take it.

Common Elements Approaches

Psychoeducation: can provide context to factors that sustain depression, educate about treatment options.
Behavioral activation: strategies to activate a positive emotional state and decrease depression sustaining behaviors.

Cognitive restructuring: examines automatic thoughts, considering their accuracy, helpfulness in the context of depression.

Problem solving: skill to consider options for behavior activation, navigating social situations, envision possibilities for the future.

Open Access Assessment Tools

Mood and Feelings Questionnaire (MFQ)

Revised Children’s Anxiety and Depression Scale (RCADS)

Patient History Questionaire-9 (PHQ-9)

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10

Chapter

Anxiety Disorders in Children and Adolescents

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Josh was shy, slow to try new things or talk to new people from infancy through middle childhood. When he hit mid-adolescence, he developed a great deal of social anxiety. He was truant from the public high school several times because of social anxiety, and he was earning failing grades. He was written off as being oppositional and defiant by parents and teachers. His parents used some of their savings and took out loans to send him to a small, private alternative high school where he was able to earn As and Bs in his classes. Josh has a part time job working for a big box retailer in the stock room where he has minimal interaction with others. He has one friend who is also socially anxious. They get together once or twice per week to play video games or watch movies at one of their houses.

In the last six months, Josh's avoidance of social situations has heightened and has affected his work schedule. He often calls out from shifts because of somatic anxiety (e.g., chest pain, leg weakness). His parents are concerned because there are weeks that he rarely leaves the house. Sometimes he reports that he feels so anxious that his mind goes blank, and he can't think for many minutes. His teachers are concerned too because Josh's grades are slipping, and he has begun cutting class. "Back to that again," think Josh's parents.

Overview of Anxiety

Josh's experience is illustrative of many anxiety disorders with onset during adolescence. Anxiety disorders have been identified as the most prevalent childhood and adolescent mental health disorder (Allen et al., 2013; Cartwright-Hatton et al., 2006), and anxiety disorders also seem to be persistent through adulthood if criteria for an anxiety disorder is met during childhood (Dias & Campos, 2016).

It is important to distinguish clinical anxiety from developmentally normative childhood fears. Common childhood fears include being alone, separation from trusted others, the dark, imagined monsters, and unexplained loud noises. Developmental sequences of fears suggest that fears about separation are most common among young children (Weems & Costa, 2005). Fears related to death and danger become more prevalent in middle childhood, and fears about how others see us, accompanied by anxieties in social or performance situations, are most pervasive during adolescence (Weems & Costa, 2005). The avoidance and/or distress associated with objects, situations, events, and memories that trigger anxiety vary widely across the seven anxiety disorders listed in the Diagnostic and Statistical Manual of Mental Disorders (DSM 5; American Psychiatric Association, 2013).

Transient fear or anxiety is often stress-induced and short-lasting. Clinical anxiety is excessive and persistent (e.g., symptoms must last longer than six months for all diagnoses with the exception of separation anxiety and selective mutism) and developmentally atypical. Some individuals are able to state that their experience of anxiety is excessive, whereas others struggle to make this distinction. In these cases, clinicians take cultural and contextual factors into account to determine if anxiety is excessive. Anxiety that is diagnosed in childhood often persists into adulthood if left untreated and puts individuals at increased risk for negative outcomes such as impairments in family and occupational functioning, substance use, educational underachievement, reduced life satisfaction, and suicide (e.g., Swan & Kendall, 2016; Wolk, Kendall, & Beidas, 2015).

Prevalence of Anxiety Disorders in Youth

Worldwide data shows a prevalence rate of 6.5% (Polanczyk et al., 2015), national data in the US showing a prevalence rate of 7.1% to 12.3% (Costello et al., 2005; Ghandour et al., 2019). Approximately 15% to 30% of children will be diagnosed with anxiety at some point in their childhood (Bittner et al., 2007; Woodward & Fergusson, 2001). Anxiety disorders are not as often diagnosed as other disorders such as disruptive behavior disorders, as disruptive behavior disorders are more likely to be brought to adults' attention during childhood years (CDC, 2020).

Anxiety occurs frequently with other behavioral and emotional disorders (Kendall et al., 2001). Palitz and colleagues (2019) outline the most common comorbid diagnoses among youth with anxiety as being a) other anxiety disorders (Kendall et al., 2001), b) obsessive-compulsive disorder (OCD; Carter et al., 2004; Kendall et al., 2010) and c) depressive disorders (Costello et al., 2003; Cummings et al., 2014). Disruptive behavior disorders such as Attention Deficit/Hyperactivity Disorder (ADHD) and Oppositional Defiant Disorder (ODD) are also common comorbid diagnoses (Palitz et al., 2019). The presence of comorbidity can influence treatment if the other condition interferes with treatment, just like treating other disorders with comorbidity (Kendall et al., 2001; Palitz et al., 2019). As mentioned in our interview, Margaret Crane suggested that if Oppositional Defiant Disorder is present, a clinician may need to consider more behavioral reinforcement strategies in session or in doing exposure work at home. If depression is present, the behavior activation could be a part of the intervention.

Transient fear or anxiety is often stress-induced and short-lasting. Clinical anxiety is excessive and persistent and developmentally atypical.

How Anxiety Disorders Develop in Children

The development of child anxiety stems from the interactions of many factors. A behaviorally inhibited toddler is an aspect of temperament that can create vulnerability for anxiety (Rapee, 2014). In terms of psychological processes, children that have attention bias towards threat related stimuli can be predictive of later anxiety, and the threat pattern can enforce a cycle of fear appraisal and avoidance (Mayer, 2017). Parental anxiety disorders can also be predictive of child anxiety, with the heritability coming from genetic or behavioral influences such as anxiety modeling (i.e., children see their parents as anxious and learn these anxious behaviors) (Havinga et al., 2017). Parenting styles that are overly accommodating can additionally serve as this social modeling of anxious behavior (Dadds, 2017). Social and environmental factors will be discussed more in the next section.

Developmental Systems Considerations for Anxiety Disorders in Youth

The case of Josh presents a good example for the discussion of developmental systems considerations. Josh appears to have had an anxious temperament during childhood, which increased significantly during middle and high school. The principles of developmental systems can be used to consider the reasons that increases in social anxiety did not lead to Josh's enrollment in therapy. Josh's parents might have normalized his experience of excessive and persistent anxiety as "just the way Josh is." Both Josh and his parents may have believed that Josh would "grow out of it." Parents who believe their children will grow out of anxiety may find themselves engaging in accommodating behaviors to help children manage anxiety "in the meantime." Accommodation refers to the actions that family members take to alleviate a child's symptoms and distress (Kagan et al., 2017). Accommodation can take the form of excessive reassurance, allowing the child to avoid new or challenging situations, or trying to problem-solve for the child. Accommodation is associated with negative sequelae for family members and results in the maintenance of anxiety (Kagan et al., 2017). Parents are instead encouraged to not give in to the child's anxiety by letting the child avoid the anxiety-provoking stimulus. Parents should coach their child to use distress tolerance skills, and over time, the child will learn that their anxiety is not dangerous or scary and that they can self-regulate.

> *Accommodation can take the form of excessive reassurance, allowing the child to avoid new or challenging situations, or trying to problem-solve for the child.*

One of the most prominent systems in a child's life is the school system. In the school setting, the term "accommodation" can refer to school-based supports that aim to increase access to general curricula for students with a range of disabilities. Students who inform school personnel about their anxiety related distress are more likely to access treatment (Colognori et al., 2012), showing how schools are vitally important to get youth the interventions they need. School-based mental health programs show evidence of impact on youth emotional challenges (Rones et al., 2000). School-based accommodations related to emotional problems are legally outlined in documents such as Individualized Education Programs (IEP) and 504 plans (IDEA, 2004; Sulkowski et al., 2012). School staff report implementing a variety of school-based accommodations, including those that are approach-based, and thus most likely to helpfully address anxiety (Conroy et al., 2020).

Accommodations can have unintended results, too. Unhelpful accommodation (accommodation that is avoidance-based) is also common in schools. For example, if Josh was nervous to give a presentation in front of the class, a teacher might have allowed him to give the presentation only to him/her, thereby maintaining the anxiety. Accommodations can be helpful if they are specific and short-term. It may have been helpful for Josh's teacher to allow him to first give the presentation to just him/her, then to a small group of students, and then to the entire class. School can also be the source of stressors that go unreported by youth, such as bullying, which may lead to anxiety. Was Josh labeled as oppositional and defiant, causing teachers to miss the connection between undesirable behaviors and anxiety? Josh's academic achievement improved at the small, private school; however, it is unclear what about this environment was helpful. Were unreported stressors at the public school not present at the private school? Did Josh receive more individualized attention and accommodation, either unhelpful or helpful, at the small private school?

The developmental systems perspective also highlights the importance of the mind-body connection. This connection also shows the importance of how development and ecology intersect; the physical body develops across time in an environment. Like an example of a baby "relearning" how to walk each day because of their growing body, youth will have to "relearn" or retrain their emotional muscles to adapt to the emotional and physical changes related to their development. Many individuals experience anxiety physiologically, experiencing somatic symptoms such as racing heart, sweating, and shortness of breath. For many individuals, anxious thoughts can lead to somatic symptoms, which can then lead to more anxious thoughts. Of note, some people report only experiencing somatic symptoms of anxiety whereas others report experiencing only cognitive worries.

Experiences of Anxiety Across Race and Ethnicity. Cross-sectional research has shown mixed findings when investigating racial variations in anxiety presentations, with some samples showing higher symptom levels for African American youth (Latzman et al., 2011), and other samples showing no differences between racial groups (Wren et al., 2007). In a separate sample, Kendall and colleagues (2010) found that Caucasian youth were more likely to meet diagnostic criteria for generalized anxiety disorder only, whereas by comparison, non-Caucasian youth were more likely to meet diagnostic criteria for both separation anxiety disorder and specific phobia in comparison. This study though, did not delineate different groups within non-Caucasian youth. This study was drawn from The Child/Adolescent Anxiety Multimodal Study (CAMS), which sought to understand the relative or combined efficacy of cognitive behavioral therapy and selective serotonin-reuptake inhibitors for anxiety disorders in children (Walkup et al., 2008).

Data from CAMS revealed similarities in baseline clinical characteristics in African American and Caucasian youth with anxiety disorders (Gordon-Hollingsworth et al., 2015) based on their scores on the Pediatric Anxiety Rating Scale (PARS, 2002) and the Screen for Child Anxiety Related Emotional

Disorders, Parent & Child Forms (SCARED-C/P; Birmaher et al., 1997). Despite similar baseline measurements, African American youth attended fewer therapy sessions than their Caucasian counterparts, which is significant because higher treatment engagement predicted better treatment outcomes (Gordon-Hollingsworth et al., 2015). Lower treatment engagement, a process variable, can increase the risk for poorer treatment outcomes for African American youth, highlighting the importance of identifying the best ways to engage patients (Gordon-Hollingsworth et al., 2015). Importantly, treatment response did not differ as a function of race (Gordon-Hollingsworth et al., 2015). These findings highlight the efficacy of anxiety treatment in youth from non-Caucasian backgrounds. Findings also highlight the importance of accurately diagnosing and treating clinical anxiety in all youth.

Experiences of Anxiety in LGBTQ+ Youth. In a review of the prevalence of mental health problems among LGBTQ+ youth, Russel and Fish (2016) found that 25% of LGBTQ+ youth meet diagnostic criteria for an anxiety disorder. LGBTQ+ youth report higher levels of anxiety symptoms compared to heterosexual youth (Russel & Fish, 2016). Youth who experience or fear family rejection because of their sexual orientation are at a higher risk for anxiety (Russell & Fish, 2016). In the lens of the minority-stress model, LGBTQ+ youth may not have skills to cope with this anxiety (Russell & Fish, 2016) because it is an experience unique to them. This can limit opportunities for social learning of skills and/or limit their ability to use such skills. The adaptation of EBPs for anxiety and LGBTQ+ youth is rather limited (Busa et al., 2018), and guidelines about affirmative care show that this care approach can impact rates of improvement with clinical symptoms in regard to depression and suicidality but not anxiety (Kattari et al., 2016).

Assessment of Anxiety Disorders in Children and Adolescents

There are many anxiety disorder diagnoses. Though treatment for anxiety disorders is largely similar across diagnosis, identifying a specific diagnosis can help clinicians tailor their interventions. Common anxiety disorder diagnoses include: Separation Anxiety Disorder, Generalized Anxiety Disorder, Social Anxiety Disorder, Specific Phobias, Panic Disorder, and Agoraphobia. Anxiety symptoms are considered clinically significant if they result in functional impairment for youth or their families (e.g., several weeks of missed school, parents being unable to leave the house without the child, failing grades, inability to form or sustain friendships) (APA, 2013; SAMHSA, 2016). For detailed diagnostic criteria related to children, consult the DSM-5 Changes: Implications for Child Serious Emotional Disturbance resource (SAMHSA, 2016).

Approximately 2% of youth meet diagnostic criteria for Generalized Anxiety Disorder (GAD; Merikangas et al., 2010). GAD is characterized by persistent and uncontrollable worry about a variety of topics (e.g., health, family issues, school, safety, minor matters, the future) (American Psychiatric Association, 2013), and it has historically been identified as one of the most poorly understood (Rowa et al., 2013) and difficult to treat anxiety disorders (Salters-Pedneault et al., 2006). However, research has indicated that exposure-based cognitive-behavioral therapy (CBT) is efficacious in the treatment of GAD in youth (Kendall et al., 2008; Ladouceur et al., 2000; Read et al., 2013; Walkup et al., 2008).

Separation Anxiety Disorder (SAD) is distinguished by anxiety, fear, or distress in a child when they are away from home or a caregiver (APA, 2013; SAMHSA, 2016). The excessiveness of the anxiety and fear must be understood in the context of a child's age and development. For example, it is more developmentally appropriate for a toddler to be afraid of being away from home than it is for a teenager to struggle with the same fears. An elementary-aged child having tantrums every morning before school would be considered developmentally inappropriate (Palitz et al., 2019). Separation anxiety can involve panic attacks and noticeable uneasiness.

Social Anxiety Disorder centers on the fear of social situations in which someone may experience or perceive scrutiny from others (APA, 2013; SAMHSA, 2016). Social anxiety may manifest as "performance anxiety" for some youth. Children with social anxiety may experience distress in the presence of both peers and adults. (APA, 2013; SAMHSA, 2016). A youth with social anxiety may experience debilitating difficulty with activities that involve public speaking, such as giving class presentations.

Anxiety symptoms are considered clinically significant if they result in functional impairment for youth or their families (e.g., several weeks of missed school, parents being unable to leave the house without the child, failing grades, inability to form or sustain friendships).

Panic Disorder has two distinct characteristics: recurrent panic attacks and fear or worry related to having future panic attacks (APA, 2013; SAMHSA, 2016). Panic attacks are typically short, intense bursts of fear (lasting no more than 10 minutes) that are accompanied by physical symptoms like difficulty breathing and tingling. Panic attacks can occur in response to a known stimulus (colloquially, a "trigger") or "out of the blue," with no identifiable stimulus. Panic attacks themselves may or may not significantly disrupt the youth's life; however, fear about having a future panic attack can lead to debilitating levels of avoidance.

Assessment Tools for Anxiety Disorders

Interview Questions for Client, Family Member, Teacher. Many of the most helpful interview questions for clients and their family members are associated with semi-structured diagnostic interviews, one of which we discuss below ("Measurement Tools and Rating Scales"). It is helpful to obtain as much specificity as possible around the client's anxiety symptoms and triggers. For example, an interviewer may benefit from asking Josh what he is worried will happen at work. Is he nervous that he will say something embarrassing that will cause his coworkers to view him negatively? Or is he worried that increased somatic symptoms will lead to a panic attack? Gaining a clear sense of the client's anxiety profile will promote accurate diagnosis and thus treatment success. Teachers and other school staff who spend a significant amount of time with youth are also a helpful resource when assessing anxiety. School staff may have more information about school-related anxiety than clients' parents and are able to provide greater context about the school environment and the youth's behavior. For example, an interviewer may benefit from asking school staff what they have noticed about Josh's interactions with other students both during and outside of class over the past several months. Does Josh visit the nurse's office often? Does he make complaints about somatic symptoms? Have they noticed avoidance in addition to Josh's cutting class?

> *School staff often have context, experiences, and observations of clients that neither parents nor clinicians have. Thus, they may contribute meaningfully to assessment, intervention planning, and intervention implementation.*

Observation in Naturalistic Settings. Where possible, it may be helpful for clinicians to observe youth in anxiety-provoking settings (e.g., Social Studies class, recess, sports practice, cafe). This may be particularly useful when working with youth who have difficulty articulating their anxiety triggers and symptoms. When observing, clinicians may attend to youths' verbal expression, facial expression, and body language. Clinicians may also benefit from observing youth in at least one non-anxiety provoking environment. For example, it may be helpful to observe Josh spending time with his friend, as well as with other students with whom he is not close.

Measurement Tools and Rating Scales. The Anxiety Disorders Interview Schedule for DSM-5, Version 5 (ADIS-5-C/P; Albano & Silverman, 2016) is a semi-structured diagnostic interview that assesses youth psychopathology based on DSM-5 criteria. Youth and their parents provide separate ratings of impairment to diagnosticians. A diagnosis is considered present if either a youth or parent report meets criteria, and the diagnostician assigns a clinical severity rating (CSR) of 4 or greater on an 8-point scale. The ADIS can only be used by diagnosticians trained in its administration. The interview for each individual can take 2-4 hours. There is also cost associated with ADIS administration materials. For clinicians who do not have access to or training in the administration of the ADIS, there are various freely available measures that can be used to assess anxiety. The Screen for Child Anxiety Related Disorders (SCARED; Birmahauer et al., 1999) is a 41-item measure that examines five factors of anxiety (panic, generalized anxiety, separation anxiety). Multiple questions that have similar constructs help to ensure a valid score. The Revised Children's Anxiety and Depression Scale (RCADS; Chorpita et al., 2000) and subscale Revised Children's Anxiety and Depression Scale and Subscales measure depression, anxiety, and OCD. Both a short-form version (25-item; Enesitani et al., 2012) and a long-form version (original, 47-item; Chorpita et al., 2000) of the RCADS are available. Both the SCARED and RCADS have a supplemental Microsoft Excel version that makes scoring easy, saving valuable clinician time and bandwidth. Anxiety can have a variety of presentations in childhood. Valid assessment tools can help to provide diagnostic clarity and inform treatment.

Intervention

The CAMS study examined the efficacy of three anxiety treatments in youth: 1) CBT alone, 2) selective serotonin-reuptake inhibitors (SSRIs), and 3) CBT and SSRIs combined (Walkup et al., 2008). The study found that both CBT and SSRIs alone were efficacious, with a combination of the two producing the best results (Walkup et al., 2008). CBT programs such as *Coping Cat* and the teen counterpart, *C.A.T. Project*, are considered the gold-standard for youth anxiety treatment (Kendall & Hedtke, 2006). The computer-assisted version, *Camp Cope-A-Lot*, has been identified as an intervention tool that can be implemented in the school setting (Khanna & Kendall, 2008). Recent systematic review and meta-analysis confirms previous findings around the efficacy of CBT based programs and SSRIs in the prevention and treatment of child anxiety disorders (Schwartz et al., 2019)

Through the *Coping Cat* program, youth learn to manage anxiety using the FEAR plan: Feeling frightened, Expecting bad things to happen, Actions and attitudes that can help, and Results and rewards (Kendall & Hedtke, 2006; Palitz et al., 2019). *Coping Cat* teaches the FEAR plan through its two core components: psychoeducation/skill building and exposure to feared stimuli/situations (Kendall & Hedtke, 2006a, 2006b). Psychoeducation focuses on helping youth understand their physiological and cognitive experience of anxiety as well as the cycle of avoidance. Youth who are not enrolled in *Coping Cat* are still likely to benefit from psychoeducation about anxiety. Trails to Wellness, a CBT program for schools developed through folks at the University of Michigan, provides open-access handouts about how to approach psychoeducation about anxiety. In the vignette at the beginning of this chapter, we met Josh, who was experiencing high levels of somatic symptoms and was calling out of work frequently. Psychoeducation for Josh might include identification of his somatic symptoms and explanation of the avoidance cycle (i.e., worry at and about work will increase if he keeps calling out).

Skill-building revolves around developing internal and external coping skills. Positive self-talk statements and thought interruption techniques can help disrupt the anxiety cycle, and identifying automatic negative thoughts can be the first step to developing coping thoughts. It will likely be helpful to help Josh to identify the source and content of his automatic thoughts (e.g., worry about a negative work scenario repeating, "all or nothing" thinking, perfectionism). External coping skills can involve self-soothing activities, such as, listening to music, going on a walk, or watching funny YouTube videos. Josh may also find relaxation strategies such as paced breathing useful to cope with anxiety.

Exposure involves the hierarchical construction of anxiety triggers in an effort to work towards systematic desensitization of the fear stimuli (Davis et al., 2020). In CBT protocols such as *Coping Cat*, clinicians help youth to build a hierarchy of feared situations to be completed from least to most anxiety-provoking. A fear hierarchy should be collaborative, with the clinician working with both youth and the parent to get input about what situations to include in the hierarchy and how to rank them. It is important to be as specific as possible when placing situations on a fear hierarchy (Davis et al., 2020). Understanding the core fear behind the feared situation or stimulus is critical. For example, if Josh is afraid to answer the phone, the clinician can help him determine if he is afraid that he will say "the wrong thing," anxiety about how his voice sounds on the phone, or something else entirely. Exposure can be an iterative process as well. Sometimes, the clinician may find that they must sometimes push the child to get out of their comfort zone, and other times, they may need to scale the parameters of an exposure back if it proves too difficult. It can be helpful to talk to youth about exposure as a way of "building your brave muscles" or beginning a new lifestyle of facing their fears. To learn more about the research and lab behind *Coping Cat*, see http://childanxiety.org/wps/parent-resources/information-and-resources/. Clinician materials can be found at https://www.workbookpublishing.com/.

> *Coping Cat teaches the FEAR plan through its two core components: psychoeducation/skill building and exposure to feared stimuli/situations.*

School staff can be a helpful resource both when building a fear hierarchy and completing exposures. As discussed above, school staff often have context, experiences, and observations of clients that neither parents nor clinicians have. Thus, they may contribute meaningfully to fear hierarchy building. School staff will also be able to guide clinicians in understanding what exposures can and cannot be facilitated by the school. Some exposures may require the involvement of school staff (e.g., having a teacher call on a student in class). Coordination with school staff is also a helpful way to gather information about the success of between-session exposures.

Clinician Exercise

Josh reports being afraid of his boss, Alex, because Alex scolded him for stocking things in the wrong location. Josh took Alex's correction personally and began feeling like he was a bad employee and would be fired. Thus, he was afraid to go back to work. Josh would go to work on the days that he knew Alex would not be there. Josh worries about messing up again, and he is worried that his coworkers will notice and think he is a bad person.

What would you ask to create Josh's fear hierarchy?

What would you do in session to help get a jump start?

The clinician decided that Josh had a fear of being judged by coworkers who could be watching him. So in session, the clinician walked down the clinic hallway and had Josh purposely trip in eyesight of another clinician. "I didn't want to do it, and afterwards, I wanted to just run into the bathroom, I felt so embarrassed. But my clinician coached me through relaxing myself and we walked back to their office to cool down." Over time, the clinician was able to build up to social exposure in more public places for Josh to work on, for instance, bringing the wrong item to the supermarket checkout so that he would need a cashier to help him end the transaction and go find the right item. "I know what I was doing, and I felt like an idiot. Afterwards, I realized no one knows what I'm thinking, they can't read my thoughts, and I can't read their thoughts. The cashier was actually pretty nice." Over time, Josh started calling out less and less, and he stopped checking to see the manager's schedule. He was on his way to being back in the driver's seat with his anxiety.

Clinical Dialogues: Anxiety Disorders in Children and Adolescents with Leslie Norris and Margaret Crane

Lesley Norris is a doctoral candidate at Temple University working with Dr. Philip Kendall in the Child and Adolescent Anxiety Disorders Clinic. She is currently completing her clinical psychology internship year at Brown University. Her research focuses on precision interventions and predictors/moderators of treatment outcome for youth with anxiety. Clinically, she is interested in the provision of exposure-based treatments for youth with anxiety and related disorders.

Margaret Crane is a clinical psychology PhD candidate at Temple University. She was the recipient of a National Institute of Mental Health F31 grant for her dissertation. Her research examines strategies to disseminate evidence-based practices for youth mental health. Margaret also is a clinical psychology resident at New York Presbyterian-Weill Cornell Medicine.

Sean E. Snyder, LCSW: We have two clinician-scholars from Temple University's Child and Adolescent Anxiety Disorders Clinic for today's interview, and this interview will provide us a unique window into a university clinic. Readers, pay attention to the core elements of what Margaret and Lesley share to adapt to your own clinic experience. Let's get started.

With engagement, we frame it as the multidimensional aspects of commitment to treatment. When working with kids and anxiety, one of the hallmark features of these types of problems or disorders is avoidance, which is really the exact opposite of engagement! Avoidance behavior sometimes gives the child short-term relief. So, knowing that, before they even get in, you're going to be working with an avoidant child or avoidant family. So, how do you join with families right in those first few sessions that are seeking treatment, knowing that avoidance is in the background.

Lesley Norris, MA: This question just made me really think about how hard it is. The things that we ask kids to do in therapy are basically taking their one coping skill that they rely on, avoidance, and then asking them to stop doing that thing that helps them get by. And that's really scary. And I never want to lose sight of that. It really should come as no surprise to us as a result of that, but sometimes kids might come to our office, not feeling super excited to be there. They might be taken here by their parents. And as a result, I think that the first session is critical in terms of joining with the family. And I think what's interesting about the *Coping Cat* protocol is that we actually do a surprisingly small amount of talk about the child's anxiety when we first meet them. We definitely take time to introduce what to expect in therapy, but the majority of the session is playing get-to-know-you games where we're getting to know the kids separate from their worries. Like, we know that you feel worried, but who are you as a whole person? And then also giving them a chance to get to know us as people, too. And I think that's really important.

Researchers show that talking about anxiety too fast can lead to drop out. So, I think you don't want to skip that step of getting to know one another. And I think, again, during that first session, we really introduce the idea that therapy is a team approach. So, this is not going to be a thing where you come for 15 minutes, and we "fix your child." We're all going to work together, and I will say things like, "I have a lot of expertise about what's helped other kids, but kid, you know yourself better than anybody else. And Mom, you know your kid, better than anybody else. So, we're all going to work together on this team to fight against this worry monster." So, I think a lot of that happens in the first session.

Margaret Crane, MA (she, her): And then just to piggyback off of that, beyond the first session, especially in *Coping Cat*, we don't actually get into exposure until session nine, and there's certainly some debate about whether that's too long. That said, though, it does mean that there's a lot of time where kids are learning new coping skills. As Lesley said, right now avoidance is one of the main skills they are using. And during the first half of *Coping Cat*, they're learning new skills, so that when they approach anxiety-provoking situations, I have those skills to offer them, to put it into practice.

Snyder: Earlier, Lesley, I heard you mentioned the term "worry monster." Do you label that as an externalizing technique? Could you talk further about terms you use with anxiety and kids?

> *Kids will engage in reassurance-seeking from caregivers; the caregiver's natural response is to attend because that's just how we're wired as parents... acknowledge that it's not natural; it doesn't feel natural to encourage your child to stay in an anxiety provoking situation.*

Norris: Yeah, I think there are a lot of individual differences across therapists in our lab with how frequently we're using that externalizing language, but I love it. Mostly because I really like to personalize the manual as much as possible. And it's a fun activity for me and the kid to come up with a name. So, we can use "anxiety monster," although I often want it to be a little bit less scary and maybe something funnier. Kids have come up with terms like "anxiety ninja," or like "worried dinosaur," stuff like that. And it makes it seem just like less of this really big amorphous thing that's taking over their lives and more like something we can all fight against.

Crane: And then even teens and adults sometimes like the term "worry monster," but I had a teen who named her anxiety "Fred" for whatever reason. I don't know if she knew Fred or whatever. But like Lesley was saying, it was personalized to, "What does it feel like your anxiety's name might be?" And then we can really say, "Okay, am I talking to you, or am I talking to Fred?" And so, I think that can also be a helpful way to have clients see is this me who's saying, "I don't want to do this," or is this the anxiety, saying, "I want to avoid this."

Snyder: Great. And that's the joy of working with kids, they can make you laugh. What they come up with and therapy can be fun. So, I mean, I'm thinking that from the child's side, avoidance is their go-to strategy. It works in the short term, as we know, but in the long term, it doesn't really work out for them. So, shifting gears is thinking about the primary thing, where the parents' role is usually reassurance-giving. Kids will engage in reassurance-seeking from caregivers; the caregiver's natural response is to attend because that's just how we're wired as parents. So, what's it like, then, to provide education to parents about not necessarily giving in to reassurance-seeking where it feels like it's, again, counterintuitive to what's the natural drive for parents?

Crane: I think one thing I do is first acknowledge that it's not very natural. It doesn't feel natural to encourage your child to stay in an anxiety-provoking situation. And then I also like to do a lot of the skills we do with the client themselves, the child client, with the parent or other caregiver. For example, "What's coming up for you in your body when you watch your child be anxious? What worry thoughts do you have? What might this mean about you as a parent, if you're not letting your child come into your bed at night?" And so, I think those similar things that we talked about with kids can be helpful to also talk about with parents. Like Lesley was saying earlier, too: it makes a lot of sense that you do this because you feel better, and the child feels better. It makes sense that you're encouraging this sort of avoidance unintentionally.

Norris: I totally agree, Margaret, and I think, broadly, just this nonjudgmental stance towards the idea of reassurance-seeking and accommodation is super important. And I think language is always important in therapy. But I think being really intentional with your language here can be helpful. I think Eli Leibowitz talks a lot about parents being drawn into the child's difficulty or the child pulling for reassurance-seeking behaviors, and I think it puts the onus on the child's anxiety disorder as what's doing these things. I think a lot of parents come in with this unspoken—or often spoken—idea that they somehow caused their child's distress and are operating from that framework. If I take that same approach, they're never going to want to be working on the kinds of behavior change that I want them to do. So, I really want that nonjudgmental approach to permeate throughout all these discussions.

Our modeling helps parents. So, I'll say, "As a therapist, I'm going to be looking out for my own accommodating behavior." Maybe I'll be pulled to want to have your child do a slightly easier exposure or something like that, and I'm going to be noticing that in myself and working against that.

Crane: The other thing I often think about with parents in these discussions is, "What do you want for your child in the long term and what sorts of lessons do you want to be teaching your child?" Like Lesley was saying, I think even that language is important to think about when you're using it to make it so it doesn't feel like it's blaming them. But thinking about, okay, in the long term most parents want their children to be independent. They want them to be able to emotionally handle many different situations. And it's hard to do that. And so, a lot of what we're going to be doing is practicing and sort of linking it towards their long-term goals. I think it can also help with parent buy-in for decreasing avoidance.

Norris: One of the skills that we use with kids is for us to model our own worries. I will say things like, "I just gave a presentation, and I felt worried in my body here, and I noticed these thoughts, and this is how I coped with it." I find myself modeling this also with parents, which I don't know if we do enough of, modeling how easy it is to accommodate anxiety, something we all do, again, because anxiety pulls for this. We see a kid who's in distress, and we want to help. So, I'll say, "As a therapist, I'm going to be looking out for my own accommodating behavior." Maybe I'll be pulled to want to have your child do a slightly easier exposure or something like that, and I'm going to be noticing that in myself and working against that. I think this opens a door to invite the parent in to consider their own accommodating behaviors, because it is something most adults do; we aren't just singling out the parent here.

Snyder: These clinical examples are great because I think other therapists and clinicians are going to be struggling with that, too, with thoughts like, "How do I push these kids?" or even just the clinician thought "I want this kid to like me so we can do the work." Clinicians are sensitive to the working alliance; we care so much about that, especially early in training or early career.

When talking about the idea of modeling, that worry is really protective. Where do you guys help the parents draw the line on what's the anxiety and what's natural worry? For instance, if I give a presentation, I'm going to have those butterflies, or if I'm doing an interview, I may have worries but that can be something motivating in the right context. So, how do you make that distinction between the helpful worry and the not-so-helpful worry?

Crane: That is where I lean on the diagnostic system a little bit, which is thinking about, “Is this impairing? How is this getting in the way?” Anxiety itself is not a bad thing if it’s not getting in the way and if it’s not really distressing where it is getting in the way of someone being in the moment of whatever it is they need to do. I also like to think about that with parents when we’re setting goals and expectations for treatment because our goal is not to get rid of anxiety. It’s to make it so that the child can cope with anxiety and can still do all the things they normally like to be doing with anxiety being present. I think it can be helpful, both to help parents know, “okay, when is this a problem,” and then it can also be helpful for parents to have expectations during therapy of, “what do we want the goal to be.”

Norris: I also love this question. It’s so important, I think, first, the introduction that some anxiety is normative. We expect that; it’s important as an intervention, just to let families know our goal here is not for your child to never to feel anxious ever again. We’ll have kids imagine what a world would be like if people didn’t feel worried, like, people being hit by trucks all the time because they just walk across the street, things like that. Here we often rely on this metaphor of a true alarm versus a false alarm. We’ll ask if they ever cook and their smoke detector goes off, and there’s no fire. That’s the type of worried that we’re going to want to work on, where you’re feeling like there’s a tiger in the room, but there isn’t a tiger in the room. I don’t want you to not feel worried if you’re presented with a tiger, and it’s a really scary thing. And I think that that’s also where some of the extra externalizing language can be really helpful.

Crane: My tiger in the room.

Norris: Yeah, exactly. It is really defining that external anxiety monster or whatever they choose to call it, as a false alarm worry. Our goal for these kids is really to educate them that it’s not that you’re never going to feel worried, but with treatment, you’re going to be able to choose whether or not you want to do whatever the monster tells you, or whether you want to do what you want to do.

We let families know our goal here is not for your child to never to feel anxious ever again… with treatment, you’re going to be able to choose whether or not you want to do whatever the monster tells you, or whether you want to do what you want to do.

Snyder: I love that, too, because it’s the idea of knowing when it is impacting functioning. That’s when we get into the realm of pathology. That may be a good lead into assessment when we think about functioning, so before we move on, any last thoughts related to engagement?

Crane: This can be a little bit harder via telehealth, but helpful to think about when the child doesn't want to go to therapy. I say it's harder via telehealth because we've been noticing in our clinic that the child doesn't want to go to therapy, so they're not really in a different setting. Being at home for therapy gives a different frame of mind, where the avoidance is different. It's not a matter of coming to our clinic; it's a matter of avoidance in a space where maybe they find that avoidance helps. It can be a big fight for parents to bring them to session, and so setting a goal, like let's try for X number of sessions and reevaluate at that point.

Snyder: Thanks for sharing that because I think we have to adapt to the realities that our clients are going through, especially during our current pandemic.

Ok, so assessment. A clinical phrase I've heard is that anxiety is anxiety. But I'm interested to know the primary drivers of anxiety that you can see when you're doing assessments. What do you see the most in your clinic? Are you seeing more social anxiety or separation? Or school refusal?

Norris: I think the most common diagnostic presentations that we see are more often a combination of what we call the "big three" disorders: Generalized Anxiety Disorder, Social Anxiety Disorder, and Separation Anxiety Disorder. I actually happened to run some descriptive recently on a subset of our clinic sample, and GAD was actually our most common primary presenting problem (I think the N in this sample is 92), followed by social anxiety, and then there was actually a pretty big drop-off where separation anxiety and specific phobia weren't very common. At the bottom of our sample was panic disorder, agoraphobia, and illness anxiety disorder. We only saw like one case of illness anxiety disorder in the space of a four-year period.

Crane: The thing that's interesting about anxiety is that they cluster together so often that sometimes in our intake reports, we do describe each anxiety disorder separately, but will say the common feature of this is anxiety. In some ways, the different disorders can be helpful to think about different situations that we might need to do exposures around. For instance, we should think about separation and how that's interfering, or we should think about how social situations are interfering; how school worries and perfectionism might be interfering, and so on. The way that those different anxiety disorders are treated are the exact same way, with OCD and PTSD being a little bit separate. I think the diagnoses are helpful because then they help guide treatment.

Snyder: Right, what is interesting is that the most common co-occurring disorders are other anxiety disorders. I'm interested though, how are you assessing the child globally then with the anxiety itself?

Norris: We always administer a semi-structured diagnostic assessment, and we do it separately to both parent and child. Administering them separately is obviously very time and resource heavy, but we found that that's worthwhile, because you get different information from parent and kid, which is really interesting. For example, a seven-year-old may have a harder time reporting on their own symptoms compared to the parent, and then a teen might know their social world a lot better than their parent. So, doing them separately has been really helpful for us. For other measures, we don't have as much of a common battery, but we do tend to always try to include a self- report measure of anxiety. We usually use the SCARED.

Crane: We're a research clinic as well, so we have a research battery. But if I were seeing clients outside of our clinic, I really like the SCARED, in part because it's free, and the subscales can map onto DSM disorders. The Spence also does that, and I think it's also actually free. I like both of those again because it can give a very brief sense of what might be going on, and this is where I see assessment really guiding treatments. I might do a questionnaire to understand diagnostic subsets but also to get a sense of what exposures will look like.

Snyder: You are already introducing the clinical language to the kid, so when you are doing an exposure, you can look back at the SCARED, let's say, and tell the youth, "Remember when I asked you about X, Y, or Z scenario? Well, we are going to talk a little more about that today." It gives predictability in a way, and it also gives the message to the youth that we are doing these assessments for a reason, not just to check boxes.

> *In the context of a social exposure or a social worry exposure, you can build in social skills as part of that.*

Ok, so second part of the previous stack of questions: what comorbidity are you seeing, and how does the presence of another disorder affect your treatment planning?

Crane: I'll start off by saying yes, comorbidity is the norm and expectation. We see comorbidities across the spectrum with OCD, depression, ODD or ODD-like behaviors, and ADHD. If there's some behavioral concerns, that's where we might use more behavior management strategies in session, so more rewards, or I'm chunking the session into smaller pieces with more time for games, perhaps. Maybe the kids don't have to be sitting down when we're doing the session, and they can be moving around. For comorbid depression, the nice thing is that while yes, the *Coping Cat* really is talking about anxiety, the skills in the *Coping Cat* protocol or any CBT program that has content related to "encouraging opposite action," can be tailored behavior activation, really. You still use an exposure framework but make that more of a ladder of different situations to build up.

Norris: Another co-occurring disorder I want to add would be Autism Spectrum Disorders. We see a lot of co-occurring anxiety within that population, and Dr.

Kendall and collaborators have recently done an RCT that shows CBT is actually efficacious for kids with ASD. I've been working more regularly with clients who also have ASD, and what is interesting is that even in the context of a social exposure or a social worry exposure, you can build in social skills as part of that. Also, when you're talking about identifying how you're feeling anxious, locating where you experience it in your body. With this group, you can again broaden that to just say, how do you feel in your body when you are sad, mad, or happy. Just extending it to have it be a little bit more broadly focused on different kinds of emotions.

Snyder: It's great to see all the connections you have made naturally in your responses between engagement, assessment, and intervention. There's one big piece I still need to bring in: school. School is a kid's job; developmentally, school is what they do. How much do you engage the school in the assessment process, and how much do you involve schools in the treatment process with your youngsters?

Crane: That's something that I feel really fortunate about with the structure of our clinic, that we involve schools a lot, and I think we're able to do that in part because we're a training clinic, so perhaps we have a little bit more time. It's also something that our clinic really values, to involve everyone we possibly can in some way. I've also spoken to people like soccer coaches and swimming coaches. Some of you might talk to a music teacher or someone very involved with music. As many people we can involve as possible is helpful to get perspectives of how this might look in different settings, and then also to getting everyone on the same page. We found that some schools can do similar behaviors as parents do, like unintentionally encouraging avoidance or accommodation. Some school accommodations for anxiety are helpful, where they slowly help a child face their fears, while others are not helpful. With these not helpful ones, they're removing an expectation so that the child isn't feeling anxious. So, a lot of the times when we're working with school as well, we often will say, "Can we not have this sort of accommodation right now because we are working towards the youth working through their anxiety."

Norris: I agree. Oh, we love to get teachers involved, especially in the intervention phase, where we are introducing teachers to the model that we operate from, which is really helpful. But this question made me think that we actually don't involve the school in the assessment process as much compared to intervention, and I think we probably should do that more.

Snyder: It makes sense; schools and teachers are well-meaning because they want their students to learn, so they might provide these accommodations that unintentionally reinforce the avoidance or reassurance, essentially an accommodating of the unwanted anxiety behavior. And when you intervene, you're still assessing; it's all feedback.

Norris: A critical piece is the idea of informed consent, just because I've had really mixed responses from kids about how they feel about me talking to their teacher or doing any challenges in school. I think some kids are totally fine with it, and other kids feel embarrassed that they're attending therapy. Informed consent goes beyond just signing a form and saying it's okay, so really talk through consent with a kid, and let them know what's going to happen.

Crane: Last point for assessment, tracking progress throughout treatment. I really like the coping questionnaire or the youth top problems questionnaire, and these are ideographic, so they are customized to the client. You can really see how we are progressing with these goals throughout treatment. Those assessments are also both free, and they're also both really short, where I think there are only three items (I would only choose one or the other). There's also no technology problem with scoring it; its quick, easy, and available.

It's important to tell families about the options for treating anxiety, with medication being an option, or a combination of medication and therapy. The other message to send to them is that realistically, gains can be maintained, but sometimes kids may need some boosters.

Norris: This is making me remember when I first started as a clinician, I thought that I would be using diagnostic information a lot in creating this really personalized coping experience for the family, but now I never want to be leaning exclusively on that diagnostic information, especially because there's so much overlap. I want to think, what does the family structure look like? What is the family's cultural background? What's their socioeconomic background? That's the piece of information that we don't get in a lot of our measures, so take a step back and really see the family, not just the diagnostics.

Snyder: Excellent, the value of a really good formulation to contextualize all these data points that we get to tell the clinical story.

Crane: Yeah, I think that's particularly important because families have different cultural or behavioral practices around things like sleep behaviors. If a child has separation anxiety, we might think about co sleeping and the parents as being a problem. But for many families, it's not a problem. Consider what makes sense for the family and what their values are- what's normal based on their culture, I think is really important with sleep in particular.

Snyder: Great way to cap off assessment, because everything requires context. Let's shift now specifically to intervention. You both are part of Dr. Kendall's lab, which is known for *Coping Cat*. It may be easier to use that as a jump off point. So tell me, what's it about, what's its evidence base, how do you implement it?

Crane: So, I guess a few things with evidence. Evidence shows that *Coping Cat* is one of the most effective therapy treatments for kids (it's not effective for *everyone*) I think it's around 60 to 80%, depending on the trial. The most effective approach is the combination of the program with medication. That doesn't mean that I think all kids should go on meds. In fact, I think trying therapy first makes a lot of sense because there'll be fewer side effects. But it can be important to consider depending on the client.

Norris: The first year it was implemented was in 1994, and there have been a ton of trials since then showing effectiveness. I think it's important to tell families about the options for treating anxiety, with medication being an option, or a combination of medication and therapy. The other message to send to them is that realistically, gains can be maintained, but sometimes kids may need some boosters. The big thing for *Coping Cat* is seeing how to adapt it to make sure that we are providing culturally sensitive and responsive care. I think there have been studies done in the Hong Kong and Argentina, but we need to really broaden how to adapt to be responsive across race and ethnicity.

Crane: In terms of the *Coping Cat* program itself, one big term to think about with any manualized treatment is "flexibility within fidelity," which is basically to say that it's important to stay consistent with the core principles of treatments but the exact details and how they're implemented can be very flexible. That can both help people adapt the treatment to the individual client and be more culturally sensitive. Also, it can just help with adapting it to different situations, like sometimes some kids don't have as many sessions as other kids. You may need to think about what information should be longer or shorter.

The typical *Coping Cat* program is 16 weeks, but there's also a brief version that's eight weeks. There's also a version that is computer assisted therapy, called *Camp Cope*, and that's online where basically the computer does the psychoeducation part, which includes things like coping thoughts. Then, the therapist or whoever's administering the program helps with the exposures live. To give a brief structure of the *Coping Cat* without going into all the sessions, the first half is helping kids identify different thoughts, feelings, and behaviors. It uses something called a fear plan. F is feeling frightened. So that is working with the youth to see, where do I feel anxious in my body? The same with relaxation: how can I feel a little bit calmer? The "E" is expecting bad things to happen, and that's what we think about with anxious thoughts. We also think about cognitive restructuring or also accepting thoughts. Sometimes these thoughts are accurate, but they're just not very helpful in this instance. Or it's a thought we have to accept, and we need to see how we can keep going.

The "A" is actions and attitudes that can help. Cognitive restructuring lends itself to attitudes of "what can I tell myself so that I can approach this situation that might be scary for me?" And sometimes that's just a simple thing that is really hard, but I'm going to give it a try. And then the second part of that A is actions that can help. That's where we think about problem solving. Sometimes people feel anxious because they're overwhelmed, or they don't know how to approach a situation. I found problem solving is a really helpful skill for anxious kids. And lastly, the "R" is results and rewards. In this step, we help kids remember that we're not looking for perfection. We're just looking for effort, really. We're not looking for social interaction to go perfectly. We're just looking for "Okay, did I actually ask my friend to hang out today?" Because that was the goal. They get rewarded by other people and other external rewards, like praise or getting to pick what's for dinner. That's actually one of my favorite rewards across clients. It can also be tangible things sometimes with teenagers, especially. They might use points to build up to getting new shoes or something like that. We also talked about self-rewards like giving yourself a pat on the back.

Norris: I summarize it to families this way: the first phase is learning skills, and the second phase is practicing those skills. I use a silly example with kids: I can learn all I want to know about the organ, but I can't play it until I actually put my fingers on it and practice. The exposure part is really just putting those skills into practice. Throughout the first half of treatment, we will create these fear hierarchies with the kid, which are really just personalized worry ladders for them. I call them fear islands with the kids, and it just really breaks down their fear into small manageable steps. For instance, if a kid is afraid of spiders, a fear ladder might be looking at a picture or cartoon spider, then looking at a picture of a real spider or watching a video of a spider, then being in the same room as a fake spider, all the way up to maybe holding a spider.

For our first exposure, we usually start around like a three or four level on a scale of zero to eight. We will do the exposure with them in session and get ratings of how their worries are throughout the exposure. Then we always give them a reward at the end because they were brave; we always want to reward brave behavior. It's the process, not the outcome for them. And then we'll plan for at least three challenges a week (We call them challenges with the kids, not exposures, because exposures is a weird word to use with kids). We'll plan for three challenges that they'll do, and then we'll also plan for the next challenge that we will do when we see each other next session. It's a really flexible process.

Snyder: That's helpful for folks because it's unveiling what's behind the curtain, which can reduce the worry or hesitancy to do manualized treatment, or to reduce clinician worry about exposure, because some may think "I'm emotionally harming my client." So, there can be some anticipatory worry on the part of a clinician new to exposure work.

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Crane: Final things with the protocol. In the last session, we always create an advertisement or a video. Basically we have the child tell another child "here's what I learned." It's essentially a relapse prevention plan, but it's a little bit more fun. Some kids would rather make a poem or a rap or just write it down. Any of those are fine. The goal is just to help the kid reflect on what they've learned from treatment. They may even just go through the fear plan and then talk about which of the different challenges or exposures were really helpful for them. We also talked about things like "how do I know when I need to come back to therapy?" I'll just mention that while *Coping Cat* is 16 weeks, there are definitely some clients who may need more like 20 sessions. We might add in some more exposures than the classic 16 sessions. Sometimes clients are done within 12.

The other key component in *Coping Cat* is the homework piece. We call this the "stick task" or "show that I can," which is basically practicing throughout the week. I always say, "You only see me for one hour week, and we want to make sure you're thinking about this between sessions." The other key piece is involving parents, which clinicians can avoid. At the end of the session, I say "Here's the skill we learned, and here's how you can help your child practice. Throughout the week, talk about where you are noticing worry in your body, or even if you're watching a TV show together. You may ask in a line at the store, how do you see worry in that other person in line? Help the parent apply the skills. There are two parent sessions in *Coping Cat* where we really talk in more depth about what parents can do. We see the over-accommodating parent to help the child avoid anxiety, and another type of parent we see is the very strict or harsh parent. These parents may need a little bit more buy-in to do things like rewarding their children for great behavior, or more attention to the parent's response to the child's anxiety which perhaps is making their child a little bit more anxious. Any parent needs the rationale of treatment. Think about the goals and get a consistent, adaptive parenting response. Lastly, we also see the inconsistent parent, meaning the parent might accommodate the child, and other times they might not. For these parents, we try different parenting skills like tracking and self-monitoring.

Norris: In addition to parents, the clinician experience of doing exposure is so important. Many studies show that doing exposure doesn't rupture the alliance, and, if anything, it can strengthen it. My stance of exposure is that you can't have a bad exposure. There's a lot of worries about an exposure going wrong, where therapists have this image of a kid just completely breaking down and thinking "I broke in this kid. I don't want that to happen." We obviously don't want that; we want the kids to have a mastery learning experience with their exposure. But let's say you start an exposure, and it ends up being a lot harder for the kid than you thought it was going to be. That's okay. That experience is more data for you so you can really understand what this kid's *actual* worries. That experience can help create this more personalized exposure hierarchy.

When you're going into exposures, plan for those moments ahead of time with the kid. You may see that your client is feeling super great today and what was planned was no big deal. You might challenge them or let them pick out what they want to do off the hierarchy. Make it collaborative in that space, and let them know when doing these challenges, that it could be hard, but that you're doing it together.

Setting up some ground rules with the child can give them a sense of efficacy, like "We're doing this together, and exposure is never something I will do to you; it is something I do with you. And I'm never going to ask you to do something that I would be willing to do myself." Ultimately, exposure can be fun for kids if you make it that way.

Crane: Exposures can be a confidence boosting experience for kids because they're doing something they didn't think they could before. That can also mean planning for what they're going to do at home with their parent for homework. You're not there with them, so make it something simple, realistic, and targeted to what you're trying to achieve. So maybe instead of a specific situation, you may say, what would make you embarrassed and what would be hard to stick in the situation? If when you practice at home and you're not embarrassed, how can we make it a little more embarrassing? That both teaches the child how to be a therapist, which is important for the long term because you're not going to be there their whole lives, and it also helps the at-home practice be a little bit more effective. Make sure that whatever they practice is really getting at their core fear.

Norris: I spend a lot of time with kids, making sure they understand the model and why we're doing what we're doing. I want them ultimately to be able to come up with their own exposures and not think we're doing this random thing for no reason. I want them to really buy into that model. Something else to consider is unconditional positive regard, where as a therapist, I believe that this kid can do it and that they are brave children. I'm just helping them to learn they are brave. Kids really buy-in with that positive feedback and positive regard. The goal, again, is not that they're not going to feel worried, rather that they understand what to do when they feel worried. The hope is that they know that bravery is what we're looking for.

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Crane: Parent involvement goes a long way with that, too. For some parents, it can be really helpful for them to be in session during exposure to observe it, because sometimes parents might think, "Oh, that's too hard for my child." So, for them to see both that you the clinician are confident that the child can do it. and for them to watch their child do the exposure and may see "Oh, my child couldn't cross the street because they were so nervous about getting hit by a car. This wasn't actually all that hard when the therapist had this structure and really believed in them and could reward them." I think it helps give the parents that confidence to then practice it at home.

Norris: Accommodating and reassurance seeking can inadvertently send a message to the kid that the parent doesn't believe they can do that thing. Exposure is us sending the message to both parent and child that, "We know you can do this thing and we're going to get you on board with our beliefs that you can do it."

Snyder: It goes back to modeling then, for both the child and the parent. You both have mentioned about being brave, and it's flexing that brave muscle to building resilience. Resilience is not a character trait; it's something that we can work on, and it's something we can learn. That's a great takeaway for readers, to use that language about being brave.

It’s been so great to hear all the things that you’re talking about, from active ingredients like cognitive restructuring, praise, and reinforcements, to talking about what it is like for new clinicians to actually do exposures. What parting words do you have for our readers?

Crane: Especially as you’re learning a new program, it’s really helpful to have either supervision or peer supervision or consultation. A great paper by Emily Becker Haimes looks at what’s different about these specialty university clinics structure wise, that enables them to do exposures and to do these therapies more effectively. The one thing is that clinicians in these clinics have peers. I really love our clinic’s peer supervision because it helps with generating ideas for exposures, and it’s so much easier to do that with other people. There are various lists online and on various websites, but I think if you really want to customize it to a child, it’s really helpful just to have someone to bounce ideas off of. For trainees or newer clinicians, if that structure doesn’t exist try to see who else in the clinic is doing exposure work and do peer consultation outside of their regular supervision.

Norris: I think we psychologists love a “yes/and” statement. I never want to lose sight of how difficult what I’m asking these kids to do is. Sometimes new clinicians can both be worried about exposures, but also overzealous in their application of exposure, so I always want to really be inspired by and be honored to watch them do this thing that’s difficult for them. And at the same time, I don’t want it to be a serious thing that is inaccessible to the youth. I want to create a playful experimental environment in the session, bringing some laughter into the room while we’re doing this really hard thing and holding space for both those things at once. So, yes this is hard, and I know you can have a good time trying. That’s the goal of therapy, getting to that middle; the middle ground is right where we want to be.

Snyder: The middle way is the way to go, where we don’t want to be overly worried or unresponsive to stimulus. We may say to clients, “We don’t want to completely take away your anxiety, and we don’t want you to be anxious all the time, so what’s that middle ground look like for you?” And that conversation puts them in the driver’s seat, where they are able to thrive and not be driven by their anxiety. To end with a very therapist-like statement: how can our anxiety serve us better?

Things Clinicians Should Know

Avoidance: the action of keeping away from something or not doing something

Accommodating: the actions family members take to alleviate a child's symptoms and distress which can reinforce anxiety

Habituation: diminishing of a physiological or emotional response to a frequently repeated stimulus

Inhibitory learning: fear extinction through learning new safety-based information that inhibits existing fear based learnings

Somatic symptoms: symptoms that are physiological, can be felt in the body e.g., stomach ache, headache

Common Elements Approaches

Psychoeducation: Teaching youth about their diagnoses and raising awareness of symptoms.

Calming skills: Taught to help youth address somatic symptoms of anxiety. Can include mindfulness practice, engagement in activities the individual finds relaxing, and release of energy through exercise. Relaxation should be scheduled and practiced to encourage the formation of habit. Making relaxation strategies habitual can increase the likelihood that the skills are used in moments of distress.

Cognitive coping: Taught to help youth manage symptoms during anxiety-provoking situations. Coping strategies can involve both coping thoughts (e.g., "I can do this!" "I don't know for sure that something bad will happen") and coping behaviors (e.g., actively practicing approach rather than avoidance, engaging in problem-solving prior to known anxiety-provoking situations).

Exposure: Allow clients to practice using coping skills during "real-life" anxiety-provoking situations. Exposures are individualized for the client.

Dr. Emily Becker-Haimes is the author of the ***Resource for Exposures for Anxiety Disordered Youth (READY) Toolkit*** *and has developed and led research concerning the implementation and utilization of exposure therapy in diverse clinical settings.*

Open Access Assessment Tools

Revised Children's Anxiety and Depression Scale (RCADS)

Screen for Child Anxiety Related Disorders (SCARED)

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11

Chapter

Trauma and Stressor Related Disorders in Children and Adolescents

Sean E. Snyder, MSW; Stevie Grassetti, PhD; Julie Nguyen, BA; Arturo Zinny, MA

Gaby is a 15-year-old (Latina/Latinx) female who witnessed intimate partner violence of her mother during early childhood and was physically abused by a non-caregiving family member during middle childhood. As a result of her family turmoil, Gaby was placed into foster care. She had difficulty adjusting to this new environment. She needed more support, so she was placed into therapeutic foster care, then residential treatment, and then acute inpatient treatment. She reported having nightmares every other day and that she felt emotionally numb “almost all the time,” feeling like she has to avoid thinking about it daily and feeling irritable “all the time.”

“I’m tired of starting again in new places, telling people about my story. I just want the past to be the past and move on from it,” Gaby told her current clinician. “I honestly want to be left alone. The thought of talking about this stuff just pisses me off. People say they want to help, but they don’t stick around. I’m tired of feeling this way and dealing with all of this stuff.”

Overview of Post-Traumatic Stress Disorder and Other Trauma/ Stressor-Related Disorders[*]

Child trauma has received considerable attention since the publication of the ACES study, which highlighted the deleterious effects of traumatic exposure during childhood on long term health and wellness outcomes for adults. The National Child Traumatic Stress Network (NCTSN) was developed in 2000 to respond systematically to the epidemic of childhood trauma, and it offers clinicians and families with resources to promote healing and resilience after potentially traumatic events. NCTSN outlines that its mission is to raise the standards of care and access to services for children and families impacted by trauma.

So, what do we mean by trauma? For the purposes of client psychoeducation, it can be defined as a scary or upsetting event that can cause big changes in the way someone thinks, acts, and feels emotionally and physically. Substance Abuse and Mental Health Services Administration (SAMHSA, 2014) sa)tates that "trauma results from an event, series of events, or set of circumstances experienced by an individual as physically or emotionally harmful or life-threatening with lasting adverse effects on the individual's functioning and mental, physical, social, emotional, or spiritual well-being." Additionally, trauma is defined by the three E's: the event itself, the subjective experience of the event, and the effects of the event. Traumatic events tend to be of bigger magnitude, with examples including being assaulted, motor vehicle accidents, and natural disasters. The subjective experience matters; no two people experience an event in the exact same way. A traumatic experience is one that overwhelms someone, often immobilizing coping abilities or access to effective coping strategies. Lastly, the effects vary from changes in feeling, to avoidance of reminders of the event, to changes in sleep or eating patterns. It's these effects that give us a window into Post-Traumatic Stress Disorder (PTSD).

Oftentimes, children bounce back from traumatic events. It's much like physical injuries; there is a time for people to recover and heal. Caregivers and other important adults (grandparents, teachers, and mentors) play a critical role in the child's recovery by supporting them in making meaning of their experiences and giving them time to heal. In PTSD, a child is stuck in their recovery process, and this is often where PTSD symptoms come into play. A person experiences intrusive thoughts about the trauma they were exposed to or have flashbacks or nightmares. These reactions perpetuate because someone is stuck in their recovery. Trauma exposure rates are high, and the good news is that some will bounce back without intervention, and some can

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receive timely, brief interventions to prevent the onset of PTSD. For those with PTSD, there are evidence-based treatments to promote full recovery.

Trauma is defined by the three E's: the event itself, the subjective experience of the event, and the effects of the event.

Gaby's experiences fall under the umbrella of traumatic events, with witnessing family violence and experiencing physical abuse. We would need to understand her experience of the event and the effects of the event from her reporting, but by impression, we can sense that she has been deeply impacted by these events. As Gaby has said, she hates starting over with new adults and caregivers, and she may identify this as the most "traumatic" part of her experience. As we will find later, there are particular types of events and experiences that will meet Criteria A for PTSD, and being in foster care would not technically fall under that category. Would we not then do treatment with Gaby? Of course not! As mentioned in her interview in this chapter, Dr. Cohen has said that we are here to help youth and families organize their experiences and to feel more in the driver's seat with their lives and memories; so, clinicians will need to rely on the art of intervention.

Prevalence of Trauma and Stressor Related Disorders

Approximately two thirds of children in the United States are exposed to at least one potential traumatic event by the time they turn eighteen years old (CDC, 2019; SAMHSA, 2017). Although only about 5% of adolescents will meet PTSD criteria (Hamblen & Barnett, 2018), more often than not, traumatic events will cause stress that leads to functional impairment even if adolescents do not meet criteria for PTSD (Alisic et al., 2014). The National Center for PTSD reports that PTSD rates are higher in girls than boys, and rates tend to increase with age (Hamblen & Barnett, 2018).

Development of Trauma and Stressor Related Disorders in Youth

In clinical conversations, PTSD symptoms are considered normal reactions to abnormal events. The kind of event and the intensity of exposure to that event are known to be predictors of PTSD; essentially, the more intense an event and the closer someone is to the event, the higher the likelihood of PTSD (Hamblen & Barnett, 2018). For instance, a child who was violently assaulted is more likely to develop PTSD than a child who witnessed the violent assault. Moreover, researchers have found that factors such as pre-existing psychiatric disorders, parental psychopathology, being female, and low social support can increase the risk for PTSD (Hamblen & Barnett, 2018). Interventions to address PTSD tend to focus on cultivating protective factors such as parent observational capacity of child symptoms, supporting the child during recovery specific to the presenting symptoms, and developing adaptive coping skills (Hahn et al., 2019; Trickey et al., 2012). Gaby's situation has many factors to consider; while she wasn't directly assaulted by her parent when she witnessed intimate partner violence at home, she was still in close proximity to be affected by it. Also, her mother may have had her own stress symptoms from the intimate partner violence she sustained, which could impact her ability to be attuned to Gaby or to help co-regulate Gaby.

Developmental Systems Considerations for Trauma and Stressor Related Disorders

So how is trauma different for children? Development matters. Trauma has the potential to derail the child's developmental trajectory, negatively impacting one or more domains of functioning (i.e., cognitive, emotional, and behavioral), which in turn may affect the child's relationships with family and friends, school performance, self-concept, and more. The cumulative effects of trauma, especially severe and prolonged exposure, can change both the functioning and structure (Cohen, et al., 2017) of the child's brain, considering that child organ development tends to resemble adults by age 15. With the brain, there have been studies that show that traumatic exposure affects grey matter and reactivity when viewed on an fMRI scan.

The family system is critical for recovery, starting with the child's primary caregiver(s). Researchers and practitioners agree that the presence of a supportive caregiver significantly improves the likelihood of a positive treatment outcome for the child. There is the reciprocal interaction between child and caregiver. Studies find that caregiver attunement to the child's needs and ability to assist the child are protective against development of PTSD after a traumatic exposure (Berkowitz et al., 2011). The Child and Family Traumatic Stress Intervention CFTSI is rooted in the idea that if there is increased observational capacity about symptoms, along with the ability for needs to get met and for proper coping skills to be employed, then the child will have a better prognosis in their recovery (Berkowitz et al., 2011). Caregivers can also have a reduction in their own stress symptoms as a result of their child getting treatment (Hahn et al., 2019), showing that intervention is mutually beneficial for the parent-child dyad.

> *Caregiver attunement to the child's needs and ability to assist the child are protective against development of PTSD after a traumatic exposure.*

Think of an example when a parent gets lost when they are driving a car. If the parent is flipping out and refusing to ask for directions, the child will react based on the parent's reactions. If the parent is lost and remains calm, the child will not even know there is a problem. This example illustrates that caregiver stress can affect child symptomatology. Conversely, child symptomatology can affect parental stress; consider what it must feel like for the parent that has a child with hyperarousal, sleep problems, and oppositionality. It becomes a dance that leads to more frustration.

When external systems (e.g., school, community, and peer groups) are not healthy and healing for the child, they can either create more risk factors and more exposure to traumatic stressors, or they can delay recovery from any traumatic exposure. Complex trauma can emerge in such cases; complex trauma is defined by NCTSN (2011) as "both children's exposure to multiple traumatic events—often of an invasive, interpersonal nature—and the wide-ranging, long-term effects of this exposure." These are the events or series of events that impact the development of self-attachments with caregivers, with much of a child's development relying on safety and stability offered from secure attachments (NCTSN, 2011). Gaby's case can illustrate some of the disruptions in attachments that lead to complex trauma.

Other developmental systems factor to consider are the interplay of time and culture. How has systemic oppression influenced conditions leading to traumas? Have the parents themselves had a trauma history, as we know that intergenerational transmission of trauma is real? How much of caregiver stress is their own trauma reminders, as well as the stress of being a caregiver of an injured child? How much does racial stress serve as a vulnerability for PTSD?

Experiences Across Race and Ethnicity. In a previous chapter, we discussed racial trauma, and the core concepts from that chapter articulate both the structural conditions that create unique risk for trauma exposure and the experience of race-based traumatic stress. One of the other core elements of a trauma-informed approach includes attention to cultural, historical, and gender issues; for this section, we will consider specific cultural and historical factors. Part of the reality in writing this chapter is that there are disparities in the knowledge base and implementation of EBPs for child trauma for racial-ethnic minority populations. For example, consider the dearth of studies specific to Asian American trauma despite the known history of state-sanctioned internment camps and other discriminatory practices. Even with our best efforts to understand the unique traumas experienced by immigrant youth (Cleary et al., 2018), the knowledge base for responsive intervention is limited (Cardeli et al., 2020). With this in mind, we will present an overview of unique experiences of trauma across racial ethnic minority groups with some information related to specific care approaches.

Studies have shown that Black and African American people have higher exposure to certain trauma types, such as community violence, hate crimes, and pervasive racism (Cheng & Mallinckrodt, 2015; Williams, 2018; Roberts et al., 2011). Consequently, the rates of PTSD are higher in non-white racial/ethnic groups than in Whites, regardless of the number and type of traumatic events (Alegria et al., 2013). Another study elucidates that coping styles matter; avoidance coping creates greater symptom presentations in Black and African American people (Weiss et al., 2017). When working with Black and African American youth and their caregivers, it is important to be mindful of their distrust and hesitancy towards mental health providers based on previous atrocious historical events (e.g., Tuskegee Experiment) and previous negative experiences (i.e., providers call child welfare agencies at a much higher rate, and there is prejudice regarding inner city youth as "troubled" children, prone to violence and crime). Especially for White clinicians, it is paramount to open the floor for conversations regarding the visible and invisible wounds of racial trauma (Rich, J & T. Corbin, personal communication), and allow oneself to practice cultural humility and curiosity regarding both the group and individual level experience of that youth. What makes this worth mentioning is that stigma can create barriers to access to care for minority populations, and avoidance coping is what perpetuates symptoms.

Oftentimes, it is the avoidance symptom that perpetuates the entire constellation of PTSD symptoms.

As mentioned above, the experiences of immigrant youth are unique from other child groups because of their experiences before migration, during their migration, and after migration/during settlement. An approach that has some data is Trauma-Systems Therapy for Refugees (TST-R), an adaptation of Trauma Systems Therapy (TST; Saxe et al., 2006; Saxe et al., 2015). TST considers the individual/family, community, and macro systems of a client's world, an approach that attempts to promote individual change but also to intervene at a social and structural level. In TST-R specifically, services are delivered in partnership with a cultural broker, much like a lay-counselor who is a community member with shared ethnic background with the client (Benson et al., 2018). This task-sharing approach has been used in delivery of other trauma EBPs outside of the United States (Dorsey et al., 2020). This team aims to enhance safety of the child's social environment, reduce acculturative stress, and help the child with regulation skill building (Benson et al., 2018). Early findings from an ongoing, multi-site program evaluation of TST-R show that it is a promising intervention for refugee children and adolescents, in particular those who experience acculturative stress and traumatic stress (Cardeli et al., 2020).

Trauma-focused intervention has been studied in Japan, and the insights from these studies demonstrate the need to understand a child's presentation through the lens of their culture. Kameoka et al. (2020) highlight that negative feelings such as fear, anger, guilt and shame are seen as undesirable and that Japanese folks avoid expression of these feelings; however, in the context of treatment, the families in the intervention study were engaged throughout the protocol. So, both points would be true; yes, avoidance of expression can be a cultural norm, but there is cultural flexibility that allows for engagement in trauma-focused treatments. Understanding culture can create better conditions for engagement of families and general uptake of the active ingredients of an evidence-based intervention.

As mentioned earlier, for more about considerations about racial trauma, please consult Chapter 2. In addition, there have been many current resources coming out of Dr. Metzger's Empower Lab, where she investigates Engaging Minorities in Prevention, Outreach, Wellness, Education, & Research. Her lab's work looks specifically at how to improve mental health treatment outcomes for Black and African American youth who are exposed to interpersonal and racial trauma. As you read the intervention section of our current chapter, reference the racial socialization strategies suggested in the article by Metzger et al. (2021).

Experiences of LGBTQ+ Youth. Sexual minorities will experience discrimination related to their sexual identities, and these affect external stressors and how those youth process those stressors (Russell & Fish, 2016). The LGBTQ+ community has been overlooked in mental health care that affirms their particular stressors, as a result of stigma or structural barriers. Roberts et al., (2012) report that sexual minorities have a risk of PTSD 1.6 to 3.9 times higher than heterosexuals, with child abuse victimization being a driver of traumatic exposure. Gender non-conforming youth tend to experience the most child abuse victimization among sexual minorities (Roberts et al., 2012).

Assessment of Trauma and Stressor Related Disorders

PTSD symptoms span intrusive and distressing memories of the event, avoidance of reminders related to the event, changes in mood and thought patterns such as negative emotional states like fear, anger, guilt, and shame, and hyperarousal (Spielman et al., 2020). For PTSD to be diagnosed, these symptoms must occur for at least one month. For Gaby, her symptoms map onto the criteria for PTSD: having nightmares every other day, feeling emotionally numb, avoidance of thoughts related to her traumas, and feeling irritable "all the time." We would need to assess further to understand if Gaby meets full criteria for PTSD; for this list, consult this SAMSHA (2014).

Avoidance is a hallmark symptom of PTSD. Oftentimes, it is the avoidance symptom that perpetuates the entire constellation of PTSD symptoms. Think of

Trauma recovery occurs in three phases, the acute phase (i.e., hours or days after the event); the peritraumatic phase (i.e., days to weeks after the event); and the post-traumatic phase (i.e., months after the event).

the avoidance model of coping: if someone avoids a scary-looking dog as they walk down the street, they feel better in the moment, and that relief reinforces their appraisal that the dog was scary. What happens the next time the child sees a dog? They will have anxiety or arousal, followed by avoidance.

In addition to avoidance, youth who have experienced trauma may demonstrate many other symptoms. Intrusion symptoms like flashbacks involve distressing memories of the traumatic event. When a youth is experiencing intrusion symptoms, they may appear distractible or as though they are "spacing out." Alternately, they may appear very scared in the absence of any identifiable stimuli in their environment. Young children may act out traumatic events in play.

Additionally, children who experience negative alterations in cognitions and mood may appear similar to children who are depressed. They may be forgetful about important events. They may present as pessimistic about themselves, other people, and the world. They may appear standoffish and have trouble connecting with others who are positioned to support them. Like Gabby, children with negative alterations in cognition and mood may appear numb and have difficulty experiencing positive emotions.

The symptom of "marked alterations in arousal and reactivity" may present in a wide range of ways. For example, some children who have experienced trauma are referred for behavioral issues and acting out. Without thoroughly assessing trauma history and PTSD symptoms, these youths may be misunderstood and mistreated.

Symptoms occur with developmental contexts. For adolescents, who are already vulnerable for at risk behaviors, trauma can increase risk taking even further. They may attempt to gain mastery over their symptoms or their situation. To borrow from the acquired capability theory of suicide (Joiner, 2005), being exposed to life threatening situations decreases the aversion that naturally comes to humans to avoid pain. For toddlers, tantrums become more frequent or more destructive. For school-aged children, there can be a withdrawal from generativity and social engagement, or externalizing behaviors because they maybe lack coping skills.

PTSD has various criteria, and it is important to note that because a person does not meet "Criteria A" which specifies the types of events that lead to PTSD, it does not mean that their experience is not meaningful or valid, or that it does not cause distress; however, to meet the official criteria for PTSD, Criteria A exposure must be evident. It is important to address that a child does not need to meet full PTSD criteria in order to benefit from trauma treatment (Cohen, 2017). The concept of post-traumatic stress symptoms (PTSS) helps us to consider other diagnostic constellations such as depression, anxiety, and behavior problems, when driven by trauma.

Assessment Tools

A child should have a semi-structured clinical interview conducted by a trained trauma clinician (someone who has worked with enough trauma-impacted youth to develop an expertise) and used self-report instruments to assess PTSD and other emotional problems that can accompany PTSD. Without a question, a clinical interview is essential and can be considered the "gold standard" in diagnosing PTSD and understanding a child's unique challenges.

When interviewing the child, family members, or teachers, use language that is direct and specific to the problem. Ask questions about observable changes like, "How has your sleep been? Have there been any difficulties falling or staying asleep?" Internal changes like intrusive thoughts can be captured in questions like, "How often do pictures of the trauma pop in your head when don't want them to?" Teachers can provide collateral in terms of classroom changes like disruptive behavior, withdrawal from peers, and drop in performance or attendance.

Measurement Tools and Rating Scales. NCTSN has a library of screeners for child trauma available for use, and they provide guidance on selecting an appropriate screener for your setting. The Child Trauma Screen (CTS) is a brief trauma screening measure for children (Lang & Connell, 2017), and it has been used in behavioral health, primary care, child welfare settings, and juvenile justice settings. It is a 10-item screener with excellent psychometric properties for use with children ages 6 to 17 (Lang et al., 2021; Lang et al., 2018). The CTS screens for potential trauma exposure and for trauma symptoms. The screener has cut points that maximize sensitivity and specificity (Lang et al., 2021; Lang et al., 2018). When choosing a screener for your setting, be sure to consider the age of child, whether parent or child report will be gathered, people/time resources to administer/score the screener.

A commonly used, open-access screener is the Child PTSD Symptom Scale (CPSS-5), a measure used for children ages 8 to18 to assess PTSD diagnosis and severity in the past month (Foa et al., 2001; Foa et al., 2017). The CPSS-5 has a trauma exposure screener to identify a Criterion A event, a set of 20 questions that assess for DSM-5 PTSD symptoms, and a set of 7 questions that assess for impact on daily functioning. The UCLA PTSD Reaction Index (PTSD-RI) is another measure that assesses for potential traumatic exposure and for the presence of DSM-5 criteria for PTSD among school age children and adolescents (Steinberg et al., 2004; Steinberg et al. 2013; Elhai et al., 2013). This measure requires a licensing agreement for use, and more information can be found here. For children ages 7 and younger, the Young Child PTSD Checklist

(Scheering, S. & Haslett, 2010) is an appropriate measure to use, as it focuses on parental observation of child functioning. For youth ages 18 and older seen in a pediatric setting, the PTSD Checklist for the DSM-5 (PCL-5; Weathers et al., 2013) can be used and found on the National Center for PTSD website.

Intervention for Problems Related to Trauma and Stressor Related Disorders

The treatments with the best empirical support for youth exposed to trauma are individual cognitive-behavioral therapy (CBT) and group CBT (Dorsey et al., 2017). Cognitive-behavioral treatments have more than twice the effect size of non-CBT interventions for post-traumatic stress symptoms, depression, and externalizing behaviors (Dorsey et al., 2017). Common elements of effective trauma treatments are psychoeducation, emotion regulation skills, imaginal or in vivo exposure, cognitive processing, and/or problem solving (Dorsey, 2016). There are treatments that work such as Cognitive Processing Therapy (Bohus et al., 2020), Dialectical Behavior Therapy (Bohus et al., 2020), Trauma and Grief Component Therapy for Adolescents (Saltzman et al., 2001), and Trauma Focused Cognitive Behavioral Therapy (Cohen et al., 2017). Cognitive Behavioral Interventions for Trauma in Schools (CBITS) is a group model delivered in the school setting and shares the same core elements as TFCBT (Stein et al., 2003). It has been designated as an effective program (highest level of evidence) by the NCTSN. Bounce Back is a similar model, but it is designed for elementary school children ages 5 to11 (Langley et al., 2015).

Timing matters for intervention, there is a difference in the immediate aftermath of a trauma or disaster scenario, and the time that follows “after the dust settles.” Trauma recovery occurs in three phases, the acute phase (i.e., hours or days after the event); the peritraumatic phase (i.e., days to weeks after the event); and the post-traumatic phase (i.e., months after the event) (Epstein et al., 2017). Psychological First Aid occurs during the acute phase, addressing imminent safety concerns and connecting the child to resources (Brymer et al., 2006). The Child and Family Traumatic Stress Intervention is delivered in the peritraumatic phase, and it emphasizes increasing the effective use of coping skills and building parent-child communication about symptomatology (Berkowitz et al., 2011; Epstein et al., 2017). The post-traumatic phase may be the most common phase of treatment known to clinicians, in which focus shifts to adaptive coping and mastery over the thoughts and feelings related to the traumatic event, typically delivered through Trauma-Focused Cognitive Behavioral Therapy (Cohen et al., 2012).

Predictability is the hallmark of trauma treatment. Engaging clients in a way that promotes transparency, safety, voice and choice, provides a solid foundation for the therapeutic process.

With Gabby, she was amenable to TF-CBT. This intervention is grounded in a phase-based approach that incorporates gradual exposure. The PRACTICE acronym spans across the phases of stabilization, exposure, and safety. So how do we approach Gaby who has been through a lot and who has seen many providers and seems to be stuck? Predictability is the hallmark of trauma treatment. Engaging Gaby in a way that promotes transparency, safety, voice, and choice, provides a solid foundation for the therapeutic process. Psychoeducation about treatment lets the child know that we as clinicians have no tricks up our sleeves and that treatment is not a forever thing. After learning about TF-CBT and how it could be helpful, Gaby said, “I guess I can try this out.” Race and ethnicity can be a big factor in engagement, and part of psychoeducation can include discussing racial barriers in past treatment and validating negative experiences Gaby may have had (Metzger et al., 2021).

With psychoeducation and trauma reactions, Gaby learned about the relationship between physical abuse and trauma symptoms. It was important to not lecture her and to bring in her experiences of “regular stress.” She knows how she felt after arguments or if she had to run to catch the bus. Stress can be helpful, but too much of it can cause problems. The clinician could bring in the notion of racial stress in these sessions, and racial socialization strategies can help to foster racial pride messages (Metzger et al., 2021). As an aside, clinical support tools such as worksheets and videos should reflect the patient as best as they can to encourage this positive racial messaging. For examples specific to black youth, consult the C.A.R.E. Package for Racial Healing available through Dr. Metzger’s Empower Lab.

__P__sychoeducation
__R__elaxation Skills
__A__ffect Modulation
__C__ognitive Coping
__T__rauma Narration & Processing
__I__n-vivo Mastery
__C__onjoint Parent Sessions
__E__nhancing Safety

The rest of the "PRAC" skills were catered to her needs; what are soothing skills that are feasible and relevant for her? What were the core feelings she felt before, during, and after the trauma? Were any feelings being left out, for good or for bad? Gradual exposure throughout this phase included naming her trauma as abuse, then labeling it as violence or being assaulted. In the instances of communicated racial trauma, Metzger et al. (2021) suggest using racial socialization in sessions in order to address any experiences of racism and discrimination in order to encourage affective expression and identify effective coping strategies for potential future discriminatory encounters. For example, coping strategies for API children can target potential microaggressions like "Ascription of Intelligence" or more overt discriminatory behaviors like the exoticization of Asian American women (Sue et al., 2007). These strategies may also overlap with the Enhancing Safety module at the end of treatment. Consider the pain and stress non-white youth face when they are asked "Where are you from?" or "Where were you born?" or given comments like "You speak good English," all of which communicate a sense of otherness and inferiority. As Dr. Cohen mentioned in her interview, we may not be able to cover all of the traumas a youth experiences, so our treatment should help to give a path forward.

Gaby was avoidant during the narrative. "Why should I write this if no one will read it?" This was an important point to join with her. "Who is an adult that you really care about that you feel like you have a bond with?" "I really like my case worker [child welfare], because she's been there throughout all of this." Gaby agreed that this person would be who she would share the story with, because reunification with her father was not a child welfare goal. The therapist acted as Gaby's secretary, writing what Gaby said. She had some distortions around, "No one cares for me; I can't trust anyone." For an initial draft, that was something flagged for the clinician to return to. Cognitive processing consisted of going back to those clinical flags and using techniques like Socratic questioning to get down to whether these thoughts were helpful or accurate. Gaby's narrative ended up covering themes of loss, the abuse itself, and the bouncing around from place to place.

"I would tell kids in my shoes to keep going; don't give up. I really didn't like doing this treatment to start, but I stuck with it, and it really has helped me. I sleep better and I don't get as mad as I used to. Talking about it with someone you trust really works."

Clinical Dialogues: Trauma and Stressor Related Disorder with Dr. Judy Cohen, MD

Judith (Judy) Cohen, MD is a Board-Certified Child and Adolescent Psychiatrist, the medical director of the Allegheny General Hospital Center for Traumatic Stress and children and adolescents at the Allegheny Health Network and Drexel University College of Medicine in Pittsburgh, Pennsylvania. She is also a co-developer, with Anthony Mannarino and Esther Deblinger, of trauma-focused cognitive behavioral therapy, commonly called TF-CBT.

Sean E. Snyder, LCSW: Dr. Cohen, you are a hero to me and many of us in the child trauma world. Thank you for sharing your thoughts regarding child trauma; we will cover topics of engagement, assessment, and intervention. With engagement, we are curious about two things for your practice: a) the actual linkage to treatment when folks are referred to you and b) the strategies and practices of joining with the client in the therapeutic process. First, with linkage and access to trauma services, what does the process look like for your clinic from outreach to initial patient contact?

Judy Cohen, MD: Our clinic is somewhat different from the typical clinic that provides TF-CBT, as our clinic solely provides TF-CBT to children who have experienced trauma, whereas most clinics that provide TF-CBT probably are general outpatient programs that provide a broad scope of service. So, engagement will look a little different because we are taking a much more selective population from the beginning. We would screen them and only take kids into our clinic if we knew they had or if we're sure they had experienced trauma. We are more of a specialty clinic as opposed to other programs that are taking kids, no matter what.

Snyder: Great points. So readers should be aware that workflow will vary from place to place. I think there are many lessons to be generalized from your clinic, so we will start with your clinic and build out from there with these questions. I am thinking about the general process of assessments with children now. For instance, when we do ADHD assessments, before the parents come, they'll complete rating scales like the Vanderbilt. For your child trauma clinic, do you have parents do some preliminary scales or other data collection measures?

Cohen: We've had two different clinics. In our current iteration, we're a center for traumatic stress. We've been here for 26 years and prior to that, we were a specialty clinic and while we saw a lot of different traumas, we were focused more on sexual abuse. In both of those iterations, we spent a lot of time doing outreach, spent a lot of time educating our referral sources in the community about what we did, the kinds of services we provided, and what kinds of kids were appropriate to refer to us. As a clinic, it is important to engage families but also the other providers who have contact with families prior to referring to us. Thankfully, there are more clinics that provide trauma focused treatment or do a lot of education (NCTSN in particular). Nowadays, we focus less on engaging and educating the providers and have turned our attention more to family work.

The whole approach of TF-CBT is speaking the unspeakable, making new meaning and so forth, and it's just as important to help therapists themselves understand that the trauma has already happened.

But back then, hardly anybody did it, so we trained everybody from family court judges to pediatricians to police officers to family, social workers to other therapists about what kinds of kids were appropriate. And the multi-disciplinary teams, once they had developed child advocacy centers, we supported them around knowing what kinds of procedures needed to happen before it would be appropriate to refer kids to us. For example, if there was an allegation of sexual abuse, we wanted them to have a forensic evaluation before they came to us so that we could focus on the treatment; we're not doing the forensic evaluations. In Esther's program, for example, they have both a forensic program and treatment programs, so they can do both.

For that evaluation part, we would have them do that before they come to us for treatment. So that's been a long educational process related to child protective services. After 30 years or so, the community knows what kind of kids to refer to us and at what point in the process. Occasionally we will get calls from families or even pediatricians, and we'll have to provide that education. In the age of the COVID-19 pandemic, we do almost everything by telehealth. Sometimes we will send assessment tools and instruments to the family for them to fill out ahead of time, but we're going to look at it during the assessment. It's not screening before they come to us. That's part of our assessment process, but our intake person is our outreach person. We have a very small clinic for everything we do, so it's the same person. She goes out into the community virtually now but in normal times, she goes out into the community and is talking to different organizations to educate them about the kind of work we do, the kinds of kids to refer to us.

When families or referral sources call, she's the one they talk to so she will get a lot of information on the phone about the kinds of traumatic experiences that child or teen has experienced if it's a team. She'll talk to the team as well, explain a little bit about the process, and get some information about the kinds of symptoms they're having. We try to give them some hope and give them some information about what will happen during this process.

Snyder: You are taking the idea of trauma-informed care right from that initial screening, giving them the predictability of what to expect. So, with outreach and initial engagement, it's less about clinical psychoeducation and more about telling them about the process, which can probably alleviate some of that anticipatory anxiety and increase some of the hope that you mentioned.

Cohen: And of course, we are assessing safety and evaluating if the child is safe, if it hasn't been reported. Safety is part of trauma-informed care as well.

Snyder: It seems that there is a lot of education with the family, and there's a lot of preparatory work and education you've done with communities. That highlights that systems need to work together even for just one family.

Cohen: I want to add that we collaborate. I'm a member of two different multi-disciplinary teams, and I'm familiar with different organizations in town. It can be a matter of referring to a child who is not appropriate for us. So, we are very collaborative. We're not competitive; we want what's best for the child.

Snyder: There are no trauma champions, where it's just one person doing this kind of care; it really takes networks working collaboratively.

Cohen: Our goal over the last 30 some years is to try to develop a network in our community. There are unfortunately way too many children who need these services, so we're reaching for a small number of children. There are always more children than can fill our services.

Snyder: And that points to the idea of scalability; with this intervention, how do we increase access and reach and penetration in care systems?

Cohen: Yes, and keep in mind, there are other interventions that work, for instance Child Parents psychotherapy or Alternatives for Family CBT. So, there are a lot of different alternatives now, which is fantastic. And certainly, we're also trying to identify children where trauma is not the first priority to address. Sometimes we don't do that until the assessment or sometimes in the middle of treatment. If we can do that at the initial phone call or before the assessment, that's going to save the family a lot

> *Telling the story is a way of going through all of those things, retrieving those memories and describing them to someone who you can trust, who is not emotionally involved in it like your caregiver is, and being able to sort through them and then organize them in a way that is more helpful and more accurate.*

of hassle and having to come in to spend two hours to do the assessment. If we can do that, immediately we can say, “It really sounds that although your child has had traumatic experiences, this other challenge probably takes precedence. Let us point you in the direction of doing this first, getting these behaviors under control.” Maybe they really need to get these medications sorted out first, or they’re suicidal, and they really need to address that first.

Snyder: That was very helpful to understand how families get to you and the nuances of that process. So, let’s kind of fast forward then. Families screen in, and they are appropriate for treatment after the assessment. What I see a lot of new trainees or students do is that sometimes they’re afraid of re-traumatizing the client by talking about the trauma itself. There’s a fear of exposure from the clinician at times. What would you say to folks that have that worry of re-traumatizing the client by talking about it?

Cohen: Well, that’s sort of the whole approach of TF-CBT, speaking the unspeakable, making new meaning and so forth, but it’s really important to help therapists understand that the trauma has already happened. The child has already gotten through that. And for some children, trauma is ongoing, but they’ve already survived at least one trauma experience. In many cases, they’ve survived many traumatic experiences, and in many cases, they’ve already had the courage to disclose it and tell somebody about it and go through a forensic evaluation.

But importantly, that experience, that memory is already there, and telling you, the clinician, about that is not going to be any harder than having survived that experience. They’ve already done the hardest part, which is going through it. I use the metaphor of cleaning out a closet. So, if you have a messy closet that’s stuffed full of stuff, and the door keeps slipping open, and the stuff falls on top of your head, that’s these disjointed trauma memories that are coming at you. The trauma reminders have not been sorted out; they have not been organized. They’re intrusive memories that you try to avoid, and you have maladaptive beliefs about them, and there’s negative cognition and hyperarousal. You’ve got all of these trauma symptoms because you haven’t addressed them, but you still remember them. It’s not that you don’t have those memories; you’ve had them. It’s just that they’re very disjointed and disorganized. They’re intrusive.

And that’s what children—or adults, for that matter—who have experienced trauma are dealing with. If we help them to make sense of that, if we give them skills and a way of mastering those memories or making sense of those experiences, it’s much like cleaning out that closet. You have a way of organizing that closet by going through it, throwing out the things that you don’t need, those maladaptive beliefs, and then organizing those memories and those reminders in a way that makes more sense.

Telling the story is a way of going through all of those things, retrieving those memories and describing them to someone who you can trust, who is not emotionally involved in it like your mother or your caregiver is, and being able to sort through them and then organize them in a way that is more helpful and more accurate. Then you can rearrange them, much like sorting through the stuff in the closet. Then you can open that closet or talk about those memories when you need to. And you might not always be able to control when you open the door; trauma reminders may come at times when you can't control it.

But even if that door does open, at least you have reorganized those shelves, the things are going to fall on your head, and you can look at it. And you have some control over what's in that closet and how it's going to show up, so it's not going to be any surprise. It's going to be much more organized. So that's a metaphor for families, but it's also how we help young therapists or even experienced ones who are hesitant, who may be thinking, "If I do this, it's going to be painful and difficult and very traumatizing." The child already has those memories; the problem is they're disorganized. They're frightening and overwhelming. Well, we're going to help them sort through them and speak about the unspeakable to make new meaning. But we're not going to do it today or even the first time they come in. They need some skills; they need a pathway to follow.

And that's what this treatment does: it gives you a pathway.

Snyder: A pathway decreases uncertainty to how to go about dealing with the memories. With the closet metaphor, I'm thinking of when adults ask kids to clean up their room, and the kids (and maybe this is more personal history) shove everything in the closet and the door is barely able to close. With it ready to burst, you don't even want to touch it, and you spend a lot of time thinking about the door. And if you need to open the door, you just throw the stuff back in and hope for the best. Great metaphors.

Cohen: It's like tidying up your room. It does take some work; it takes some organization at the beginning. At the end, you can see where everything is, and you can sort it out. You can find it when you need it, and it works better for you.

Snyder: Let's take an example with our favorite age group. How do you approach adolescents or even kids in middle childhood that are so avoidant, and the last thing they want to do is be there, talk to you and certainly not talk about the exposure? I know that that exposure piece comes much later and that you do spend a lot of time focusing on skill building and rapport building. Do you have

Clinical judgment is particularly important when considering avoidance. It could be avoidance of the trauma itself, or it could be they don't want to talk to you at all. And that's not so much avoidance, as their opposition or they don't want to be here.

any particular strategies that you use with adolescents who may really present as if they just don't want to be there at all?

Cohen: Sure. The typical scenario that we have is an adolescent who has experienced multiple traumas, who has been in multiple placements, who has a challenge with trusting you, and who does not want to talk about their trauma experiences and perhaps wants to go back to their birth parent or wants to go back to a prior placement and doesn't want to tell you about what's going on because they think it will be problematic if they disclose something about what's going on because child protection or the judge or somebody will hold it against somebody if they're honest with you.

One of the tips I share with trainees is, first of all, being transparent and starting with recognizing, "You don't know me, I'm a stranger. There's no reason for you to trust me. And asking why or how I can be helpful, or what do you want, what's your goal? If I could help you with something, what would it be?" Sometimes kids will say, I just want to go back to my placement, or I want to go back and live with my parents. I'm really pissed about being here, whatever it is.

That might give an opening to either doing a really quick timeline about where you lived or what are these placements you've been in, and asking about "What's your understanding of why you were removed from that place and put here?" Even if they give a story of "The judge is a jerk or "Child Protection Services have just fed me lies all my life," that might open a door to at least asking, where did they get that information? What is it like for you to be away from your parents? So, you might tap into the traumatic separation aspects, even if you're not going to get them to acknowledge or talk about the alleged domestic violence or physical abuse or whatever they don't want to talk about. At least you could identify some legitimate problems they're having with being taken away from their parents, which might be a starting point. And if they see that that's valuable to them, it might be an engagement point for you to start some kind of working relationship with them.

Snyder: I think that you can apply that strategy to initial engagement but also throughout the course of treatment. Helpful things to think about if you're going through a protocol, and you hit that plateau, or you hit that resistance. They are great ways to get to the function behind the behavior.

You mentioned great strategies for engagement, and there is a lot of great data coming from the engagement process; in a way, it's a pre-assessment. When you formally do an assessment, what are some of your go-to instruments?

Cohen: We use free instruments, especially because we tend to train low resources or public mental health clinics. We use the Child PTSD symptom scale for DSM-5 because it's free, and I think it's very reasonable for kids from eight years old up to teenagers. When we do see transition age youth, we use the PCL-5, so for older teenagers and young adults. For the younger kids under seven, we have the parents fill out the Young Child PTSD Checklist, as it follows the DSM-5 criteria. These three are basically our go to instruments.

Clinical judgment is particularly important when considering avoidance. It could be avoidance of the trauma itself, or it could be they don't want to talk to you at all. And that's not so much avoidance, as their opposition, or they don't want to be here. Maybe they don't trust you at all. So, there can be a lot of iterations of why they're not very talkative or not very cooperative or not very engaged in the process.

Part of good supervision is helping clinicians figure out why the child is not talking. Are they just not talking generally, or are they just not talking about trauma? There's a difference. Depending on how avoidant they are and what they're avoidant of, then you have to gauge clinically if they're really avoiding trauma. If that's the case, then that's going to affect how they're going to report certain symptoms.

And then even on the self-report instruments, obviously there's overlap between what's on the scale and general symptoms not specific to trauma. We talk about these as the "second page" symptoms (on the CPSS-5). A lot of those symptoms overlap with DMDD or depression or conduct behavior problems. So, consider if most of their score is racking up on the second page or on those overlapping with other disorders. We have to take that into consideration as opposed to the more trauma specific items. How much of this really is trauma specific versus other kinds of comorbid problems. And that's where our history taking and clinical skills come into play.

Snyder: Very important point there, because more often than not, they're probably not just dealing with a traumatic experience. Especially in our Community Mental Health clinics, there's more than one presenting issue.

You've already mentioned a couple of treatments that can be helpful with youth and traumatic exposure such as TF-CBT and AF-CBT. Youth present with complexity of needs and some make quicker recoveries than others, and I've seen that firsthand with TF-CBT. How much is enough treatment, thinking about what dose of treatment is needed? I've had youth that do well with just psychoeducation and skill building; others need full protocols.

I think it's really important to focus on the proportionality for those youth with complex histories, and one of the biggest mistakes that therapists make when working with a youth who has really complex traumas, really severe trauma types, or hundreds of episodes is, "I had to fit all this in. I have to give them a chance to talk about all these trauma types."

Cohen: Yeah, it's a great question.

Sean, you work in juvenile justice and for really profoundly complex traumatized youth, I would say probably most of those youth could benefit from the whole model, just because of the complexity of their experiences, how many they've had, how long it's been going on, and the profound nature of how that's changed the way they look at themselves and other people. I think they would get some benefit from the skills, and something is better than nothing. And don't let the perfect get in the way of the good.

I do want to mention that after 9/11, there was a big study done with around 500 plus kids, most of them inner city, African American and Latinx kids. They were looking at exposure to 9/11, and youth reported that their main trauma were interpersonal traumas like child abuse, domestic violence, community violence, and other big hitters. So even though, yes, they were exposed to 9/11, that's not what was bothering them. They had multiple traumas, and they were the private, typically interpersonal traumas.

So, among those children, the mental health response was looking at how to triage when we have a large-scale disaster, considering what level of treatments is going to be best, a matching algorithm basically. In terms of TF-CBT, they were investigating what level of symptoms would get just the practice skills (around four to six sessions) work versus the whole model for 12 to 15 sessions.

They found for children who had mild to moderate symptoms that they experienced an improvement of about nine points, which in the DSM-IV days was a reasonable improvement down to about normal levels. So that worked well, just the practice skills, about four to six sessions, whereas children who had more moderate to severe PTSD symptoms needed the whole model.

And that makes perfect sense because the more severe your symptoms are, the more likely you are not to get that much better with just the practice skills. But they did. And those kids with more severe levels of symptoms experienced twice as much improvement, but they had further to go.

Those findings would suggest that for kids who have lower initial symptoms, the practice skills alone can be good enough. Mid-treatment scores require ongoing conversations with the family. Even if they improve, my instinct says there are a lot of kids that they would be better off to continue and do the whole thing. Their real difficulties might not show up on their CPSS score. I think you would probably need to look a little deeper and see. Do they still have maladaptive cognition? Negative cognition can really do a lot of damage, and that doesn't really get corrected until you do trauma narration and processing. So, I would say it depends on which items are elevated on the CPSS. It's not just the score. An analogous example: let's say a youth with depression is improving on measures and has suicidal ideation; that's one item, but it could be a really important item.

Snyder: Yeah, this reminds me to think also where the child is developmentally because when we look at adolescence, their thinking is more complex, and they will need some processing to unpack more complex thoughts. But with youngsters whose thinking isn't as complex I wonder if the cognitive coping

PRAC skill could clear up some things for them. So, the theme of this part of our conversation is that small doses can make an impact, but consider the multitude of clinical factors in making treatment decisions, not just the scores.

Cohen: The other issue is, where's their avoidance? Some kids after four to six sessions, if their avoidance has really improved because you've done such a great job of engaging them and they trust you more, their score is going to go up. But it really means they've improved, not that they've gotten worse. Whereas other kids, if they're still really avoidant, their score might still be kind of low. That doesn't mean they're ready to start treatment. It means they really need more treatment. So, you have to be really clinically astute to figure out what does that treatment score mean.

Snyder: With the back end of TF-CBT, the narrative exposure, I immediately think of the youth with complex trauma or history of multiple placements or polyvictimization. They'll have a lot to tell right and part of the technique in the narrative is to focus on themes so it's not the whole life story. The question I have with these youth is how long is too long with doing the narrative work? In the protocol, typically six sessions are the maximum. How long is too long with narrative work?

Cohen: I think it's really important to focus on the proportionality for those youth with complex histories, and one of the biggest mistakes that therapists make when working with a youth who has really complex traumas, really severe trauma types, or hundreds of episodes is, "I had to fit all this in. I have to give them a chance to talk about all these trauma types." And the therapist is pretty overwhelmed. The kid is pretty overwhelmed, and the therapy is not structured enough. And I would say the more complex and profound the trauma is, the more that a youth needs that structure and guidance of, "we're not going to do this forever. This is only going to be six or seven sessions." Keep in mind the maximum is 24-25 sessions at the very most for the whole model. So let's say you've taken 12 sessions for the practice skills and you take say eight sessions at the most for trauma narration and processing (it's not right for the narrative). It's a five or six for telling the story, and then you have three or two or three for the processing, you're up to 20 sessions. Then you only have four sessions for conjoined sessions and in vivo work, and then enhancing safety, which is also going to take some time.

You have to look at the proportionality: how are you going to divide that up for sessions? More importantly, is eight sessions really the right amount for this youth? Are they going to be overwhelmed with that? And how can I help work with, as the copilot, structuring this narrative and this narration process so that it's not overwhelming? If the kid looks at this as, we're going to be doing this for two months, that's eight weeks, that's eight sessions, and they might start missing appointments. They might start saying I can't do this for eight sessions; six might be a lot more palatable or even five. Five is just one more than one month.

This is not prolonged exposure. They do not have to tell every detail about everything that ever happened. They have to speak the unspeakable, and they can choose this was the worst, or this is the thing that I've never told anybody about, or this is the thing I'm most ashamed about.

So how can we structure it? Maybe it's one session to talk about sexual abuse, it's one for the domestic violence, then one for when my parent was murdered. That might be a lot more containable for this kid. You need to be thinking about not just how many things happen and how much time they need, but how much can they manage? What is a safe holding environment for them? They don't have to tell you about everything they have to talk about, perhaps just the most striking example, and it will generalize. You don't have to get everything in.

Snyder: Absolutely. And again, going back to the closet metaphor, we're just trying to organize it to get something that they can actually use; that's an adaptation. Like you said, eventually, they will probably generalize a lot of the learnings they get from processing those index events. Yeah, it can clear up some things later on in their own time,

Cohen: Yes, this is not prolonged exposure. They do not have to tell every detail about everything that ever happened. They have to speak the unspeakable, and they can choose this was the worst, or this is the thing that I've never told anybody about, or this is the thing I'm most ashamed about. It doesn't have to be every single episode. So, on the whole, would say eight sessions of trauma narration and processing is too much for pretty much every kid. From experience, usually six is what the youth can tolerate.

Snyder: That makes sense. Generally, the kids that I have treated with complex trauma, and well most youth with any trauma history, they just want to be heard. I think that part of the job of the clinician is to give them the space, and they will take it because they think "someone's actually listening and not judging me." There is a responsibility to open the space but to contain it, and I'm reminded of Carrie Epstein here: we don't want venting because that shows the prefrontal cortex is disengaged and that is not helpful. They aren't learning to regulate. So, your idea of proportionality is a great guide of how we contain that for them while still attending to them, of being empathetic and joining with them, without overwhelming them.

Cohen: And I think, giving them the context of what the purpose of this is, is really important. It's to organize to give you a way of speaking about the unspeakable and making meaning and giving you a roadmap for how to do that. And you may, when you go home, or after therapy, you may be doing this for a lot more of the episodes that you've experienced. This is not the end of the road; you have the rest of your life. To do this, you don't have to close the door on this and be finished with it forever, although a lot of people are. The idea is that it will generalize.

It's really important that they take away that this is a process, and you learn how to do this, and you can continue to do this for your recovery. Kids want to just say, "I'm done with this. I'm going to burn it. I'm finished with it. I can close the door on it. The closet is finished now." But some kids will write things in their journal and do things outside of therapy, and they will see things differently as they age, where they see themselves developmentally. It's like a slinky that unfolds: here I was at 15, 25, 55 years old. It takes a long time. And that's life. Life is a long time. And I think, if they trust you, which hopefully most kids will at this point in therapy, you are able to say this is enough processing or narrative. I think sometimes they don't trust themselves enough to say this is all you need.

Snyder: I'm thinking of what's next or what's outside of therapy with the kids that I see in detention. When they leave me, they're going back a lot of times to the neighborhoods where it isn't very safe. The likelihood of multiple exposure is very high for these kids, so if they are able to generalize lessons learned, they can have something protective in the face of new stressors. And that leads me to ask: what does the evidence look like for different populations?

Cohen: We do have some new data for Hispanic youth in Puerto Rico on that, and it shows effectiveness that's very strong. We have the demographics in Pittsburgh and Stratford, New Jersey. There haven't been as many black and Latino kids in our randomized trials, but we had an overrepresentation relative to the general population of Black kids in our studies. We found no differences between African American and Caucasian kids in our outcomes. It's equally effective. We had a pretty good representation, and all of our randomized control trials have African American kids, and so that's probably 1000 kids out of all of our nine randomized control trials. We have international data as well. We have several studies in Africa, Japan, and European countries. So the model is pretty generalizable. We certainly have implementation manuals for American Indian/Native American kids and LGBTQ+ kids, and we have some pilot data for those populations as well.

Admittedly, we don't have large samples of hundreds of kids in randomized control trials, yet we welcome those. While we don't see a lot, we see some. Dr. Metzger, who is psychologist, has worked to incorporate racial socialization for Black families, and we're hoping to work more with her on developing an implementation manual and gathering data for the racial injustice that Black families experience and specifically addressing those issues because it's certainly an ongoing issue for many, if not most Black families in the US. But today, we don't have any data specifically to address that particular pervasive kind of trauma.

Snyder: Dr. Metzger's study is going to be very, very powerful in moving things forward. There's a lot of promising things; it seems like a lot of excitement around making adaptations and being responsive.

Cohen: We're so grateful to all 70 some trainers and many consultants and supervisors who are further advancing the data we have. And I know that you did a study in juvenile detention with TF-CBT. It's so great that there are so many certified therapists that are doing such great work to further our knowledge and just our clinical wisdom about how to use our model in a variety of settings for different populations of youth and families experiencing different kinds of traumas. So, it's really wonderful we've learned so much from all of you, and we hope that that continues to expand the ways that we can help children who experienced trauma.

In closing, I do want to mention just a little bit about our telehealth applications considering that is how a lot of people are operating these days. We have a small pilot that has less than 20 kids, but we just did publish a much larger pilot that has close to 80 kids using telehealth in schools and at home. It had really positive outcomes, and the best part of it is that it's exactly what we're finding in our clinic. There's a much lower dropout rate and higher retention rate of course because families really enjoy it; they don't have to even get dressed, and they don't have to leave home. And we're finding that in our clinic, the outcomes are comparable to what we found in our randomized trials, very good outcomes in terms of PTSD, but also higher retention rates in treatment, less than 10% drop out. So, it's really getting very good for including minority families, and hopefully insurance will continue to pay for it.

This is not the end of the road; you have the rest of your life. It's really important that they take away that this is a process, and you learn how to do this. You can continue to do this for your recovery.

The challenges, of course, for families, and we're encountering this all the time, is when they have a loss of electricity, or they don't have computers, or you can't share your screen. It requires adaptation on the therapist's part; you have to learn to send stuff ahead of time or be creative or talk them through stuff or just do without all of the creative nice neat things and just use your clinical skills. I mean, we're basically doing therapy with some people just over the old-fashioned telephone. Because it is manualized, it lends itself to a balance of fidelity and flexibility.

On our certification website (which is TFCBT.org) you'll find a telehealth implementation page, and the wonderful folks at MUSC developed a three-hour webinar to help people who don't know much about how to use computers. It's just a primer basically about how to do TFCBT by telehealth. There's a lot of information on how to select a platform, how to share confidentiality, how to figure out privacy for kids of all ages, how to engage families, how to send materials, and how to go through each component and implement it via telehealth. So, it's really great, a lot of great resources.

We've also worked with Sesame Street to figure out resources for younger kids and how to adapt what they have with Sesame Workshop. We are trying to figure this out to help our families.

Snyder: And that's where the networks come into play, so we're all doing it together to move things forward and be responsive.

Cohen: It's just another example of how collaboration works better, and cooperation works better than competing, too. Our goal is just to help kids recover after trauma and share what we have learned. We are all in this together, and it takes us all cooperating to best help those families that need it.

Things Clinicians Should Know

Trauma and PTSD are not the same thing; PTSD is a specific disorder that can happen after exposure to a potentially traumatic event. Not everyone will go on to have PTSD after a trauma (less than a quarter do).

There are many emotional and behavior problems that can occur after a traumatic event. Be mindful of challenges like depressive withdrawal or anxiety disorders that can occur in the presence of PTSD or other trauma/stressor related disorders.

Most treatment for problems after trauma focus on engagement, as opposed to avoidance of reminders, stabilizing with skill-building, and some sort of exposure work. Safety is always first!

Common Elements Approaches

Psychoeducation: about traumatic events, traumatic stress symptoms, trauma reminders, the protocol for treatment

Relaxation skills: for use in the presence of trauma reminder, including during exposures

Cognitive coping: using a mental activity to manage the stress of a trauma reminder e.g., identifying automatic negative thoughts, using positive self-talk

Praise: Highlight non-avoidance behavior related to trauma reminders (even about coming to therapy!).

Exposure: imaginal exposure happens during the narrative, in-vivo are the real life reminders

Open Access Assessment Tools

Child Trauma Screen (CTS)

Child PTSD Symptom Screener (CPSS-5)

PTSD Checklist for the DSM-5 (PCL-5)

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12

Chapter

Disruptive Behavior Disorders in Youth

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"I don't care what you think, you can't tell me what to do! I'm not doing this schoolwork and I'm never going to do anything you say!" James just went into one of his typical outbursts at his school, and he knows that he will go to the counselor's office because of it. "I'll just let myself go to the counselor; I don't need you to tell me." On his way out, he uses the marker in his hand to leave a thick, dark line across the teacher's desk.

James's teacher and parents would tell you this has been going on for quite some time now. His mother said "He was a colicky baby, and he just never could fit in at his pre-school. We had to go to many places before kindergarten. We got him an IEP, but even still, I just don't know what to do anymore. It makes me feel depressed. His older siblings didn't give us this trouble. I guess it was all saved for our youngest. We just do this dance over and over again, and we're just burned out."

Overview of Disruptive Behavior Disorders in Youth

Mental health challenges can pose problems for social integration (Sijbrandij et al., 2017) and the main developmental tasks of children are to properly socialize, develop networks, and cooperate in group settings (Winiarski et al., 2020). As we see with James, his early social life and developmental tasks have been largely disrupted by his problem behaviors. The most common disorders in children tend to be externalizing (Erskine et al., 2015), which can disrupt the main developmental tasks of children. Externalizing disorders are often characterized by problems with regulation of action, where there is difficulty managing impulses, self-regulation of affect, and problem-solving skills (Shader & Beauchaine, 2020). Externalizing disorders present on a spectrum that ranges from problems such as impulsivity, aggression, and substance use, or from diagnostic categories including attention deficit/hyperactive disorder (ADHD), oppositional defiant disorder (ODD), and conduct disorder (CD; Shader & Beauchaine, 2020).

For James, these problems are extending beyond the typical age for externalizing problems, and it can be inferred that the outbursts are frequent and big enough that there is an impairment in his functioning. Without proper intervention, these problems can create disruption in the many systems of James's future.

Prevalence of Disruptive Behavior Disorders

Externalization is typical for children ages 2 to 3, fitting the developmental appropriateness of testing limits, learning about the world, and being shaped by social and behavioral norms. Externalizing problems beyond these early years (i.e., 3 years old and beyond), becomes problematic, as they can predict negative health behaviors later in development, such as substance use and delinquent behavior (Pardini, 2016; Winiarski et al., 2020). One of the biggest predictors of delinquent behavior is the presence of problematic behaviors in childhood (Pardini, 2016).

The main diagnostic categories for problematic externalizing behaviors are ODD and CD. These diagnoses have a high global prevalence, and oftentimes, disruptive behavior is one of the main reasons for referral to services (Waddell et al., 2018). There are shared etiologies within the spectrum of externalizing disorders, warranting the attention of transdiagnostic intervention application (Shader & Beauchaine, 2020).

Labeling theory assumes that labeling someone as deviant or a problem child makes the person more likely to continue to have acting out behavior.

Recent estimates of the prevalence of ODD and CD have a range of 3 to 5%, with a combined prevalence of ODD/CD estimated to be 6.1% (Boat et al., 2015; Riley et al., 2016). Most of the studies are estimates because there is no population level prevalence data, and community samples can show upwards to 16.1% prevalence of ODD (Boat et al., 2015). Data from SSI allowances show that there was an increase of the rate of SSI recipients for both ODD and CD (Boat et al., 2015). Lifetime prevalence hovers around 10% in adult community samples, with similar rates for both males and females (Boat et al., 2015). Comorbidity is typical for children with either ODD or CD. ADHD co-occurs in 14 to 40% of children with ODD, with anxiety being present in 14% of ODD cases (CDC, 2020).

Development of Disruptive Behavior Disorders in Youth

The developmental systems perspective considers biological, familial, psychological, and environmental processes as facilitators for problem behavior. Our umbrella theory can accommodate the various explanations of problematic behavior. Social structure theories, or functional perspectives, all stress that externalizing problems result from the breakdown of society's norms and social organization (University of Minnesota, 2016). A popular explanation is social disorganization theory, which defines social disorganization as a weakening of social institutions such as the family, school, and religion that in turn weakens the strength of social bonds and norms and the effectiveness of socialization (University of Minnesota, 2016). Social process theories all stress that crime results from the social interaction of individuals with other people, particularly their friends and family and the influence they have on us, as well as the meanings and perceptions we derive from their views and expectations (University of Minnesota, 2016). Hirschi's social bonding theory focuses on family and school processes. When the family relationship is warm and harmonious and children respect their parents' values and parents treat their children firmly but fairly, children are less likely to commit antisocial behavior during childhood and delinquency during adolescence (University of Minnesota, 2016). Schools also matter; students who do well in school and are very involved in extracurricular activities are less likely than other students to engage in delinquency (Bohm & Vogel, 2011). Labeling theory assumes that labeling someone as a deviant or a problem child makes the person more likely to continue to have acting out behavior (University of Minnesota, 2016). This result occurs, argues the theory, because the labeling process gives someone a negative self-image, reduces the potential for prosocial activities like employment or extracurricular interests, and makes it difficult to have friendships.

Externalizing disorders tend to have multiple risk factors that accumulate over time. Some of the common biological factors include nicotine use by parents, prenatal nutritional deficiencies, and developmental delays (Riley et al., 2016). Psychological factors range from insecure attachment, harsh parenting practices, parental psychopathology, and inconsistent parenting (Riley et al., 2016). Social factors include poverty, community violence, peer rejection, and poor academic achievement (Riley et al., 2016).

Developmental Systems Considerations for Disruptive Behavior Disorders

Bronfenbrenner's (1977) ecological theory finds direct application here. It highlights the transactional cycle that contributes to externalizing problems, as it explains what begins in one system (e.g., the family system can translate to the school system or neighborhood system). Deviant peer relationships and neighborhood disorganization or distress can influence children and serve as an attractive outlet for problem behaviors, as these deviant networks normalize problematic behavior (Shader & Beauchaine, 2020). Family influences and power dynamics with authority figures such as school personnel play a significant role with the development of CD, often acting as the starting points for problem behaviors that are later generalized to peers (Shader & Beauchaine, 2020).

Costello & Klein (2018) conducted a study that revealed that more than 80% of children in the United States witness intimate partner violence (IPV). Exposure to community violence is a major risk factor for externalizing disorders (Dinizulu et al., 2014). These behaviors can be precipitated by early traumatic or adverse childhood experiences, inconsistent parenting and power struggles with authority figures at school or affiliation with delinquent peers (Pardini, 2016). The risk factors for these disorders can go beyond the treatable symptoms in the therapy office (Waddell et al., 2018) and unfortunately increase the likelihood of involvement with the justice system (Becker et al., 2012).

The transactional cycle that contributes to externalizing problems describes the pattern of what begins in one system (e.g., the family system can translate to the school system, or neighborhood system).

So, what's going on with James? We can see there's some difficulty with school and the family system. A key component here can be time, or what

Bronfenbrenner calls the chronosystem (Bronfenbrenner & Evans, 2000). Are his parents experiencing new stressors that weren't present when raising the other children? Are the school staff judging him on the standard of the "normal" experiences they had with James's siblings? Lastly, we should consider what is seen as developmentally appropriate in the context of culture or the family system, and as we've seen, James's parents have had a prior understanding of the development of their other children. Based on this family's experiences with their other children, James's behavior is seen as not in line with developmental expectations.

Experiences Across Race and Ethnicity. Some literature suggests that despite similarities of prevalence of ODD across racial groups (Boat et al., 2015; CDC, 2020), the practice of diagnosis in real settings show that Black children tend to have higher diagnoses of ODD (Ballentine, 2019). There are some factors to consider with this claim. Clinician bias can confuse culturally bound behaviors with psychopathology, and often Black youth can be misdiagnosed as a result (McNeil et al., 2002). Even in the realm of disruptive disorders, racial and ethnic minority youth tend to receive a diagnosis of ODD opposed to a disruptive behavior disorder (Fadus et al., 2020). Diagnosis is complex, having to account for the various biopsychosocial factors; however, the reality is that diagnostic disparities still exist.

White clinicians may overlook the experience of preferences of black and brown parents (Ballentine, 2019), or even the experience of those in poverty who tend to use more authoritative parenting practices (Ballentine, 2019; Fadus et al., 2020). This inequity in the mental health treatment of Black and Brown children points to the larger inequities seen in the US (Okeke, 2013), and it can be historically situated within the accounts of medical experimentation on Black people and the overall lack of proper care and compassion at the hands of predominantly White medical professionals (Okeke, 2013). Because of the distrust between Black and Brown people, and White medical professionals, Black and Brown people tend to be wary of seeking mental health support which can further exacerbate mental health outcomes.

Take a pause to reflect on your own interpretation of James. Did you envision him in a particular race or ethnic group? Be aware of culture, power, and privilege, as well as your own biases and prejudices when working with communities of color. Oftentimes, when working with Black and Brown people, they feel disempowered due to experiences of perceived racism. This not only perpetuates the stigma of mental health but can exacerbate symptoms the individual is already experiencing (Bailey et al., 2017).

Experiences of LGBTQ+ Youth. LGBTQ+ youth have difficulties that are particular to their own life experience. Studies have shown that these youth can frequently engage in disruptive behaviors such as fighting or problematic behaviors such as truancy (Hafeez et al., 2017). Consider the etiology of these behaviors, knowing that LGBTQ+ youth are frequently bullied in school, are victims of sexual and physical violence, and are known to experience greater severity of violence (i.e., injury aggravated by use of a weapon; Hafeez et al., 2017).

Sexual minority girls are 400% more likely to engage in drug and alcohol use and report higher than average ODD and CD symptoms than heterosexual girls, as well as higher rates of suicidal ideation and self-harm behaviors (Marshal, et al., 2012). In the family system, youth may be experiencing emotional distress if they have not come out to their family, or if they have, they may be experiencing rejection (Hafeez et al., 2017). Disclosure of their sexual preferences and identities often leads to interpersonal problems (Hafeez et al., 2017).

Experiences of LGBTQ+ POC. Folx who are from minority populations are already at a disadvantage living in the United States, and furthermore, someone who identifies as a member of multiple minority populations is at an increased risk of increasing minority stress due to their intersectionality. Cyrus (2017) defines minority stress as, “Stigma, prejudice, and discrimination create a hostile and stressful social environment that causes mental health problems” (p. 195). In this instance, the stressors of LBGTQ+ POC would be homophobia and racism.

In the previous passage, the increased drug usage amongst sexual minority youth was highlighted. Similarly, sexual minority women of color showed higher substance abuse rates in comparison to white sexual minority women (Marshal et al., 2012; Cyrus, 2017). It must be noted that although some research has found higher rates of drug use amongst folx who identify as both Black and a sexual minority, research is still conflicted on if a significant difference is truly present. There are factors that may account for the discrepancy in the existing literature. Due to extensive history of trauma that folx from the LGBTQ+ and Black communities experience, it can be hypothesized that they have built some resilience to the racism and homophobia, making them less susceptible to negative mental health outcomes than someone who is not a part of a minority group (Meyer, 2010), which could point to fewer psychiatric diagnosis amongst LGBTQ+ POC. On the opposite side of the coin, it could be said that LGBTQ+ POC do not seek out mental health resources or do not feel comfortable turning to mental health resources. Historically, POC are underserved and underrepresented in mental health research. This leads to fewer diagnosis and misdiagnosis when POC seek out treatment (Sohail et al., 2014). When working with minority groups, resiliency must also be examined. When working with the LGBTQ+ POC population, it is important to look at their distinct experiences (e.g., their experiences as an LGBTQ+ community member and their experiences as a POC), the cumulative or synergistic effect of both of these experiences, and how their experiences shape their view of the world (Sutter & Perrin, 2016).

Assessment of Disruptive Behavior Disorders

The two primary disruptive behavior disorders are ODD and CD. The clinical features of these disorders are discussed below, along with sample screening and assessment approaches for these disorders.

Clinical Features of Oppositional Defiant Disorder

Oppositional defiant disorder is characterized by a pattern of angry or irritable mood, argumentative or defiant behavior, or vindictiveness lasting for at least six months (American Psychiatric Association, 2013; Riley et al., 2016). It typically manifests earlier in life (i.e. prior to age 8), and it rarely has an onset in adolescence (American Psychiatric Association, 2013; CDC, 2020; Riley et al., 2016). With children with oppositional defiant disorder, there can be a power struggle in which they may feel threatened or have a hostile appraisal of an encounter, which points to some insights offered from neurological studies (Ghosh et al., 2017). Given this potential for sensitive reward state and threat state (Ghosh et al., 2017), the non-directive approaches of parent management training explained in the intervention section can be an effective way to engage with these youth and promote positive behavioral change.

Clinical Features: Conduct Disorder

Conduct disorder goes beyond ODD and is characterized by serious violations of rules and social norms (CDC, 2020). Conduct disorder does not equate to delinquent behavior, but it is very common. Violating social norms includes prescriptive things such as school attendance, extreme disobedience of parental expectations, or destroying another's property (e.g., vandalism or theft; CDC, 2020). ODD is known to be a significant predictor of conduct disorder (CDC, 2020).

Screening and Assessment Tools

There are limited formal screening instruments for disruptive behavior disorders, and the need for various data points is even more critical for these disorders. Keep in mind that the behaviors do need to go beyond behavioral norms for someone their age and that the frequency, duration, and magnitude of the behavior matters. These diagnoses require even more clinical judgment. In considering the core aspects of ODD and CD, the assessor should note and ask questions such as: Are conflicts with peers or with authority figures? With authority figures, is it just the child's caregivers or is it all authority figures like teachers and other adults? Are there any current life stressors that can be affecting your child right now?

Disruptive behavior disorder screenings tend to come as a subset of broad focusing batteries. The Vanderbilt measure has screening questions for these disorders. The SDQ has subscales that address disruptive behaviors as well as prosocial questions. The Connors Rating Scales –Revised also have items. These scales do not assess ODD and Conduct Disorder separate from ADHD though.

The Child Behavior Checklist aggressive behavior syndrome can be predictive of ODD and conduct disorder (Hudziak, 2004). Much like with ADHD, observation in the school domain as well as collateral from the home domain elucidate the level of impairment (if any).

Intervention

Both prevention and treatment interventions have shown success in addressing problems related to ODD and CD. The following sections will provide an overview of prevention services as well as treatment approaches.

Prevention

In the example of James, how could his behaviors have been prevented? It seems that his parents had effective strategies for the other siblings, so was it really an issue of parenting? There could have been many other factors at play then with James, such as new parental stressors like job transitions, the cumulative stress of already parenting other children, or changes in their neighborhood. Prevention requires targeting multiple risk factors and starting at critical transition years, before it is “too late” (Fisher & Sexton, 2017), as child conduct problems have a constellation of risk factors, and there are multiple bio-ecological factors at play with the onset of externalizing problems (Fisher & Sexton, 2017). Early intervention, particularly in the preschool years, can be effective for preventing conduct problems in adolescence (Fisher & Sexton, 2017). Prevention programs are best delivered to youth prior to their entry to high school (Modecki et al., 2017). Family influence can serve as a mediator between stressors and the development of mental health challenges, making family involvement critical in any prevention program (Dinizulu et al., 2014). By incorporating family, a child will be more apt to disclose their difficulties or their exposure to adverse events, as there can be a lack of help-seeking from children from their desire to not burden their caregiver (Dinizulu et al., 2014)

The American Psychological Association defines executive functioning as an individual's ability to plan, make decisions, solve problems, assign and complete tasks, and resolve conflict. By caregivers developing their executive functioning skills, they will be able to model good emotional regulation techniques.

Research into delinquent populations shows that there is vast heterogeneity within the population, but there are signs that consistently show that 5-10% of youth are on a high-risk trajectory for adult justice system involvement (Pardini, 2016). When it comes to Black and Brown children, there are higher rates of recidivism in comparison to their white peers (Becker et al., 2012). Prevention of juvenile delinquency focuses on reducing the overall prevalence of risk factors and targeting children exposed to early socio contextual risk factors (Pardini, 2016), as well as indicated prevention to disrupt the onset of more offending and treatment for those with chronic offending behaviors. (Pardini, 2016). Coping Power is a prevention program with success in reduction of incidence of conduct problems (Modecki et al., 2017).

Parenting programs are effective for reducing or preventing child externalizing behavior (Modecki et al., 2017) as it is noted that improvement in parent functioning can have an effect on child outcomes (Wang et al., 2019) The most effective programs are the Incredible Years, Triple P, Family School Partnership, and Promoting Alternative Thinking Strategies. (Waddell et al., 2018) They have been delivered in community settings, and most involve parent training, as well as developing social and academic skills. (Waddell et al., 2018). Fast Track shows improvement of prosocial skills with children and with positive parenting practices (Fisher & Sexton, 2017) Fast Track and Early Alliance are seen as an integrated model of prevention and can incorporate other curriculums like PATH (Fisher & Sexton, 2017).

Treatment

Recommendations for treatment for externalizing disorders such as CD and ODD tend to focus on problem-solving skills with the child and parent management training (Riley et al., 2016; Waddell et al., 2007). Programs need to enhance regulation of action skills while improving the relationship of children to key adult figures (Modecki et al., 2017). The child focus tends to generate alternatives to the problematic behavior or assist with emotional dysregulation that can drive the behavior (Winiarski et al., 2020) and ensuing power struggle with the parent or other authority figure. Parent training focuses on decreasing unintentional positive reinforcement of disruptive behaviors and disrupts the power struggle that ensues from problem behaviors (Riley et al., 2016). Both of these approaches can be delivered individually or in group settings, with modalities focused on CBT approaches showing effectiveness (Riley et al., 2016). Medications, especially antipsychotic medications, are not recommended as a first-line intervention; however, given the comorbidity of other conditions, medication may be indicated for other problems (Riley et al., 2016). With James's parents, treatment would most likely be similar to coaching around problem-solving strategies and ensuring that the parents remained in control of the executive system of the family.

Problem Solving Skills Basics

- Describe the problem.
- Brainstorm a list of possible solutions or responses, even if they don't seem like they will work.
- Think it through. What are the outcomes you can expect from each option?
- Weigh the pros and cons of each option.
- Pick the solution and try it out.
- See how it goes. If it doesn't work out, try another option.

Example with James

Chuck sent James a nasty-gram to his Instragram inbox and James feels mad.

What's the problem: "I feel disrespected and need to do something about it."

Possible Responses: "I could respond back to him on Instagram, I could confront him at school and argue; I could hit him; or I could ignore him."

Outcomes: "We go back and forth on Instagram; he might get his friends involved at school; he could hit me back; or he might think I'm a turkey."

Good or bad outcomes: "Not sure for the first one; could be bad with the second; the worst with the third; and I'm not sure for the last one, but that might be worse than just keeping it on Instagram."

Pick it out: "I responded back to him on Instagram and didn't threaten him at all. He didn't reply back, and that's it."

Treatments for externalizing problems center on adaptations of CBT and parent management training (Winiarski et al., 2020). The most significant interventions for conduct disorder include the good behavior game, Classroom Centered Intervention, and Fast Track. Resilience focused interventions can be effective for externalizing problems, though they are more effective with internalizing problems for children and adolescents. (Dray et al., 2017). DBT has also been identified as helpful for externalizing disorders, as there are components to address emotional distress and build skills. (Winiarski et al., 2020). Mindfulness by itself and as part of a DBT program has promising results on externalizing disorders in middle childhood (Winiarski et al., 2020). For adolescents, there are programs like Chicago Becoming a Man, a CBT derivation meant to slow down thinking to allow for better problem-solving skills (Ludwig & Shah, 2014). Effectiveness studies show that it reduces recidivism and impacts other risk factors for delinquency (Ludwig & Shah, 2014).

An evidenced based treatment that has shown to be effective in reducing symptoms of ODD is family-based therapy (Christenson et al., 2016). When working with a family, each member involved with treatment should be viewed as a piece of the puzzle. To be specific, they cannot be whole until they are put together. Family therapy has been found to be effective regardless of setting, culture, and family type (Christenson et al., 2016). Family based therapy is often viewed as an alternative to hospitalizations, or in some cases a last step before hospitalization (Lear & Pepper, 2016). Individuals with ODD are more likely to experience suicidal ideation and self-injurious and suicidal behaviors, which can be caused by the lack of proper emotional regulation skills (Aebi et al., 2016). In many instances, the goals of family-based therapy are to foster attachment between the child and their caregivers, decrease/eliminate referral behavior(s), and to work with the caregivers on executive functioning. The American Psychological Association defines executive functioning as an individual's ability to plan, make decisions, solve problems, assign and complete tasks, and resolve conflict. By caregivers developing their executive functioning skills, they will be able to model good emotional regulation techniques in order to give their child the love and support that they need.

How should we proceed with James? Could this have been prevented? We know that the family must be involved in treatment, this case will not be focused on James by himself. James could benefit from skill building to help with potential stress intolerance or with communication skills. Conversely, the parents may need these same skills. They may be experiencing the cumulative stress of raising other children, coping with new stressors, and having difficulty adjusting to having a “problem child.” The dysfunction can be unintended in the family system.

We can borrow from the active ingredients of Parent-Child Interaction Therapy, an evidence-based intervention to treat disruptive behavior problems in children between the ages of 2 and 7 years (McNeil & Hembree, 2010; Lineman et al., 2017). The PRIDE skills are taught to parents to help with their child’s disruptive behavior, and they include Praising appropriate behavior; Reflect appropriate talk; Imitate appropriate play; Describing appropriate behavior, and Enjoy and show interest in the child (McNeil & Hembree, 2010). With James’s parents, they may need some therapist modeling of these skills or basic psychoeducation about them; however, we’ve seen that they’ve had some success with managing the behavior of their other children. In this case, they may know these skills, so it is reminding them they have the skills and working to change the conditions around their use. For instance, when parents are stressed, they can resort to default skills that may not be in line with the PRIDE skills. Tabbi (2015) calls this distinction of problems of learning (not having a skill) or problems about learning (managing conditions related to the use of the skills, such as stress). The effective use of these skills can strengthen the relationship of the parent and the child.

Effective parenting programs place an emphasis on strengthening parent-child relationships. A phrase commonly used by therapists in family-based therapy settings is, “Connect before you correct.” This means that in order for the parent to successfully correct a child’s negative behavior, they must first have a strong, positive relationship with their child. The child should feel secure enough in the parent-child relationship where if they were to make a mistake, it is not the end of the world and the relationship with their parent is not threatened.

In the case of James, it would appear as if there is a disconnect between he and his mother, to the point where she is unsure of what to do next when it comes to ensuring James’ academic and social success. It can be speculated that James feels disconnected from his mother, and she from him. In certain situations, therapists put “therapy” on the back burner, and focus on building the attachment between the child and their parent. By bringing a fun activity that the family enjoys doing together into the session, it not only promotes a positive interaction, but it could help James to put his metaphorical wall down and assist his mom in understanding the root of his distress.

“We just don’t really talk to each other.” James agreed, saying, “I get in trouble a lot, so we don’t really get to have fun. I’m usually on punishment, and mom’s just in the family room watching T.V.”

The clinician suggested, “Well, fun is definitely the medicine for this family. But we have to be reasonable. We need some rules around behaviors, but we also need to consider how to highlight when things are going well. Maybe at this point, if James is good with his behavior during the week, he can pick the movie for Friday. Or maybe what’s for dinner one night?”

The session wrapped up. “So mom, you and I will talk about how the plan is going and what you need. James, you and I are going to work on some problem-solving skills together to help you when things get tough. And we absolutely need to work together; you both are a team, so we will spend some more time working together as a family, as a team.”

Clinical Dialogues: Disruptive Behavior Disorders with Dr. John Siegler, PsyD

John Siegler, PsyD is a licensed psychologist in Pennsylvania, who has worked with children and families that are considered at-risk or vulnerable for about 20 years. He has worked in almost every publicly funded type of setting, from hospital-based services, community wraparound services, school-based evaluation settings, and drug and alcohol outpatient centers. He currently directs services for a clinic that provides ABA services to children and their families that children are living with autism. He works for the Philadelphia family court providing evaluations for children involved in the juvenile justice system and in Child Protective Services.

Sean E. Snyder, LCSW: Today, we’re going to look at disruptive behavior disorders, which covers oppositional defiant disorder, intermittent explosive disorder, and conduct disorders. Our interview today will focus on three core areas including engagement, assessment, and intervention. To start off, what’s your approach with parents of children with conduct disorder. For instance, about discussing conduct disorder as a new diagnosis and treatment option: how do you get buy-in?

John Siegler, PsyD: The place I would start with is to acknowledge that kids with conduct disorder can be considered very sick children that are born with conduct disorder. The classical conceptualization of conduct disorder is that it develops in a family context, where there are inconsistent parenting approaches that kind of oscillate between permissive to coercive or authoritarian, which can be quite punitive. In some cases, parents may not be paying close attention to the child, and when the child gets in trouble, the reaction of the parents is quite punitive. From a social learning perspective, this process is how the children learn about coercion and control, then they start to engage in what we see as a cycle of vicious efforts to coerce the parent, followed by the parent trying to coerce and control the child. This process continues and spirals up through oppositional defiant disorder; eventually, this cycle goes on long enough or severe enough, and we start to consider it conduct disorder.

Snyder: I can see this information as helpful with psychoeducation as an engagement strategy. Tell us more about conduct disorder.

Siegler: When the child's aggressive behaviors start to occur in the community, and where they may have seen previously physically aggressive towards siblings or parents, or may have been destructive to property in the home, now this is spilling out into the community. So that's the classical example of a child ending up with conduct disorder.

Snyder: How would you explain the "here and now" concerns of parents? Sometimes they are more receptive to hearing about the child as the identified patient.

Siegler: Right, sometimes parents like to know about the reasons for their stress. We normally think of conduct disorder as breaking up into two parts and a kind of a two-factor solution. For almost all, the children will have behaviors that we would say would fall on the delinquent lifestyle factor, which is what I described in the last response.

> *From a social learning perspective, this process is how the children learn about coercion and control, then they start to engage in what we see as a cycle of vicious efforts to coerce the parent, followed by the parent trying to coerce and control the child.*

The second factor is what they described as the callous and emotional factor, and this is a very small subset of children who will meet criteria for conduct disorder frequently meeting criteria in childhood. These are children that are high risk to meet criteria for antisocial personality disorder as adults. The reason for this, as best as we understand, it has to do with some neurodevelopmental diversity that these kids have in terms of how they experience the aspect of other people. That neurodiversity makes it much more difficult for them to learn from interpersonal experiences and develop meaningful connections to people in the way that we understand connections. So encountering children with conduct disorder that has this factor is almost a different approach than without.

With these factors in mind, to provide conceptualization, it has to start out from the standpoint that the parents are usually feeling overwhelmed and lack some of the basic skills that they need to be effective in working with their child. There may also be a number of contextual factors that contribute to their inability to keep their eye on the child and to maintain the level of supervision that the child needs. A lot of these can be financial and resource based. Parents will feel stressed because the child now needs a level of supervision that would be more typical of a child that was four or five years younger, but because of the nature of their disorder, they need to be watched and supervised much more closely, which ultimately is a challenge with parents. Then there are parental negotiations between each other or between a single-parent and their support system to come up with a strategy on how they're going to ensure that their son or daughter has adequate supervision and that the people that are involved in supervising the child have effective strategies to maintain supervision.

Snyder: A lot of ecological systems theory going on with this response, where it is family systems, school systems, community, intrapersonal systems with the caregiver going through their personal resources.

Siegler: You've got to look at it from their perspective, because the whole issue around engagement in joining is to look at it from an ecosystem perspective, which comes out of Bronfenbrenner's work. Really, you've got to really consider the phenomenological experiences of each family member. In working with families in this predicament with a child with conduct disorder, they're typically thinking in rather black and white terms, which is a function of their stress. This may not represent their true capacity for being able to tolerate any complexity or engage in any kind of more thoughtful consideration. The engagement process requires patience, and it requires the clinician to really think about how they're picking your battles in terms of what they're going to try to address immediately.

Snyder: This may be where parental guilt or shame could come in as well, if a clinician dives in too quickly for behavior change, and the child doesn't change because of the clinician's unrealistic expectations.

Siegler: Right, that's humiliating for the parent because the clinician is not really acknowledging their situation, their predicament. We're looking at getting the parent engaged in parent training to look at specific strategies that would work without just coaxing them to try those strategies and try to reignite some positive interaction with their child. The first step in the engagement is the parent has to experience the clinician as non-judgmental and supportive and to feel like they're being heard in terms of the challenges that they're facing as the leader of the family.

Snyder: It's real empathy with the family and realizing the function of the stress and that the present is the history of reciprocal interactions between the parent-child system.

Siegler: Yes, a clinician has to be able to empathize with them without excusing the choices. They can join them around their emotional experience.

In working with families in this predicament with a child with conduct disorder, they're typically thinking in rather black and white terms, which is a function of their stress.

Snyder: I think this empathy-accountability dichotomy is very apparent with youth in the juvenile justice system. Not every child with conduct disorder goes on to have justice system involvement, but I am wondering: how does that system involvement affect engagement?

Siegler: There is still some of the self-blaming parent. I think the parents generally anticipate blame from the system and from the clinician. They most likely have had numerous experiences in the past where they felt blamed, and really the juvenile justice (JJ) system for the most part holds parents accountable for their kid's behavior. Parents are the ones that have to pay the fines, the ones who get the looks from the police when they bring their kid home, or when they are humiliated because they have to call the police when they can't control the child in their own home or don't know where their child is. So, this is all more apparent when there is justice system involvement. On the whole, there are some universal things seen despite the unique situation of each family.

Families with and without JJ-involvement go through a second stage when the parents start to accept the clinicians being engaged in wanting to be helpful, where they may feel like they're not up to the task, and they may blame themselves. There's also some literature on maternal depression as being related to conduct disorder, and that usually would only come up in some cases over a longer-term treatment. Maternal depression may not be an issue with initial engagement necessarily, but it is something to consider with ongoing engagement.

Snyder: What is interesting about blame, too, is the idea of labeling and attribution theories. I wonder if this blaming is part of the sequelae to conduct disorder. Is it something that may have happened as a result of adversities or traumatic exposure?

Siegler: I like to take a resilience approach with conceptualization, and the

America's Promises Alliances (which came out of the Presidents' Summit for America's Future), outlines five things that have to be in place for the average kid to have resilience. One of these promises is that they have to have a healthy start, which would reflect living in a healthy home with good nutrition and their needs being met, psychologically and medically, up until school age. Another promise is the involvement of a responsible adult; a third promise is effective and accountable education; another is safe places to play; and a final promise is the opportunity to give back.

When looking at kids involved in the juvenile justice system, I look at it in terms of what pieces are missing for them in that conceptualization. And a lot of times, all of them are missing. I tend to assume that these kids are where they are because of what's happened or hasn't happened to them as much as it is who they are. Within that assumption is that some degree of adverse experience has been at play, and the extent to which it's traumatic is largely a function of the kid's individual resilience and their capacity for resilience. When working with JJS-involved youth, the needs tend to be more complex, and it becomes easy for the families to become what Minuchin calls "entangled." The systems themselves may even begin to describe themselves as feeling like they're entangled with the family. They're trying to offer services, and they feel like their family's partner expression, and it becomes like Chinese finger trap that they can't get it off. They try, and that makes them more stuck.

Healthy boundaries are needed for family and systems in order to self-regulate themselves. Not having boundaries leads to entanglements and limits the successful discharge. It's like having an exit strategy from the start.

Snyder: Right, systems don't want to institutionalize kids, but at the same rate, systems also can create dependence when there isn't an exit plan.

Siegler: And there are a lot of systems underestimating the parents' capacity for competence. The parents get kind of infantilized, and the system takes over and *loco parentis*. Unless systems establish a goal to increase the parents' confidence and competence as the primary person in authority and the primary person in charge of regulating their family system, it is easy to fixate on the kids behaviors, which leads to a continued behavioral cycle. There's no end to it.

Snyder: I'm thinking about general child interventions. It really is about family work and establishing the executive system in the family. So, engagement is engaging the family system as well as other systems.

Siegler: Working with families is 95% parent consultation and 5% working with a kid. I think that's true even when most of your work is with the child individually. The change that you can create is to influence the family as the context for change (unless you're talking about transitional-age kids where the goal is really to like getting them standing on their own two feet).

Snyder: You're probably thinking about all of that when you are doing assessments. Tell us about your process.

Siegler: In assessment, I bring the resilience conceptualization I mentioned. To start, it's worth mentioning the impact of trauma influencing what is being assessed. There are a number of measures that can be used to screen for adverse experiences from the child and from the caregiver. There may be some things that the child doesn't want to share or may not even recognize as being as impactful on them. Then screen for symptoms, and I tend to find that youth will have a lot of the criteria but not intrusive symptoms. Keep in mind the full-blown PTSD requires the presence of the intrusive symptoms, so there are youth that have trauma symptoms but not meet full criteria for PTSD. Now, that doesn't mean that those other kids aren't affected by their adverse experiences. It's important to understand how the child would describe his current context, the current challenges, and the extent to which the description reflects an accurate or unhelpful view of themselves in the world.

Snyder: We know a lot of the times with these youth that previous trauma symptomatology can be a risk factor for delinquent behavior; for instance, hyperarousal could lead to severe aggression, or intrusive thoughts could prompt maladaptive coping like extreme risk-taking behaviors.

Unless systems establish a goal to increase the parents' confidence and competence as the primary person in charge of regulating their family system, it is easy to fixate on the kid's behaviors which leads to a continued behavioral cycle.

Siegler: That's exactly right. Sadly, a very common thing that I encounter with the kids that are cross adjudicated or those served by both child welfare and delinquent courts. These youth clearly had issues with receiving appropriate care and ended up on their own, engaging in survival behavior that leads to arrest. A lot of these kids are runaways and come into the delinquent system for shoplifting or being involved in a group of people where there's a robbery. It's driven by the need to get money to live. So, is that really conduct disorder or a trauma reaction or an adaptation?

Snyder: Yes, there's a sense of resiliency there that can be seen as resourceful albeit something that may "violate" social or legal norms. But what happened to them is a violation of social norms in and of itself!

Siegler: Exactly so. In those cases, we really try to work with the court system to get them to recognize that the child clearly needs help with their problem solving, but that they also need to live in a place where they will consistently have these needs met so that they can be comfortable enough to stay there.

Snyder: It's Maslow's hierarchy, right?

Siegler: Yes, and this is probably as old as written history, the notion of looking at the poor in a way that's negative because of their proclivity to engage in criminal behavior like when they're starving.

Snyder: We are looking at assessment through a trauma lens with this. To broaden the conversation, what other types of comorbid conditions do you see with court-involved youth?

Siegler: The most common ones are diagnoses those kids may already have, in particular attention deficit hyperactivity disorder (ADHD). In some cases, there's enough evidence that I can gather from history, from the child's behavior in the assessment, from multiple collateral reporters. There may be a history of mood disorder, either depression or disruptive mood dysregulation disorder. A lot of kids are self-medicating with marijuana, so they could be seen as having cannabis use disorder mild to severe. What I find interesting is that the vast majority of kids that say they use marijuana give me a hard "No!" when asked about alcohol use or prescription pills. They really see marijuana is an acceptable thing. Self-medicating is related to trying to find a way to manage their self-regulation.

Those are the main ones. Occasionally, I've seen maybe one or two kids every couple of years where I think, "This youngster may have autism spectrum disorder and needs to have that type of an evaluation because their behaviors got so out of control and so dangerous before they came to the attention to the system." I see the occasional unspecified psychotic disorder but that is usually related to the substance use. But those are rare. To summarize, the vast majority are ADHD or mood disorders like depression.

Snyder: Great, thank you. A few more things about assessment. How much weight do you put on the court related presentation? What types of collateral do you need to really understand the child?

Siegler: Well, a guardian or teacher, definitely. I cannot make that diagnosis solely on the affidavit of probable cause for the child's offense. There has to be some information about the child's functioning that would reflect their attitude towards authority outside of the session with me and outside of their interaction with the police. So, ideally, the parent would be able to say "He's fine when he's at home, but after he goes out the door, I'm afraid." But then when I probe, I can drill down that he's fine at home because the parents have given up on trying to hold them accountable. Then parents that are hostile or distrusting in the system will insist that their kid is fine at home but he's getting railroaded. I have to have something to go on.

And it may even be their interaction with authority figures at the end, the detention center but I always try and get school information. I want to know where he went to school, since kindergarten, how many absences, how many suspensions. Parents are incredibly sensitive to your interest in their child's ability to function academically, so establishing that as a priority helps with them being generally cooperative and giving consent. And if they had to choose between their kid behaving at home and behaving at school, 90% of them would choose school because they know that's the kid's future. It comes back again to basic principles and understanding what parents value, and getting that information is key. It doesn't necessarily require having a teacher fill out a rating scale; it can be perspectives on things like why he got suspended or how often he cuts class.

Snyder: There's the story that's important. I'm thinking about when teachers rate the children on those rating scales; is the observation accurate? How helpful are those ratings, especially if you see all scores at the max rating with no variance?

Siegler: There are a couple different levels of analysis of those forms that we call "the cry for help." When everything is labeled as a three, the teacher could have written, "Help me" across the form. It could be that bad for a number of reasons, like the child could be struggling that much in the classroom. It can depend on the school. The other issue could be if this is a really bad fit for this child in that classroom. Or is that teacher a very good fit? Behavior rating scales are really good for initial rating of what's going on, but teachers take a while to change their opinion about a child. I encourage the clinician to look past the actual T scores and say, "I think I need to talk to this teacher or somebody to figure out what's going on," because if the child's that bad, I would be saying I'd want to talk to somebody at school and ask, "Have you called crisis?"

The problem-solving training can be successful, even if the parents refused to participate in the parent training. With younger kids, parent training is critical.

Snyder: It would seem that the child is causing a whirlwind of sorts, and it may inhibit good decision making on a school's part, or it may mask something else.

Siegler: Initially, it is the parent who is caught in a very serious cycle of coercive interaction and that has now generalized the child's relationship with authority figures at school. There may also be other factors at play, including overlooked learning issues and speech language issues. 70% of kids with disruptive behavior disorders also have an expressive or receptive language problem that's diagnosable. The effectiveness of the interventions for the disruptive behavior disorder is a lot better after the kids have speech language therapy.

Snyder: Right, it's like with differentials: understand if there is another etiology to the disorder before jumping to a purely behavior problem.

Siegler: And conceptual functioning is key, along with other adaptive functioning domains.

Snyder: So, after engagement and assessment, do you find yourself going to common intervention approaches?

Siegler: Well, the research for conduct disorder kids and kids with serious ODD is a combination of problem-solving skills training and parent training. The problem-solving training can be successful, even if the parents refuse to participate in the parent training. With younger kids, parent training is critical. Family based, systemic interventions engage with the parent, changing the relationship between the parent and the child to be at least as positive as it can be, and working with the parent to increase their confidence. It has a spirit of motivational intervention, where we are in the position of guiding the person, not pulling them along or following them. It's talking about change in a way that is helpful. And what we want to do is to coach the parent and to engage in those types of conversations with their child.

Snyder: Functional family therapy centers on family motivation before behavior change.

Siegler: Yes, and with FFT and MST, there has to be consistent support for the clinicians with training, consultation, and supervision in order for these interventions to be effective. Therapists have enough resilience to actually work with the family to meet them where they are; it is really key.

Snyder: Investment in the clinicians and investment in children will have the best return on investment.

Siegler: Well, I think you got to build your own balance. You have to maintain your own resilience and not get worn down by the stress associated with the work; that's number one. Number two is that working in this population, you cannot do work in this population in spite of the community, in spite of the systems that may be involved. You have to do what you can do to engage them and communicate with them. It doesn't guarantee a good outcome, but not engaging and communicating with them pretty much guarantees a bad outcome or unequivocal outcome at best. We have to work very hard to experience occasional success, where we can see the success at the point that we're still involved. Because the decks really stacked against these kids and their families. You may need to think about systems that may not be specifically mental health that can provide some of those missing pieces, like a safe place to play, getting another responsible adult involved, or, most importantly for older adolescents, the chance to give back. When you talk to some of these kids about the idea of volunteering, they look at you like you got three heads, but there are those that have had the experience of doing that, not just to work off their community service, but to have the experience of seeing someone value something they can create. That is a restorative experience for them, not just in a sense that it may restore some harm they've done to someone else, but it may restore their sense of their own humanity.

Snyder: At the end of the day, it sounds like it's just putting things in place to allow kids to be kids; it's allowing opportunity for resilience and for youth to develop. Thanks for your thoughts, John; these ideas are needed to have a person-centered approach to youth with disruptive behavior disorders!

Things Clinicians Should Know

Oppositional defiant disorder and conduct disorder can be highly political, meaning there are a lot of value-based criteria that come with these diagnoses. It may be hard to specifically assess for these behaviors using a rating scale, so an accurate history that includes school-based observation/data, and other reports from adult figures can help with understanding if such problems rise to the level of pathology. Intervention should be family focused, and if family cannot be safely incorporated into treatment, problem solving skills are priority.

Common Elements Approaches

Problem solving skills: can be used to decrease likelihood of hostile appraisal, limit an aggression-based response.

Parent psychoeducation: focuses on the cycle of coercive interaction; parent management techniques like reinforcement, modeling, active ignoring can help.

Social skills training: negative interactions with adults can be transferred to peers; social skills can help a youth navigate peer pressures, neighborhood pressures.

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Chapter

Substance Use Disorders in Youth

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Roger is a 15-year-old male who was seen by his primary care physician for a routine wellness check. An integrated care social worker was asked to join the encounter because the parents indicated they hoped for a behavioral consultation when they checked in for the appointment.

The doctor asked about substance or alcohol use, and he stated "No, I don't do anything like that." His parents looked disapprovingly, saying "Well, what about you smoking weed?" Roger laughed it off, "Mom, that's not a drug. It's natural, and there's nothing harmful to it. It's legal in most states, so what's the big deal?" The physician asked further questions about how often Roger used it and for what purposes. "I do it by myself, just to relax, calm down. Sure, I forget some things, but who doesn't when school is really boring? I'm not going to college anyway, I already decided on that." Roger's mom pleaded with the doctor, "Isn't there anything you can do? All he does is sit around. He doesn't go out with his friends anymore, his appetite is all off, and he just doesn't care at all. Is there some sort of medicine for that?" Roger laughed, "Look, weed is my medicine; I can't function without it. It gets me through the day. Again, what's the big deal?"

Overview of Substances

Substances, for the purpose of this chapter, include any psychoactive compounds or chemicals that change states of consciousness, alter mood or perception, and have the potential to cause social and health problems (McLellan, 2017). Substances are found in everyday consumer goods such as over the counter drugs, sodas, and chocolate; some have legal permissions for use (e.g., caffeine, prescriptions when used as directed such as opioids, benzodiazepines, or stimulants), others are deemed illegal (e.g., heroin, methamphetamine), and others are illegal for adolescents (e.g., alcohol prior to age 21 in the US, nicotine prior to age 18 in most US states). All of this being said, there is a difference between the physical effects of the substance and the social norms related to the use of the substance.

Seven classes of substances categorize the substance based upon their pharmacological and behavior effects: nicotine (e.g., tobacco products); alcohol; cannabinoids (e.g., cannabis); opioids; depressants (e.g., benzodiazepines); stimulants (e.g., cocaine and amphetamine), and hallucinogens (e.g., ecstasy, LSD) (McLellan, 2017). When discussing pharmacological effects, these are how the substances affect neurotransmission in the central nervous system (University of Minnesota [UM], 2015). As outlined in our psychopharmacology chapter, neurotransmitters can be modulated to either excite or inhibit the neural synapse; this will affect how the nervous system operates. Frequent use of external substances can create changes in how someone's nervous system operates; in a way, the body has to rely on these substances.

Increased use of substances can lead to what is known as tolerance, and that is defined as the increase of the dose of substance needed to produce the same desired effect (UM, 2015). Think of this example: for someone who has consistently consumed three alcoholic beverages a day, they may need to consume more than three drinks to get a "buzzed" feeling. As tolerance increases, a person may be reliant or dependent on the substance. Signs of dependence emerge when a substance is not consumed, for instance irritability or cravings or fatigue. When these symptoms emerge, it can be a sign of withdrawal. Lastly, with continued use because of increased tolerance and dependence, a person may develop an addiction to the substance. For regular coffee drinkers, consider if you ever tried to cut back on your coffee consumption; it can be painful, and it may seem like you *need* coffee to function.

It can be easy to downplay the effects substances have, often because of social and cultural standards and expectations. For the coffee drinker, there is a coffee culture; it can be something social, a norm of the workplace, and funny to talk about when "you haven't had your coffee yet." And there are other substances that may appear less dangerous, for instance, when cannabis is compared to opioids. This may be part of the logic that Roger uses when he says, "It's natural." What is more concerning for his case is that while he thinks he is consuming safe amounts of cannabis (UM, 2015), his executive functioning is not able to look for potential complications over time. The teenage brain, prone to taking risks, may gravitate to substance use, and substance use can further lead to risk-taking or unforeseen problems. Let's turn our attention now to substance use as it pertains to adolescents.

Overview of Adolescent Substance Use

An adolescent undergoes significant biological and psychological changes, which is dovetailed with the developmentally common increase in experimenting with risk-taking behavior (Becker & Fisher, 2018; Hernandez et al., 2015; Steinberg 2007). Experimentation with drugs and alcohol during adolescence is no exception, and the Monitoring the Future Study: Trends in Prevalence of Various Drugs for 8th Graders, 10th Graders, and 12th Graders showed the following rates of illicit drug use from 2017 to 2020 (Johnston et al., 2021).

Rates of Lifetime Use of Various Substances

Illicit drug use (lifetime)

- 18.2% of 8th graders in 2017 to 21.3% in 2020;
- 34.3% of 10th graders in 2017 to 37.3% in 2020;
- 48.9% of 12th graders in 2017 to 46.6% in 2020.

Alcohol use (lifetime)

- 23.1% of 8th graders in 2017 to 24.5% in 2020;
- 42.2% of 10th graders in 2017 to 46.4% in 2020;
- 61.5% of 12th graders in 2017 to 61.5% in 2020.

Vaping (lifetime)

- 18.5% of 8th graders in 2017 to 24.1% in 2020;
- 30.9% of 10th graders in 2017 to 41.0% in 2020;
- 35.8% of 12th graders in 2017 to 47.2% in 2020.

The last year use of illicit drugs follows a pattern of increases for 8th and 10th graders, and a slight decrease for 12th graders, and the last year use of alcohol use follows a similar pattern. Past year rates for vaping increased for all grades from 2017 to 2020, reflecting the popularity of vaping products like nicotine, THC cartridges, and flavored cartridges (Bell & Keane, 2014). Despite leveling out in 2020, vaping rates have had striking increases across all age groups. Decreasing rates of opiate use, including heroin and prescription opiates in the midst of the ongoing opioid epidemic, are promising. Opioid death rates still account for a majority of drug overdose related deaths in youth (CDC, 2020). Data collection during 2020 was incomplete due to the COVID-19 pandemic.

Prevalence of Substance Use Disorders

Alcohol, nicotine, and cannabis are the most commonly used substances by adolescents Among those aged 12 to17, 9.4% (~2.3 million youth) drank alcohol in the past month, 13.2% (~3.3 million youth) used cannabis in the past year, and 2.3% (~572,000 youth) smoked cigarettes in the past month (SAMHSA, 2020). For youth ages 12 to17, the rate of illicit substance use (17.2%, or 4.3 million youth) has remained somewhat the same since 2015 (SAMHSA, 2020). A review of substance-use disorders in teens range from 4.0 to 8.9%, with a lifetime prevalence of 11.4% (CDC, 2020a; Swendsen et al., 2012). Alcohol use disorders (AUD) have a 3 to 6% prevalence, and prevalence rates drastically climb at the age of 17, with rates of 15.1% compared to younger groups at 1.3% (CDC, 2020a; Swendsen et al., 2012). Substance use disorders (SUD) often co-occur with other conditions, with an average comorbidity of 60 to 80% (Hersh et al., 2014; Swendsen et al., 2012).

Substance Use Disorders in Adolescents

Adolescent experimentation with substances is developmentally appropriate; as will be discussed in the clinical features section, substance use disorders emerge because of patterns of problematic use. Biological factors for SUDs encompass the genetic heritability (see Hussong et al., 2011) and parental drug/alcohol use and intrauterine exposure to drugs/alcohol can create biological vulnerabilities (CDC, 2020b). The neurophysiological changes in adolescence manifest at different ages of adolescents, with timing of puberty and its stages having an influence on substance use (Patton et al., 2004). Psychological vulnerabilities include personality traits like externalizing problems like impulsivity and novelty seeking (see Wiers et al., 2012) and internalizing problems like negative affectivity, and most developmentally apparent, pubertal change.

Social factors stand out as highly influential on adolescent substance use. In

Becker and Curry's (2014) review of adolescents and peer patterns of substance use and SUDs, they highlight socialization (the adoption of peer behaviors and peer selection, the desire to affiliate with like-minded individuals) as theories that describe social factors leading to SUDs. Drug use is in part the result of socialization, and the National Institute on Drug Abuse (2014) reports that deviant peer groups and limited prosocial outlets can lead to SUD. Families, specifically parenting, can influence the development of adolescent substance use, considering the role of parental behaviors like monitoring and supervision (Tobler & Komro, 2010), involvement in their child's activities (Ryan et al., 2010), inconsistent or permissive parenting practices (CDC, 2020b), and parental beliefs like disapproval of substance use (Mrug & McCay, 2013). Other social and environmental factors include exposure to negative life events like trauma (Swedo et al., 2020).

Substance use is not without consequences to adolescents, which can alter developmental trajectories. Sexual behavior can be influenced by substance use, with literature reviews (Becker & Fisher, 2018) highlighting substance use in adolescence increasing the likelihood of sexual intercourse, earlier sexual debut, and high-risk sexual activities like unprotected sex and sex with multiple partners. Such factors can increase the likelihood of teen pregnancy and increase the risk for sexually transmitted infections (Yan et al., 2007). Adolescent substance use can affect academic performance, ranging from less severe consequences like falling grades to more dire consequences like dropping out (Becker & Fisher, 2018). Lastly, adolescent substance use has been linked to delinquency (Tripodi & Bender, 2011). Substance use can be a gateway into the juvenile justice system as a result of high-risk behaviors, or it can prolong involvement with the system as substance use monitoring is typically part of court related supervision.

Developmental Systems Considerations for Substance Use Disorders in Youth

With Roger, adolescents will typically downplay their use, but they may not realize the impact it has. Even though he wasn't planning on attending college, his use was interfering with planning for his future. We would need more information about his socialization patterns. How was cannabis introduced? Was there a family history of cannabis or other substance use? The developmental aspects of our guiding theory would urge us to stress the adolescent brain here, too; adolescence is a time of seeking autonomy, pushing boundaries, and engaging in risk taking behavior. The adolescent may developmentally be prone to substance use, and their frontal lobe is still developing; frequent substance use could hamper this frontal lobe development, the part of the brain responsible for executive functioning (Winter & Arria, 2011).

Experiences Across Racial and Ethnicity. Mennis and Stahler (2016) indicate that treatment rates in general for adolescents are low, and in particular, Black and Hispanic youth experience the lowest treatment rate across racial and ethnic groups. These disparities can vary depending on the primary substance of choice of the adolescent, but the disparity of treatment rates is observed across all substances for Black youth. Mennis and Stahler (2016) identified that there are acute disparities in treatment completion rates for Black adolescents who use alcohol and methamphetamine. For Hispanic youth who use heroin, treatment completion rates are particularly low compared to White youth. The lack of access, engagement, and completion of care elevates the need for culturally responsive clinical practices, and research indicates that culturally responsive treatments for substance use youth treatment are associated with significant reductions in post-treatment substance use (Steinka-Fry et al., 2017).

More problematic than the disparity of treatment rates is the fact that minority youth have more substance use related problems despite having less use. In the context of the juvenile justice system where there is disproportionate minority contact to be with, drug abuse violations for youth, on the whole, have decreased over 50% for both White and Black youth from 2007 to 2019 (Office of Juvenile Justice and Delinquency Prevention [OJJDP], 2019), and the rate for Black youth in 2019 has been at its lowest since 1980 (OJJDP, 2019). Despite this radical decrease, drug abuse arrests are still higher for Black youth than any other same-age racial group (OJJDP, 2019).

Experiences of LGBTQ+ Youth. In a national sample of sexual and gender minority adolescents, more than half reported alcohol use in their lifetime, and one-fourth reported cannabis use (Watson et al., 2020). These researchers found adolescents assigned male at birth had higher substance use prevalence compared with adolescents assigned female at birth, and greater risk was identified for transgender adolescents in comparison to cisgender adolescents (Watson et al., 2020). Generally speaking, sexual and gender minority adolescents disproportionately report problematic substance use compared to cisgender peers (Watson et al., 2020). It can be assumed that substance use can be a coping skill used when faced with stress related to discrimination, fear of the consequences of disclosing sexual or gender identity. Indeed, a recent meta-analysis found that the strongest risk factors for sexual minority youth are largely driven by marginalization and minority stress: victimization, lack of social support, psychological stress, negative disclosure reactions, and housing status (Goldbach et al., 2014). It is therefore important to consider the different psychological and social systems at play as a driver of substance use.

Assessment of Substance Use Disorders in Youth

Substance use disorders are characterized by a pattern of use of the substance that results in significant impairment or distress (American Psychiatric Association, 2013). Criteria span problems such as taking larger than intended doses of the substance, desires to cut down often accompanied by unsuccessful attempts, spending a significant amount of time acquiring or using substances, intense cravings or desires for use, social impairment, risky use of the substance, and what is known as pharmacological criteria, which includes tolerance of the substance's effects and withdrawal symptoms (American Psychiatric Association, 2013).

The fifth edition of the Diagnostic and Statistical Manual (DSM-5) brought changes to the way SUDs were diagnosed. Substances were separated into distinct use disorders: alcohol, cannabis, hallucinogens, inhalants, opioids, sedatives/hypnotics/anxiolytics, stimulants, tobacco, and other/unknown substances. Severity levels include mild (2-3 symptoms present), moderate (4-5 symptoms present), or severe (6 or more symptoms present).

Becker and Fisher (2018) highlight that these diagnostic criteria do not appropriately reflect the developmental characteristics of adolescence. They note the criteria related to physiological changes as troublesome, citing Winters and colleagues' (2011) critique of the definitions of tolerance, withdrawal, and craving; in summary, the move from experimenting from regular use may not indicate tolerance, craving during adolescence is not well understood, and withdrawal may be rare because of the time needed to become physically dependent on the substance. The social difficulties and risk domains of the diagnosis may be based in developmental norms (i.e., navigating the pressures of their developing social world and the normative behavior of risk taking itself). Becker and Fisher (2018) offer a more in-depth discussion of these and other diagnostic criteria issues.

State of the Art Assessment Tools

Screening to Brief Intervention (S2BI; Levy et al., 2014) asks respondents to indicate how many times he or she has used eight different substances. Screening is meant to identify levels of risk for a disease or condition. Screening is critical, especially with adolescent substance use because of the nature of experimentation versus problematic use. Youth that experiment do not necessarily need outpatient counseling, or, when parents find out about their child's use, residential treatment. Screening in general should follow with systematic clinical decision-making.

The S2BI specifically uses a stem question and forced response options to understand the past year use of tobacco, alcohol, and marijuana, as well as five other substances commonly used by adolescents. If a youth endorses use of tobacco, alcohol, or marijuana, the clinician should then ask about youth use of prescription drugs, illegal drugs, inhalants, or synthetic drugs. If a youth denies use, the clinician should use positive reinforcement of that behavior.

CRAFFT Score	***Likelihood of SUD***
One	*32%*
Two	*64%*
Three	*79%*
Four	*92%*
Five	*100%*
Six	*100%*

The S2BI is highly sensitive and can discriminate risk-categories, and a youth's response on it can correlate closely with the likelihood of a SUD (Levy & Williams, 2016). Youth with frequency responses of "once or twice" correlates with no SUD and this should be followed up with brief advice and medical home follow-up (Levy & Williams, 2016). A response of "monthly" correlates with mild or moderate SUD which should illicit a motivation intervention from the clinician that focuses on assessing for problems, advising to quit, and making a plan. Lastly, responses of "weekly or more" correlates with a severe SUD, and this should follow the previous motivational intervention and add a *referral to treatment*. The motivation intervention can follow the items on the CRAFFT, an evidence-based screening and brief intervention tool for problems related to substance and alcohol use of youth ages 12-21 (Knight et al., 1999).

The CRAFFT has been widely implemented in a variety of settings, from medical to community settings (Knight et al., 1999), and it also has validity for adolescents with varying socioeconomic and racial/ethnic backgrounds (Knight et al., 1999) The main ideas of the questions contribute to the acronym CRAFFT: operating a CAR while high, use of substance to RELAX or fit in, use while ALONE, FORGETTING things while using, if FAMILY/FRIENDS tell them to cut down on use, and getting into TROUBLE (Knight et al., 1999). Ask each question on the CRAFFT, and positive responses can indicate opportunity for brief intervention. For instance, if a youth is using substances alone, inquire about social networks- is this an issue with social skills? Or ask about other clinical hunches like depressive withdrawal- is there some behavior activation needed if there is the presence of depressive symptoms? The CRAFFT also has a brief intervention script that reviews the "5 Rs" for brief counseling: reviewing the results, recommending not to use, riding/driving risk counseling, response eliciting of self-motivational statements, and reinforcing self-efficacy (Knight et al., 1999).The CRAFFT also provides a scoring guide with score ranges about the probability of a DSM-5 substance use disorder.

The S2BI and the CRAFFT with Roger

Let’s unpack what happened in the primary care office.

The physician and clinician team first asked about frequency of use using the S2BI. Roger was open about his use. “I do it probably once a week, mainly on the weekend.” When asked if he uses synthetic substances like K2, Roger retorted, “Hell no! You think I am some sort of fiend?” The team praised Roger for not using other substances. “Thanks for talking with me today about your physical health. Your social worker will take it from here to talk behavioral health and wellness.”

From there, the integrated care social worker proceeded to ask more about the problems related to Roger’s use, referencing the questions on the CRAFFT. “I do it by myself, just to relax, calm down. Sure, I forget some things, but who doesn’t when school is really boring? I’m not going to college anyway; I already decided on that.”

The brief intervention included some education about cannabis’s effect on brain development and asked about increasing pleasurable activities not related to substances like going to the mall or going to concerts. “I like those things, but I don’t think that’s going to make me stop smoking.”

Noting the resistance, the social worker asked about pros and cons of use. “Well, the only reason I wouldn’t do it is to get a job. And my parents are definitely gonna make me stop if I want to drive and get my license. But what’s the use anyways? I’m not really going anywhere.”

The clinician replied, “Roger, it seems like there’s a lot to unpack here. Why don’t we schedule a follow up, you and me, then we can see where to go from there.”

Other Helpful Measures

The S2BI and the CRAFFT are considered to be the most state of the art screening and assessment tools, so the following discussion will touch on alternative options and contextualize the use of instruments in a structured interview. There are a variety of well-validated and reliable assessments available for assessing substance use problems in adolescents. Depending on your referral question and purpose of assessment, you can choose between self-report screenings, structured interviews around problems and consequences of use, or structured and semi-structured diagnostic interviews. Consult the National Institute on Drug Abuse site to see what fits your particular setting.

With other screening options, the Michigan Drug Abuse Screening Test (DAST) has 10, 20, and 28-item versions and has high reliability and validity in a variety of settings with adolescents (Yudko et al., 2007). The DAST does not differentiate between substances and so may be helpful for youth with polysubstance use who may have family conflict related to one substance but legal issues or impairment at school related to other substances. Screenings should be followed up with more in-depth assessment.

Structured interviews that assess a variety of substance use problems and consequences, as well as motivation for treatment and reasons for cutting down, including the Global Assessment of Individual Needs (GAIN; Dennis et al., 2003; Titus et al., 2013), which takes approximately 1.5 to 2 hours to administer. The GAIN also assesses internalizing and externalizing problems, and common psychosocial problems that accompany substance use (e.g., school problems, legal problems), so could be used in your routine practice as part of a multi-dimensional assessment. The GAIN – Short Screener (Dennis et al., 2006) takes about 30-45 minutes to administer. Clinicians could choose to only administer the substance use section, which would take considerably less time. The GAIN-I, GAIN-Q3, and GAIN-SS are all freely available from Chestnut Health Systems.

Diagnostic interviews (interviews conducted by the clinician to diagnose a substance use disorder) include the Teen Addiction Severity Index (T-ASI). The T-ASI is a structured clinical interview that can be used to assess substance use severity, past treatments, years of use, and common risk behaviors (e.g., IV drug use; Kaminer et al., 1991). The T-ASI also assesses functioning in other psychosocial domains, including family, peer/social relationships, justice involvement, employment/school/training, and psychological distress. The T-ASI does not include a diagnostic checklist and so may require more clinical judgment or an additional tool to make a formal diagnosis. The T-ASI takes approximately 30 to 45 minutes to administer.

The Kiddie Schedule for Affective Disorders and Schizophrenia-Present and Lifetime (K-SADS-PL) is a semi-structured interview that includes both adolescent and parent-report sections. The semi-structured nature of the K-SADS gives the clinician more flexibility in phrasing than a structured interview but also requires more clinical judgment. The K-SADS-PL is freely available from Kennedy Krieger Institute and also includes a computerized version with automatic scoring. Instruments like the GAIN and K-SADS-PL do require additional training in their administration and interpretation of scores to make diagnostic decisions. Training materials and online training are available for the K-SADS and GAIN on their websites. The T-ASI does not require specific training; however, the T-ASI should be administered by a person trained in clinical interviewing techniques, such as a social worker.

Intervention with Substance Use Disorders

The combination of the S2BI and the CRAFFT constitute a scalable way to implement brief intervention that is tied to the level of risk. For youth that require treatment and long-term care, there are various approaches to take. Common components of treatment such as advancing motivation, developing skills for harm reduction or abstinence, reorganization peer networks to include prosocial peers, with most interventions being sourced from motivational interviewing approaches, CBT, and contingency management (Fisher et al., 2018; Gray & Squeglia, 2018; Hogue et al., 2018; Jhanjee, 2014; Waldron & Turner, 2008). Hogue and colleagues' (2018) update of the evidence base for adolescent substance use treatment identify five approaches that are deemed Well-Established: ecological family-based treatment (FBT-E), group cognitive-behavioral therapy (CBT-G), individual CBT (CBT-I), motivational enhancement therapy/CBT (MET/CBT), and MET/CBT + FBT-B.

Hogue and colleagues' review (2018) review highlights the inconsistent performance of motivational interviewing as a stand-alone, brief intervention (Hogue et al., 2018), although it is worth noting that motivational approaches can be used in combination with other treatment modalities like CBT. The systematic review that Dr. Becker mentioned in her interview that compared to treatment as usual, motivational interviewing reduces alcohol use, heavy alcohol use, and overall substance-related problems, but not cannabis use (Steele et al., 2020). In general, there are few effective treatments of cannabis use and cannabis use disorder among adolescents.

Motivational technique center on motivational interviewing (MI), which is a treatment model that is brief, lasting usually between 1-2 sessions (Fisher et al., 2018). This intervention is not focused on "curing" the substance use, rather its meant to target the intrinsic motivation of the adolescent to change. Clinicians explore the youth's ambivalence to change in hopes to build motivation, and in motivational enhancement models, the motivational interviewing session will have provider offers non-confrontational, normative feedback in client feedback sessions (Fisher et al., 2018).

CBT has been shown to be efficacious (Hogue et al., 2018), and it also can be adapted for cultural considerations (Hogue et al., 2018). In fact, CBT for substance use has a better impact on youth substance use treatment outcomes when it is delivered through the lens of the culture of the youth (Hogue et al., 2018). In general, CBT approaches will consider the thoughts about use, consider the triggers for use, and the impact of feelings on substance use and include skills to help reduce relapse (Hogue et al., 2018). The Adolescent Community Reinforcement Approach (A-CRA; Meyers et al., 2011) is one such CBT intervention that has been shown to be efficacious. A-CRA uses operant condition techniques to understand and change the rewards that adolescents typically experience with substance use and replace these rewards with those from non-substance use activities, such as the rewards associated with being on a sports team, joining a club, or learning a new skill. First, a functional analysis of substance use is conducted, in which the antecedents and consequences of substance use are explored, as well as rewards and punishments associated with use. Then a period of time of abstinence is chosen (e.g., one month), not an agreement or declaration of lifetime abstinence, in an effort to move adolescents toward abstinence and practice skills needed to achieve more long-term abstinence. The therapist and adolescent plan for this period of abstinence followed by skills training and relapse prevention. Parent communication and monitoring is also included in A-CRA in two parent-only sessions and two parent-adolescent sessions. A-CRA is one of the only interventions shown to reduce cannabis use problems in adolescents (Dennis et al., 2004).

Family Therapy

Treatment should consider the many systems of a child's life, which largely center around the family (Gray & Squeglia, 2018). Protocols such as functional family therapy, brief strategic family therapy, and multisystemic family therapy have shown to be superior to control groups (National Institute on Drug Abuse, 2014). Even beyond these specific family-based interventions, adolescent interventions for substance use that include parent/caregiver involvement tend to be superior to ones that do not (i.e., that include only individual, or group therapy focused on the adolescent alone; Waldron & Turner, 2008; Tanner-Smith et al., 2014).

Multicomponent Interventions

Multicomponent Interventions are treatment packages that combine more than one approach; three of five well-established or probably efficacious combinations include contingency management (Hogue et al., 2018). Contingency management tends to be used in SUD treatment settings, and, as Dr. Becker mentioned, is highly efficacious in adults. It has not been evaluated as a stand-alone intervention in adolescents. It is an approach that uses operant behavioral principles and awards; incentives are given to youth for either attendance or treatment compliance goals (Gray & Squeglia, 2018). Rewards vary based on the type of system with both vouchers and prize-based models. As an example of the prize-based model, if 500 slips of paper or tokens are placed in a large jar or fishbowl, 250 may include positive comments (e.g., "Good job!"), 209 small ($1), 40 large ($20), and 1 jumbo prize ($100). Prizes worth roughly these amounts or vouchers in these amounts would be given if chosen, and only for a specific behavior, such as attendance in individual or group therapy, or submitting a negative urine drug screen that day. Drug screens need not be negative for all drugs, and often contingency management reinforces only negative cocaine or opioid screens (Stanger & Budney, 2010).

Increasing chances of earning prizes in conjunction with continuous or repeated positive treatment behaviors (e.g., earning 2 draws from the fishbowl for 2 consecutive visits or 2 consecutive negative urine screens) is also associated with improved abstinence outcomes. Contingency management can be a helpful strategy to improve attendance and retention in treatment (Stanger & Budney, 2010; 2019).

Screening, Brief Intervention, And Referral to Treatment. SBIRT has been discussed at length across this chapter. It is an approach done frequently in primary care, in which population-based screening occurs to identify youth who are at-risk and provide an appropriate dosage of intervention (Knight et al., 1999). Typically, youth screened fall into three categories: those not at-risk (no intervention), moderate-risk (brief intervention like psychoeducation), or high-risk (psychoeducation and referral for ongoing care). This is a great way to align provider resources with patient needs. SBIRT related interventions show good improvements over control groups (Winters et al., 2014). There is also a mobile app version that can guide clinicians through the SBIRT steps, including administering screening tools and guiding treatment decisions (Curtis et al., 2019). This app is freely available for Apple and Android phones and includes decision points to help guide clinicians in screening, intervention, and choosing treatment referral options.

Referral for Medication Management. It is important to understand that adolescents may be interested in medication for substance use disorders and may experience substance use problems severe enough to warrant medication. Medications can help manage cravings and withdrawal symptoms, thereby decreasing use and increasing likelihood of abstinence or lower levels of use. There are several medications that are effective for adolescents with opioid use disorders (Camenga et al., 2019) and growing evidence for medications for alcohol use disorders (Clark, 2012). Referral to treatment may therefore include both psychosocial treatment and medication management.

If you find that you need to refer an adolescent for specialized substance use treatment, the National Institute of Alcohol Abuse and Alcoholism (NIAAA) has designed a Treatment Navigator, which is an online tool to identify signs of high-quality treatment for alcohol use disorder in the community, directories of alcohol use treatment providers, psychoeducation on treatments that work for alcohol use problems, and guidance on how to choose a treatment. However, the Treatment Navigator does not currently include adolescent-specific treatments in its directories but is likely expanding to adolescent treatment in the coming years. Currently, families and clinicians can search for treatments by the Family Resource Center or Partnership for Drug-Free Kids (both available on the NIAAA website). The Substance Abuse and Mental Health Services Administration also has a behavioral health (which includes substance use services) treatment search engine (available on SAMHSA's website).Treatment providers can be searched by geographic location and include psychosocial treatments as well as buprenorphine and methadone prescribers, two medications that help reduce opioid use. Though treatments are not specified by age, many times facilities have the word children or families in the title of the facility. Given the relationship between substance use in families, both the NIAAA and SAMHSA treatment locators may be especially helpful when referring parents/caregivers or other adult family members for their own substance use treatment. If you are interested in more specialized training in effective treatments for substance use problems, there are trainings, webinars, toolkits, and apps available from the Addiction Technology Transfer Centers, available on their search engine. There are 10 region-specific Addiction Technology Transfer Centers, as well as a specialty center for Native and Hispanic/Latinx populations, which are all funded by SAMHSA.

Putting It All Together

As we saw with Roger, he was screened by his primary care team using the SBIRT approach. Parents must be supported in this process, as youth who minimize the impact of their use on their life or downplay the severity of their use will likely not want to engage in treatment. Parent management training skills may be helpful for parents, considering how to reward and incentivize the youth to engage in treatment. Roger was ultimately referred to an outpatient program. The clinician there wanted to include the family in the treatment process. Roger's parents recognized what could motivate him as a reward; he would soon express an interest in driving, and he loved playing video games. They set a reinforcement schedule: if Roger completed treatment, the parents would help with Roger obtaining a learner's permit. To shape behavior, the parents developed a teen points system. Attending treatment allowed Roger more time on his gaming system. While this approach seems to be appeasing the youth, the parents held the belief that decreased substance use was more preferred than not providing the reward schedule. So, what could happen if Roger's substance use seems to require longer-term treatment? What if the parents are on board with and follow through on the plan, but Roger still has problematic substance use?

Motivational Enhancement and Cognitive Behavioral approaches could be helpful in this case. A few key aspects of treatment would be teaching Roger problem-solving skills, affective management, communication skills, and relapse prevention, as well as ways Roger's parents can reinforce and reward the use of these skills. It would be helpful to evaluate for a co-occurring disorder, but let's say that that isn't the case for Roger. As Dr. Becker mentions in her interview, highlighting ambivalence is a key part of motivational interviewing, and problem-solving skills can help Roger engage in the creative process of generating and evaluating options regarding his use. Even after learning these skills, in the midst of his peers, Roger may need help with assertiveness in communicating his own needs and preferences. Relapse prevention focuses on the triggers for use and would help Roger identify his personal triggers for use and match appropriate skills for such triggers (e.g., self-talk, distraction, and engaging social supports). For worksheets and supports in this consider the linked resource from Webb and colleagues (2007).

Clinician Exercise

The follow-up appointment did not show much change two weeks later. Roger still was stuck on "What's the use?" The primary care social worker noted that the motivational techniques in their session could help set up for long-term care.

- You've received Roger's referral in an outpatient setting. Where do you begin with him?
- What aspects of his development do you need to consider?
- What ecological factors play a role in his ongoing use?

Clinical Dialogues: Substance Use Disorders in Youth with Dr. Sara Becker, PhD

Dr. Sara Becker, PhD is a licensed clinical psychologist and implementation scientist dedicated to bridging the gap between research and practice. Dr. Becker studies both patient-focused dissemination (e.g., direct-to-consumer marketing, technology-assisted interventions) and provider-focused implementation (e.g., multi-level implementation approaches, workforce development) strategies. The overarching objective of her work is to increase both the demand for and supply of effective treatments in community settings.

Sean E. Snyder, LCSW: Over the course of this dialogue, Dr. Becker will be discussing engagement, assessment, and intervention in the world of adolescent substance use. To start, I am thinking about engagement with our population and in those initial meetings, I tend to see that the youth from the beginning will minimize their use, or they're like, "You know this isn't a big deal. I don't know why the adults are overreacting." As a clinician, we know substance use can be serious because of its potential to be harmful, but we don't want our righting reflex to come out and alienate the child, right? How do you approach joining with adolescent clients that have a history of substance use?

Sara Becker, PhD: With adolescents who have a history of substance use, the first thing to keep in mind is that the primary pathway to treatment is typically through the justice system, and then the secondary path to treatment is usually that the kid is sent to treatment by an authority figure because they got in trouble with their parents or their school. The vast majority of kids presenting for a treatment for adolescent substance use will be mandated or coerced in some way. They were either mandated through the justice system or are being coerced to go by their family or school, so it's important to recognize that most teens who present will have very low motivation to be there.

Because of that, the predominant and most effective approach for engaging teens is to use motivation enhancement techniques. Specifically, brief techniques that fall under the umbrella of motivational interviewing are most recommended, with the idea that you really try to highlight the teen's ambivalence about cutting down their substance use and try to join with them and recognize that. A phrase we use is "roll with the resistance;" it means that you reflect with the teen what you're hearing and validate the advantages they get from substance use, as well as the disadvantages. And again, try to highlight areas of discrepancy and ambivalence related to their use to try to promote them to build internal or intrinsic motivation to change.

Snyder: In that approach, you hold up both the pros and the cons and not push the teen towards one side. And depending on what programs the child is referred to, there can be a difference between the abstinence approach versus the harm reduction approach. How much does that philosophy of care influence how you engage with a youth?

> *The predominant and most effective approach for engaging teens is to use motivation enhancement techniques.*

Becker: Yes, abstinence-only approaches tend to not be favored, as more harm reduction or use reduction approaches tend to be more developmentally appropriate. It's important to consider child development because developmentally, some level of experimentation with substances is normal for kids. It's normal for kids to experiment at some level, and so coming at teens at a young age and requiring that they'd be abstinent as a condition of treatment is really what teens are expecting when they present to treatment. They're expecting to be confronted and they’re expecting to be given a “just say no” approach. The approaches that tend to be most effective with this age group really try to disengage their expectation of “just say no” by teaching them skills to cut down and helping them build the motivation to cut down. These approaches are typically more in line with a harm reduction approach than an abstinence-only approach.

A phrase we use is roll with the resistance and really just reflect with the teen what you’re hearing and recognizing the advantages they get from substance use, as well as the disadvantages.

Snyder: With adolescents specifically, autonomy is their developmental task. They want to be autonomous, and we as providers have to consider autonomy and what that means with different ecological systems, such as the justice system, the school system, and the family system. In the clinician’s office, direct systems work comes from directly working with parents. How do you balance adolescent need for autonomy and parental expectations for treatment? How do you hold up those two parts of the family system?

Becker: There are a couple of ways that we could think about this question. One is that one of the evidence-based principles for working with adolescents who have a history of substance use is to involve the family. The treatment approaches that involve parents and other family members tend to be more effective than those that are adolescent-only approaches, and that’s been shown in multiple meta-analyses and systematic reviews, including several that I’ve been part of. These reviews show that involving the family is an effective evidence-based principle. Having the parent and teen in the same room and using family approaches to understand the role that the teen’s substance use plays in the family system is an approach that tends to be effective.

A colleague of mine, Aaron Hogue, is trying to distill in lay language and lay terms for providers out in the field, what exactly should you do with a family of a teen that has used substances. He and his team have watched over 300 hours of family therapy sessions of different family therapy models to code them and try to distill what exactly you should do. Readers, stay tuned for that, because it can tell you what specific ingredients of family therapy work. I can say multi-system family therapy works, multidimensional family therapy works, and family behavioral therapy works, but what we don’t have a good handle on is the core ingredients of those approaches, what makes them work.

The other way that I would answer your question is when you meet with the teen individually, and you're using a motivational building approach, there's an acronym called OARS that is the key principles of motivational interviewing: using your Open-ended questions, Affirmations, Reflections, and Summary statements. You can highlight the tension about the adolescent's enjoyment of substances and then the consequences they're experiencing at home, the pressures they're experiencing from parents. When I train, I spend a lot of time on reflection statements and I talk a lot about double-barreled reflections. I will actually highlight that tension that you were just talking about and say, "On the one hand, it sounds like you really enjoy smoking cannabis with your friends and it helps you to relax it reduces your anxiety, *on the other hand*, your parents are really on your case and your parents are telling you absolutely cannot use it all. How can we reconcile that? What kind of plan do you want to make before you leave today?" The goal is to acknowledge those tensions.

Use your Open-ended questions, Affirmations, Reflections, and Summary statements. You can highlight the tension about the adolescent's enjoyment of substances and then the consequences they're experiencing at home and the pressures they're experiencing from parents.

Snyder: Yes, practitioners have these great micro skills, and we just have to remind ourselves to use them because they go such a long way. Something separate but also fundamental to clinician training is trauma-informed care as a basic mindset. So let's say a clinician takes a trauma-informed approach; they recognize the person they are seeing has been exposed to trauma and note that the client has substance use challenges. Almost immediately, the clinician is thinking about maladaptive coping for managing PTSD or anxiety. What do you make of that? Is that the case, that substance use is largely maladaptive coping?

Becker: I think that's an impression that a lot of behavioral health folks have, that substance use almost always is maladaptive coping, and I would say that's not necessarily the case. There are a lot of teens that just use substances because they enjoy it, because they're bored. Both things are true. We have teens that certainly are using it because they have underlying mental health challenges, like trauma or anxiety or even ADHD. ADHD is actually the most common co-occurring disorder with substance use in adolescents.

And so, certainly, I would say, the first step in assessment is understanding a teen's level of substance use, and the predominant screening tools are frequency-based to really get a sense of the level of concern that you should have about the substances in particular. If after assessing you are concerned about a teen's substance use, I would say, as with all good clinical practice, you would want to do a more multidimensional assessment and understand more factors. Are we concerned about anxiety? Are we concerned about depression? Are we concerned about traumatic stress, attention issues? And we always need to ask about suicide. I think any good assessment of adolescents needs to understand suicide risk as well.

But usually, the first step in screening is just very brief, frequency-based questions to understand whether this is a kid that's experimenting once or twice, or this is really something that is raising a red flag for us. Or this teen is at risk of using on a regular basis.

Snyder: Yes, we are formulating from the beginning to get those contextual factors, and you've made me think, too, as a clinician, sometimes our assumption goes right to thinking of maladaptive coping because that's something I as a clinician can treat. Maladaptive coping feels like a low-hanging fruit in a treatment context, when really, as you mentioned, substance use can sometimes be enjoyable; it can just be like other things that teens enjoy. I appreciate you doing a little boundary spanning here for the conversation.

Back to contexts, one of the big things to consider is peer groups. I feel as a clinician, I have no control over the kids that my clients hang out with and other social factors like that. I'm wondering, maybe clinicians frame substance use as maladaptive coping because it gives some locus of control for the clinician, like "I can actually treat that!"

Becker: Part of why family-based therapy models are so effective is that parental monitoring and parental communication around norms and expectations around substance use are huge risk/resilience factors. Kids whose parents are more able to monitor on a daily basis and are aware of the kids their child is hanging out with, those kids tend to be at lower risk of substance use. Parents that have very strong communication about norms in the house and expectations around substance use also tend to be a protective factor for youth. That's one of the reasons that family approaches, we believe, are more effective, because you're teaching the parents skills to be able to monitor the teen more effectively.

Snyder: Yes, it's situating the presenting problem amongst a constellation of factors; it's not just this one kind of clinical transaction that goes on.

Becker: You're exactly right; about half to two-thirds of adolescents with a substance use disorder will have at least one co-occurring mental health problem. So, it is very common. Yet, even in those kids with multiple problems, when you do your functional analysis, it isn't always the mental health problem that is why they're using substances. Sometimes they're using because they're bored or because it's fun, and they enjoy hanging out with friends.

Kids whose parents are more able to monitor on a daily basis and are aware of the kids their child is hanging out with tend to be at lower risk of substance use. Parents that have very strong communication about norms in the house and expectations around substance use also tend to be a protective factor for youth.

Snyder: A key takeaway here, too, in practice, is that sometimes individual therapy feels a lot easier for clinicians, and it's hard to make that conceptual leap into family therapy. It just feels different because clinicians have to deal with a lot of things in the room. So maybe for the clinician that has difficulty with running family sessions, they can still have a family therapy mindset in doing individual work

Becker: Absolutely, and that's something my team has done, layering in separate parent sessions to an adolescent one-on-one intervention, and I think sometimes that can be a helpful interim step for providers out in the community, if they're not quite ready or comfortable with doing family therapy. Just meeting with the parent one-on-one and giving the parents some psychoeducation about how to monitor and to know how to communicate with their teen can be a very effective adjunct to an intervention.

Snyder: Really meet them where you feel most component—sage advice! Now, before moving on to more formal assessment questions, are there any other kinds of takeaways for clinicians about engagement with this population?

Becker: There's been some cool work in the field about how we engage parents and families. I think that's a separate set of skills. It speaks to your point that some clinicians are comfortable engaging adolescents, comfortable using motivation building approaches but really struggle to get the parent involved. Two of the most well-supported family pre-treatment engagement strategies are Structural–Strategic Systems Engagement (SSSE) and Community Reinforcement and Family Training (CRAFT).

Snyder: With assessment, you hinted at this when at the beginning of treatment, you're just really trying to understand the level of risk, frequencies, onset of use, determining experimentation versus pervasive patterns of use frequency. It can be a lot to think about with assessment. So, screening to the rescue! One of the screeners that I've found helpful in practice is the CRAFFT, the screening and brief intervention tool. Does your team use that? What are your thoughts with the CRAFFT?

Becker: Yes, so the CRAFFT is excellent as an evidence-based screening tool. I believe that evidence is most strong with youth 14 to 18. Members of the team that developed the CRAFFT based at Boston Children's Hospital actually now recommend a different screening tool, called the S2BI which I use extensively. The CRAFFT Version 1.0 used a "Yes-No" question format for the first three screening questions, like "Have you ever used alcohol? Have you ever used cannabis? Have you ever used other drugs?" Not surprisingly with adolescents, those types of yes-no questions lead to a lot of false reporting.

With teens, if you ask them a yes-no question, they are more likely to say no. To address this, CRAFFT Version 2.0, which is what is out now, uses frequency-based questions, which are shown to yield more honest and accurate responses because they normalize use. The questions ask questions like, "Over the past year, on how many days would you estimate that you have used cannabis alcohol and other drugs?" But estimating the number of days out of 365 is hard for teens to do.

The gold standard screening tool that is now recommended by the American Academy of Pediatrics was developed by members of the same team and is used very extensively in statewide rollouts in Massachusetts. The tool is called S2BI, which stands for Screening to Brief Intervention. It's seven items, and each item asks, "Over the past year, how often have you used [a specific substance]?" and the choices are never, once or twice, monthly, or weekly. It's a little bit easier for teens to answer. Basically, it starts with three gateway questions, which are alcohol, cannabis, and tobacco/nicotine products, because those are the ones that are shown to catch the largest number of kids, and then, if teens answer yes to any of those, you ask an additional set of questions about other high-risk drugs of use, such as prescription and synthetic drugs. If a teen screens as positive on S2BI, then they would get the CRAFFT, because the CRAFFT items are problem-based items that can help you assess the level of severity. Each letter of CRAFFT represents a type of problem with teens: riding in the car while under the influence or using friends to *relax*. And you go through each letter.

The new recommendation is to use the CRAFFT as a pivot point in a brief intervention, with the teen using a motivation-building approach. You would actually ask the CRAFFT and for each answer that they say yes to, you would say, "Tell me more about the last time that you drove in a car," or "tell me about the last time that you used when you forgot what happened." You would actually use those pivot points as part of a brief motivation-building intervention. In sum, absolutely you can still use the CRAFFT, but I would say that leading national organizations now advocate to use the S2BI, in part because the S2BI is more sensitive if you're going to use a universal screening approach.

My biggest takeaway message for the screening of substance use is that universal approaches are the most widely recommended because clinical judgment about which teens need to be screened is imperfect. We can use broad-based universal screening because it reduces an adolescent's sense of and resistance to being singled out. I would suggest using the S2BI and the CRAFFT Version 2.0 universally, then using those results to guide your decisions about what to do with the teen. This advice comes from my clinical research experience, in which I frequently use adolescent SBIRT.

My biggest message for screening substance use is that universal approaches are the most widely recommended because clinical judgment about which teens need to be screened is imperfect.

Snyder: Oh, I love SBIRT! It's something I've shared with my students, especially because as social workers, we will be in a variety of settings like pediatric primary care clinics, schools, or after-school programs. SBIRT can be done anywhere really, and it's feasible to provide brief intervention. It can also be critical because there are difficulties with the referral to long-term treatment for a variety of problems related to provider availability and accessibility promotion challenges.

I think what's great about the CRAFFT as a brief intervention tool is that you can really tailor it to the youth, where you can highlight if the challenge is related to social skills, is it something related to relaxation skills, or is it related to behavioral activation? Or if it's that they're bored, it can be a jump-off point for general motivational interviewing, or even brainstorming about alternatives. So you can really tailor the brief intervention to the client's needs.

Becker: Yes, with the CRAFFT, it helps make good sense of why the teens use and what they get out of it. You can say, well, "It sounds like using helps you to relax, and at the same time, you're getting into trouble. Help me to understand which of those is more important to you or how that tension is affecting you?" and you can get more detail.

Snyder: It really does help with making the link. Now, shifting gears to another assessment measure, I wanted to get a sense of an instrument that I've seen that your lab has used for some of its studies, the GAIN. Could you talk a little bit about what's on the GAIN and what's the utility of using it? I'm thinking about how that instrument could be applicable in certain settings.

Becker: There are a number of excellent validated tools out there, so people should use what makes sense for their context. That being said, the GAIN is something my team has found useful. The Global Appraisal of Individual Needs is one I've used for a long time, because in my first ever exposure to clinical research in 2003, the GAIN was the instrument being used across a SAMHSA national initiative. The GAIN is for both adolescents and adults, and it's really a family of instruments. There are assessments of different lengths that you can use to assess substance use. There's a very brief screener called the GAIN Short Screener, and there is a version called the GAIN Lite that you can use to get a handle on some of the teen's biggest presenting concerns. Then there are versions called the GAIN Core, the GAIN Initial, and GAIN Monitoring, a 90-day follow-up version. It's a family of comprehensive assessment tools developed by Michael Dennis and colleagues that has some really good psychometric data.

Snyder: What I like about GAIN is that it has specific substance use questions, whereas I've used the Strength and Difficulties Questionnaire, and substance use questions do appear on that inventory. It's helpful to see an instrument that integrates substance use questions on it.

Becker: Yes, and there are others like that. For instance, the Teen Addiction Severity Index by Yifrah Kaimer and colleagues. There are a number of comprehensive adolescent assessment tools that are like one-stop shops.

Snyder: Thank you for all your wisdom and insight about engagement and assessment! In that, we talked about intervention with how it is a part of SBIRT, we talked about motivational enhancement family strategies as a way to guide engagement. Are there other intervention techniques or guiding principles with an intervention that you would recommend for clinicians?

Becker: Great question! To take the 10,000-foot view of the field, SBIRT tends to be an approach that's recommended in settings where teens are present but aren't necessarily presenting because they have a substance use concern. SBIRT is an excellent fit for school counseling centers, primary care, emergency departments, and other places where teens are being referred for either physical or mental health issues, and you want a quick assessment of whether you should also be concerned about substance use. If you are a clinician in one of these settings, you could use the S2BI or some of the tools we have discussed to get a sense of the adolescent's level of substance use risk.

If you're in a specialty substance use setting, you obviously wouldn't need to do SBIRT; you could just do an assessment of the types of co-occurring problems that the adolescent might have. SBIRT is what we would call a prevention/early intervention model where you're trying to assess as many teens as possible and then provide or refer to appropriate care those teens that need an indicated intervention because of documented substance use problems. Some teens will only need a brief motivation-building intervention while others will need referral to specialty treatment. For teens that need specialty care, that's when we start looking at approaches like cognitive-behavioral therapy that help teens to learn skills to reduce their use and to prevent relapse, or approaches like family-based approaches, where you're providing some sort of parenting education or support and potentially involving the teen and the parent sessions together.

Snyder: Something that I've seen especially in group settings or group programming is contingency management. Have you seen that being widely used?

Becker: Thank you for asking about that. Contingency management is another passion of mine! Contingency management is a highly effective intervention for reducing substance use in adults, and it has been studied less in adolescence, although in studies of it in adolescence, it looks to be highly effective. I recently did a major systematic review of the adolescent substance use literature, and it's a little bit harder to tease apart because, for some reason, in adolescent literature, contingency management is rarely studied by itself. In the literature, you will see CBT combined with contingency management or contingency management with some family sessions. It's harder for me to say as a standalone intervention that contingency management is highly effective for adolescents. It's super clear that contingency management is an effective standalone intervention for adults, and it's a little bit more difficult to tease that apart in the adolescent literature.

Contingency management is an intervention that provides patients with some sort of tangible reward or motivational incentive for meeting specific, well-defined treatment goals. There are a range of possible treatment targets. You might reward the teen for submitting negative urine screens, attending their sessions, remaining engaged in care, or other treatment goals that somehow you're able to monitor consistently, like the teen attending school for an entire week. You can also train parents to use contingency management with their adolescents by setting goals or using a chart to track and reward the teen's behavior.

Contingency management tends to be effective with whatever treatment goal you select, and what you will find is that whatever you target is what you will get from the youth. So, if you target attendance, you will get improvements in attendance. If you target urine screens, you'll get reductions in negative urine screens. Contingency management has been shown to have positive spillover effects, so when you target attendance, you tend to see some reduction in the level of substance use. But, the strongest effects are typically exactly what you target, so it's important to choose your target carefully! Unfortunately, the biggest challenge with contingency management is that it's just not available in the community. It's very hard for a family interested in it to find it because very few practitioners in the field do it. In a national survey, only about 10% of clinicians say that they've used it, and very few know what it is.

But let me again take a broad view. The principles of contingency management are monitor behavior, track it, and then reward doing that behavior very consistently. Providers can do that, or providers can teach parents to do that. Principles of contingency management are definitely attractive to use with teens.

Snyder: Thank you for sharing the principles about it and highlighting that if you target that one thing, you're going to get that one thing. Contingency management is not the catch-all, wonder intervention that's going to cover everything.

Becker: You have to be very mindful that you'll get the biggest effects on the one thing you target, and you'll get it while you're targeting it. There's some data suggesting it's sustainable, but the effects will generally be strongest while treatment is active. This may help to explain why when you look at the adolescent literature, you often see contingency management paired with something like CBT; you're using contingency management to get a quick, accelerated start to treatment. When you want the teen to be able to cut down quickly, the CBT comes in to teach the kid relapse prevention skills. Developmentally at this age, I think there's concern if you just reward them and then pull the rewards away; it might be a little bit harder for a teen to sustain their progress.

Snyder: So, we are nearing the end of the interview. There are two things that I wanted to go over; the first is related to health equity, and the second part is around things like dissemination and implementation, seeing that you have expertise there.

With health equity and thinking about the experiences of Black and Brown youth, and about sexual and gender minority youth, are there trends that you're seeing with those groups?

Becker: Yes, there's a lot I would love to say about this topic. In this field, in particular, there's a lot of very concerning disparities when you actually look at national data. White kids tend to use substances more often than kids identifying as Black or African American, or kids identifying as Hispanic or Latinx. But what you tend to see is that kids who identify as racial or ethnic minorities, particularly Black and Latinx, have more substance-related consequences than White kids. There's a disparity issue where, if you were to just look at the number of kids with substance use problems, we should be seeing mostly White kids in treatment, and we should be seeing mostly White kids in juvenile justice facilities, but we actually see the opposite. I've worked in a state juvenile justice facility, and I believe the data in our state juvenile justice facility was fairly indicative of the data nationally, where 90% of kids in the juvenile justice facility were admitted because of substance related "crimes." It's essentially the youth equivalent of incarceration; these kids were being held in a detention center where they were because of substance use, and the kids were predominantly Black and Latinx. And yet we know that in our communities, the kids using most tend to be White kids. I think this speaks to really concerning issues with the system itself; there is structural racism, such that Black kids get diverted to punitive places where they're less likely to get treatment and white kids get diverted to residential treatment centers or places that are more treatment focused. So that's a huge concern.

And then, you were talking about sexual minority youth as well, I have several wonderful colleagues (Lourah Kelly and Benjamin Shephard) that study this and will try to do their work justice. My understanding is that in both adolescent and adult populations, individuals identifying as asexual or gender minority have higher rates of substance use and higher rates of substance-related consequences than those that identify as heterosexual.

Snyder: Thank you for highlighting those disparities; naming the problem is the first step in solving the problem. And then, the last formal item for me is around dissemination and implementation. So that is a big note to end on, but I have to think about rolling out evidence-based practices for adolescent substance use. I know this could be a whole book in and of itself. At its core, how do we build momentum for these types of EBPs?

Becker: The research-to-practice gap for adolescent substance use is probably the biggest gap that we could think of. The Institute of Medicine has released several reports about how big the evidence-to-practice gap is in mental health and substance use fields. And their conclusion is the gaps are much bigger than in the physical health field. The Surgeon General's report and several other follow-up reports talk about some of the unique challenges of the substance use field. We essentially have two problems; one is that parents and teens aren't aware that treatment even exists for substance use. There's a real knowledge gap. I've been on the side of having parents discover a bong in their kids room and call asking how they can get their teen into residential treatment. They just don't know what to do; they don't even know that outpatient therapy or counseling is even an approach that works for teens. And then the other piece is on the supply side, where there's very few programs that deliver treatment for adolescent substance use. There's even fewer that deliver what I would call effective treatment for adolescent substance use. There's a huge gap in services out in the field.

Another reality that we have to face is that a lot of mental health providers will not treat kids with adolescent substance use and will take the kids out of treatment and say, "Get your substance use under control and come back when you are ready to work on mental health." There are all sorts of problems, and there's not a quick answer to how to address this; we could talk about this for days! But I do think we need to be promoting substance use treatment principles and effective intervention principles much further upstream in training programs. I'm of the view that even though substance use is common among adolescents, it's a very high-risk behavior. I would like to see effective principles of screening and brief intervention, some of the things we've talked about, infused into the medical school curriculum. I'd love to see it infused into Ph.D. programs for clinical psychology. I'd like to see it infused in social work programs, because really

> *The principles of contingency management are to monitor behavior, track it, and then reward meeting that behavior very consistently. Providers can do that or providers can teach parents to do that; it's a very active intervention for substance use in teens.*

anyone who works with adolescents should be aware of and screening for substance use; it's such a common behavior and such a high-risk behavior.

The work that I think really needs to happen is that providers of all types need to be equipped to deal with this.

Snyder: That seems feasible to train folks because it is embedded into established training programs. Integrating substance use more into existing settings would be a huge positive step in the right direction. And thank you for sharing all your wonderful insights. I'll leave you for final thoughts before we wrap up.

Becker: I would love to close by noting that substance use in this age group is normal yet probably not as pervasive as teens think. There's this common trend where you see teens say "I use substances because every teen in my high school uses substances." They don't realize that it's normal for a lot of teens to experiment but not normal for a lot of teens to use often. Those teens that use substances most often tend to be the ones at the greatest risk. If you are a clinician out in the community, you can start off by getting a sense of how frequently a teen is using, and if the teen is using more than monthly, that's a teen that should be on your radar as possibly having some problems related to use. In sum, if you screen for substance use, you can help close this remarkable gap in treatment for youth.

Things Clinicians Should Know

Tolerance: needing higher amounts of substances to achieve intended effect.

Craving: strong need, urge, or desire to consume the substance.

Withdrawal: symptoms related to stopping use of a substance, often signaling a physical need for the substance.

Ambivalence: having two opposing views, with difficulty choosing between the two.

Common Elements Approaches

Psychoeducation

Motivational Interviewing (MI)

Contingency Management (CM)

Motivational Enhancement and CBT

Open Access Assessment Tools

Screening to Brief Intervention (S2BI)

CRAFFT (2.1)

Global Appraisal of Individual Needs (GAIN)

Kiddie – Schedule for Affective Disorders and Schizophrenia – Present and Lifetime (K-SADS-PL)

Teen Addiction Severity Index (T-ASI)

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14

Chapter

Eating Disorders in Children and Adolescents

Valerie Everett, MA; Sean E. Snyder, MSW; Amy Mack, MSW

Sammy is a 17-year-old, Black, Christian, cis-female who is an avid soccer player at a predominantly White high school. After college, she hopes to play on a college soccer team and would do anything to achieve that goal. During the season, Sammy has four days' worth of practices and games and does her own workouts on her "off days." She trains hard on her "off days" because she wants to be in the best shape possible to become an elite soccer player. She insists on "clean eating," and the rare times she eats food she deems as "bad" or "unhealthy" (e.g., fast food), she goes home and uses a laxative "to get it out of [her] system." Sammy says that she needs to be perfect in everything she does, including being the best singer in the church choir, in the top 10% of her graduating class, and the best possible friend for all of her friends.

Sammy is active on social media platforms Instagram and TikTok, posting videos and pictures with friends. However, for the past year, an anonymous account has been consistently sending her hurtful and racist messages about her hair, body, and cultural identity. Every time she blocks the account, they create a new one and continue to bully her. Sammy has confided in her close friends about being cyber-bullied but knows they do not understand what it's like to be Black in a mostly White town. When she feels isolated, she focuses even harder on her training so she can get recruited and get out of her hometown.

One day, Sammy passed out at soccer practice and was rushed to the hospital for evaluation. After a medical workup, the treatment team determined that Sammy was restricting her caloric intake and had lost significant weight in the past month. She admitted to eating appropriate amounts of food when her family was around her during mealtimes (e.g., family dinner every night), but restricting her intake during all other meals. Occasionally, Sammy would use laxatives or go for runs when she felt she ate too much in a day.

Overview of Eating Disorders*

Eating disorder (ED) symptoms include disturbances in eating behaviors that significantly impact someone's health and wellbeing, spanning disorders with restrictive patterns (e.g., anorexia nervosa, bulimia nervosa) to liberal patterns (e.g., binging eating disorder; Morgan et al., 1999). In the United States, body weight receives much attention in health promotion, as 19.3% of children and adolescents ages 2 to19 years old were considered obese (i.e., a body mass index at or above the 95th percentile), in 2017-18 (Fryar et al., 2021). While health promotion is meant to increase quality of life, fixation on weight management or fear of gaining weight can lead to problematic feeding behaviors. This childhood fear of gaining weight is not a new phenomenon, with the literature pointing to youth being afraid of being fat or wanting to be thinner (Collins, 1991; McNutt et al., 1997; Gustafson-Larson & Terry, 1992). As such, it is crucial that clinicians are well-versed in ED etiology, symptomology, and treatment. Three of the most common EDs are bulimia nervosa (BN), binge eating disorder (BED), and anorexia nervosa (AN).

For those experiencing bulimia nervosa, a behavioral pattern emerges in which an individual eats an objectively large amount of food in a discrete period of time (e.g., less than two hours) while experiencing a sense of loss of control overeating (American Psychiatric Association, 2013). This is then followed by a purging or compensatory behavior to prevent weight gain. Common examples of compensatory behaviors include inducing vomiting, misusing laxatives (Spielman et al., 2020), and engaging in excessive amounts of exercise. These

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episodes of binging and purging must occur, on average, at least once a week for three months to meet full criteria for BN (American Psychiatric Association, 2013). Additionally, individuals with BN may demonstrate an overvaluation of shape and weight, especially as it relates to self-esteem. Symptoms of BN also include a fear of gaining weight or strong desire to lose weight.

Binge eating disorder (BED) is characterized by consuming quantities of food that are larger than what most people would eat in a short period of time, relative to what others would eat under the same conditions (American Psychiatric Association, 2013; Devlin, 2016) coupled with a feeling of a loss of control over their eating. (American Psychiatric Association, 2013; Devlin, 2016). Other symptoms may include eating much more rapidly than normal, eating until uncomfortably full, eating when not hungry, eating alone out of embarrassment, and feelings of guilt or shame after binge eating (American Psychiatric Association, 2013). BED shares similar clinical features with BN, without the compensatory behaviors to “undo” the binge episode.

Few with eating disorders will actually get specific treatment for it, and this unmet need is alarming as eating disorders have the highest mortality rate of any psychiatric disorder.

Lastly, anorexia nervosa (AN) is characterized by the fixation towards and maintenance of a low body weight through caloric restriction and/or purging behaviors, (e.g., starvation, excessive exercise) (Spielman et al., 2020). Additionally, those with anorexia nervosa commonly display traits of perfectionism or rigidity (Jacobi et al., 2004). Distorted body image is also common among individuals with AN (e.g., they may view themselves as overweight even though they are not; Spielman et al., 2020). Two subtypes of AN are as following: the restricting subtype, which involves severe restriction of caloric intake and/or excessive exercise; and the binge-eating and purging subtype, which involves severe restriction along with recurrent episodes of binging and/or purging behaviors. Given the similarities between BN and AN binging/purging subtype, the DSM-5 differentiates these two disorders by body mass index (BMI) of the individual affected, with BN as the diagnosis if BMI is average or above average (American Psychiatric Association, 2013). However, treatment for these two disorders is often similar, depending on symptom overlap and severity.

As we saw with the case illustration of Sammy, she was demonstrating symptoms and behaviors indicative of anorexia nervosa binging/purging subtype, as she was highly perfectionistic, restricting her caloric intake and engaging in excessive exercise. Occasionally, she would engage in purging behaviors, though her BMI was below average. While she did not report wanting to fit an “ideal” body type or standard, she did report wanting to manipulate her body to be as fit as possible.

Prevalence of Eating Disorders

Lifetime prevalence of AN for youth aged 13 to 18 was 0.3%, with an identical prevalence for both males and females (Swanson et al., 2011). With BN, there is a lifetime prevalence of 0.9%, with a greater prevalence in females than males (Swanson et al., 2011). BED has a lifetime prevalence of 1.6%, with a greater prevalence in females than males. The study by Swanson and colleagues (2011) was a national study that also brings to light the unmet treatment need for these youth, as a small amount of those with the disorder will actually get specific treatment for the disorder. This unmet need is alarming as eating disorders have the highest mortality rate of any psychiatric disorder (van Hoeken & Hoek, 2020 b), and there are strong associations of eating disorders with other psychiatric disorders and suicidality (Swanson et al., 2011).

Eating Disorder Development in Youth

The biopsychosocial model, which is nested within our developmental systems perspective, points to different pathways or contributing factors in the development of an eating disorder. Biological factors include heritability of the disorder (Mitchison & Hay, 2014), and for individuals with eating disorders, there can be dysregulated serotonin levels (Jacobi et al., 2004), pointing to bio-psychiatric aspects of the disorder. Regarding life course, the age of onset varies but tends to peak during adolescence (Jacobi et al., 2004; Mitchison & Hay, 2014) with females between the ages of 15 and 19 being most at risk (Mitchison & Hay, 2014; Spielman et al., 2020). This could be in part to the developmental pressures on this age range, explained by various social factors.

Social factors tend to be a default explanation for the development of an eating disorder, often pointing to cultural standards of beauty and social acceptability. The extant literature points to potential precedents to the development of an eating disorder that include family factors like perceptions of parental acceptance and rejection, low parental support, low peer support, and psychosocial impairment (Stice & Van Ryzin 2019; Jacobi et al., 2004; Mitchison & Hay, 2014). These factors may contribute to the pursuit of a thin-idealization by the child, whereby they judge themselves against what they think is the cultural standard and attempt to lose weight to conform to that standard in hopes of gaining social acceptance (Stice & Van Ryzin 2019). With eating disorders, it can be difficult to tease out whether factors are what lead to the disorder onset or if they are the secondary effects of the disorder.

From the social perspective, early reviews show a higher prevalence of disordered eating with females (Jacobi et al., 2004; Mitchison & Hay, 2014) and claims about ethnicity can be hard to determine (Jacobi et al., 2004), with one review noting that ethnicity does not appear to have strong associations with eating disorders (Mitchison & Hay, 2014). This could be in part due to the variance in cultural standards and how culture relates to an individual's perception of their physical and mental health (Assari & DeFreitas, 2018). Related to mental health, it is common to see childhood factors, such as overly anxious traits or anxiety-related disorders (e.g., social phobia, OCD; Jacobi et al., 2004). Adverse life events, in particular sexual abuse victimization, is a common risk factor (Jacobi et al., 2004).

Developmental Systems Considerations for Eating Disorders

At first glance, Sammy appears to be struggling with normative developmental worries for an adolescent—especially in the context of her hobbies (e.g., soccer) and identity (e.g., goal-driven, high-achieving). Some may say these are problems of affluence, but as we see in the literature, this is not the case (Assari & DeFreitas, 2018; Gibbons, 2001; Gard & Freeman, 1996). Eating disorders comprehensively demonstrate how external systems (e.g., societal standards) can influence the development of emotional problems. Weight stigma and fat phobia are cultural phenomena that may lead to discrimination and stereotyping someone based on their weight or shape. The effects of weight-based stigma are further complicated by the prevalence of bullying, which may be associated with disordered eating (Copeland et al., 2015). Further, adolescents have even greater access to one another with the rise of social media and technology, potentially increasing access to social support, as well as cyber-bullies, as we saw with Sammy.

In treating a child or adolescent with an eating disorder, depending on the child's unique needs, clinicians should seek to include parents, teachers, guidance counselors, physicians, dieticians, and anyone else relevant to holistic needs of the patient. Biological systems are imperative to consider because of the physiological processes related to weight loss and the mental models that accompany such physiological changes. There is behavioral reinforcement each time she steps on a scale or engages in "body checking" behaviors. Further, macro-based interventions focusing on dissemination of anti-bullying and anti-weight shaming programs in a variety of contexts (e.g., schools, hospitals, etc.) are

Thin idealization by the child happens when they judge themselves against what they think is the cultural standard and attempt to lose weight to conform to that standard in hopes of gaining social acceptance.

crucial for providing accessible psychoeducation on disordered eating. Lastly, bullying or other social factors related to eating disorders point to the disruption of social networks for children (Copeland et al., 2015), which can lead to isolation and hopelessness. For Sammy, providing culturally supportive and affirming care, coupled with increasing her connection to the Black community, may improve her treatment outcomes.

Experiences Across Race and Ethnicity. It is crucial to consider racial/ethnic identity in the identification, treatment, and conceptualization of eating disorders. If conceptual models of disordered eating are constructed with white females as the standard, clinicians may miss clinically significant symptoms from youth of other races and genders. Recent research findings suggest no significant differences exist between racial/ethnic groups in the prevalence of sub- or full-threshold eating disorders (Cheng, et al., 2019; Mitchison & Hay, 2014; Solmi et al., 2016), meaning that these challenges affect individuals across racial/ethnic groups, not just White women. As such, screening measures should seek to be culturally relevant and consider cultural-specific barriers to seeking treatment. One review found that ethnic minority participants may be less likely than White or European-American participants to seek treatment for eating disorders (Regan et al., 2017). As such, it is crucial that clinicians thoroughly assess for disordered eating in these populations and address barriers to receiving treatment accordingly.

Experiences of LGBTQ Youth. The Minority Stress Model (MSM) posits that individuals with sexual and gender minority status could be at increased risk for developing negative mental health sequalae (Meyer, 2003), such as eating disorders, due to a variety of distal (e.g., discrimination) and proximal (e.g., identity concealment, internalized homophobia/transphobia) stressors (Park & Herringer, 2020). One survey suggests that approximately 54% of adolescents identifying with the lesbian, gay, bisexual, and transgender (LGBTQ) community have been diagnosed with an eating disorder, with approximately 21% reporting they have had an eating disorder at some point in their lifetime (The Trevor Project, National Eating Disorders Association, & Reasons Eating Disorder Center, 2018). Treatment considerations should keep in mind that risk factors related to the MSM differ by LGBTQ subgroup (Park & Herringer, 2020). Unique strengths should be identified and utilized in treatment, as research has identified multiple protective factors (e.g., self-compassion, social support) against disordered eating among LGBTQ youth (Rainey, et al., 2018; Watson et al., 2017). Further, clinicians should not only assess for disordered eating psychopathology but also contextual and social factors which may be impacting or maintaining symptomology (Parker & Harriger, 2020). Youth with intersectional identities (e.g., gender, sexual, and/or racial minority status) may warrant the development of culturally relevant and individualized treatment methods.

Assessment

In the treatment of ED, it is critical to evaluate for medical complications that are associated with frequent caloric restriction and/or purging. Importantly, there is no one look to individuals with eating disorders. Though body mass index (BMI) is an important piece in the assessment for disordered eating, it is not enough alone to determine eating disorder presence and severity. For example, individuals with BN are more likely to be about average or slightly above average weight (American Psychiatric Association, 2013) and may be overlooked if a clinician does not assess for other key features of eating disorders.

For patients who engage in purging behaviors, medical complications may arise such as menstrual irregularities, cardiac abnormalities, dental degradation and complications, problems with the esophagus and stomach, and irregularities with electrolyte balance (Mehler et al., 2010). For those with anorexia nervosa, it is common to see issues with bone density, alongside cardiovascular, pulmonary, muscular, gastrointestinal, and neurological complications due to the physical effects of malnourishment. Notably, patients of this disorder often die from medical complications related to cardiac health and dysfunction.

Binge eating is typically seen in youth who have depressive symptoms, larger weight fluctuations, and dissatisfaction with their weight (Devlin, 2016). In assessing for binge eating disorder, clinicians must distinguish between objective and subjective binge episodes (OBEs and SBEs, respectively). OBEs consist of eating objectively large amounts of food in a short period of time while experiencing a feeling of loss of control overeating. SBEs consist of eating a portion of food that is subjectively large to the individual but is not an objectively large amount of food. Gold-standard screening measures, such as the Eating Disorder Examination (EDE; Fairburn & Cooper, 1993), are useful to help parse apart these two binge episodes and determine if this criterion is met in the diagnosis of BED.

Because it is a neurobiological disruption to the reward system in the brain related to eating, a clinician can ask questions like, “Do you feel worried when you have to eat or eat in front of others?” Eating is aversive and anxiety producing; restricting or purging is rewarding. A follow-up question then to ask, “how do you feel when you don’t eat or if you purge after you do eat?” A clinician can ask parents about mealtimes and what they observe in their child during shared meals. Family dynamics and social relationships can sometimes unintentionally contribute to the maintenance of an eating disorder but only within the context described above. Cross-disciplinary collaboration is key as well, and questions to ask medical providers include “What was the historical growth curve for this child?” This can help with seeing previous patterns and establish a future benchmark to determine weight goals.

Intervention

The treatment of EDs requires an interdisciplinary team that includes a mental health clinician, a dietitian, and medical provider (American Psychiatric Association, 2006). In respect to the cognitive aspects of the disorder, therapy will focus on the primary thoughts and behaviors (e.g., restriction, purging) as well as how these behaviors impact family and social relationships, as well as overall functioning (American Psychiatric Association, 2006). ED prevention programs can be helpful with disseminating psychoeducation for common symptoms of eating disorders, such as the idealization of thinness, body dissatisfaction, BMI indicators, eating behaviors, and eating-related emotions and cognitions (Stice et al., 2013). Programs conducted in schools with multiple sessions have demonstrated increased effectiveness in reducing future eating disorder onset (Stice et al., 2013). While there is research about what works for treatment, barrier to seeking and receiving treatment is gatekeeping, which, in the context of EDs, involves the held belief that an individual (whether self or someone else) with an ED is not "sick enough" or "thin enough" to warrant serious treatment or attention. Clinicians should be mindful of and address these barriers when discussing treatment options with their client.

In treating AN, it is recommended that the client receives a combination of psychotherapy, nutritional rehabilitation, and medical monitoring (American Psychiatric Association, 2006; Linardon et al., 2019). For youth requiring more intensive medical services, the primary and initial focus will be on rehabilitation of the body (American Psychiatric Association, 2006). Higher calorie refeeding has been seen to reduce days of inpatient treatment (Garber et al., 2020). For those who are not medically compromised, the level of care can range from inpatient programs to partial hospitalization to outpatient programs (American Psychiatric Association, 2006). Weight gain is a core part of treatment, which is a major barrier among individuals with EDs seeking treatment. In inpatient recovery, patients are observed during mealtimes and are not allowed to restrict, binge, or purge. Patients are giving up control over the type and amount of food they are consuming, which can change their weight and shape. It makes sense, then, why individuals with EDs may be ambivalent about receiving treatment, as it would involve losing perceived control over their bodies. Providers should be aware of something known as refeeding syndrome, a metabolic problem that can be fatal (American Psychiatric Association, 2006; Garber et al., 2020), in which someone who is malnourished consumes too

Biological systems are imperative to consider because of the physiological processes related to weight loss and the mental models that accompany such physiological changes.

much food too quickly, and the body has difficulty digesting it, causing other medical problems.

Cognitive behavioral therapy has been the recommended therapy for eating disorders (Linardan et al., 2017). Third-wave behavioral interventions such as Dialectical Behavior Therapy (DBT) and Acceptance and Commitment Therapy (ACT) have yet to show the same efficacy as CBT for eating disorders. However, there is promise of their use in prevention programs (Linardon et al., 2019). Motivational interviewing can be a key part of therapy as well, as motivation is a key predictor of change for individuals with EDs (Wade et al., 2009).

In creating a treatment plan for Sammy, her care team took a family-based perspective. Clinicians started treatment by providing psychoeducation on EDs to family members. Sammy's parents were incorporated into treatment to help re-enforce Sammy's use of relevant coping skills and foster an environment that is conducive for treatment. Additionally, the clinician discussed the role that family systems can play in maintaining and treating disordered eating (e.g., accommodating behaviors, held beliefs of the parents, parental expectations, etc.).

Sammy did not require hospitalization for complications associated with severe weight loss and starvation, though refeeding was a critical part of her treatment. The treatment team identified ways to physically nourish Sammy through family meal planning and bolster her social support through fostering social interactions that did not involve exercise. CBT-oriented approaches were used to help Sammy become aware of cognitions related to her body and eating habits and address maladaptive core beliefs (e.g., "I'm only worthy of love if I'm perfect"), as well as use mindfulness strategies to defuse from those unhelpful thoughts and implement distress tolerance skills when her emotions and thoughts felt distressing and overwhelming.

Clinical Dialogues: Working with a Family in an Eating Disorder Program with Amy Mack, LCSW

Amy Mack, LCSW is a licensed clinical social worker who has been at Children's Hospital of Philadelphia (CHOP) in the Eating Disorder Program for seven years. She has had previous experience in community mental health and in school settings, where she focused on family-centered interventions.

Sean E. Snyder, LCSW: To start, Amy, how does someone enter into the world of treating eating disorders? It's such a specific area.

Amy Mack, LCSW: What drew me to the CHOP position was not so much that I had eating disorder experience, because I didn't. I had family therapy experience, and our model of treatment at CHOP is family-based treatment. It was a fit for me practice-wise, and then I became competent and well-versed in the eating disorder specialty.

Snyder: I appreciate hearing those clinical stories too, because it can be hard to know what you're passionate about until you do the work. So, it seems you had some foundational skills, and as you worked with eating disorder cases, you built a passion and a specific skill set.

Mack: I always try to highlight that I did take a hiatus for a number of years and had three kids and then was able to really return to the field and have a good job. I feel that's something as a woman that is important for readers to hear. You can make it work for yourself professionally.

Snyder: Absolutely, it can take some creativity to sustain the work as a helper. Thanks for sharing your background.

Let's pivot now into your world at CHOP's eating disorder program and start with engagement. It's interesting for eating disorders because it's so medically complex; there's many psychological layers, and in practice, I've seen youth have multiple psychological assessments before they finally land in the right spot with an eating disorders clinic. Given all that, what is it, then, for you when you come in contact with these families? What is it to engage with them, and what are some strategies that you use to join with them?

Mack: The families that make their way to the CHOP eating disorder program typically have early onset restrictive eating disorders, so we're catching it in the first year or two of diagnosis for the most part, which has the best outcomes.

Across the specialty, if you can intervene early and quickly, you can have good results. When we get them at intake, families are typically very stressed, very overwhelmed, and scared. For some of these families, the diagnosis of anorexia nervosa is out of left field. Parents feel very guilty, thinking "how did I miss this?"

Sometimes parents can be in denial, based on their own experience with eating and weight stigma. You never know what's going to walk in the door. Sometimes a family is "we're all in, we're all on board, anything you say we will do." But then other times, it takes a ton of psychoeducation and a ton of hand holding and support to really help them understand what's happening to their child. Plus with the complication of the medical piece alone, a lot of our kids end up in the hospital for medical stabilization, which is not the same as inpatient eating disorder treatment. It's medical stabilization, and then they will either discharge to our outpatient program or sometimes kids need more than what we can offer, so they'll discharge to programs outside of CHOP.

So, if a patient and family—I am in the field social work, I hate calling them patients, but in the world of CHOP we call them patients—so when a family, because we only treat the family, it's a family-based and evidence-based treatment model called family-based treatment which is not structural family therapy. It's a manualized treatment protocol rooted in both understanding the neurobiology of anorexia but also rooted in some family systems theory. Our program is influenced by the family-based team model; we don't follow the evidence-based practice by the manual, but it's influenced by that model.

In treating anorexia nervosa, it is recommended that the client receives a combination of psychotherapy, nutritional rehabilitation, and medical monitoring.

Sometimes parents will come in having done some research and understand that this is a family-based treatment model. Our early sessions with families are really around supporting them, to understand the diagnosis, then collaborating with the medical team to get the kids out of the acute medical crisis. Then, the behavioral health component continues from there, but when we're first meeting families, it's really about getting them stable. I always say, "If you had a hole 'n the boat, you wouldn't spend a ton of time trying to explore why the hole got there… you'd want to get to shore, and then we do that work on the other side."

Snyder: When we meet with our patients or clients, everybody has a unique circumstance, but it sounds like especially with eating disorder patients, there's so many different things going on. How do you prioritize tasks in treatment?

Mack: It's so confusing to families that the treatment is weight restoration first and therapy later. Parents think, "Wait, this makes zero sense!" But there's neurobiological elements to anorexia. The reward system in the brain gets very malfunctioned, so there's no insight and no ability to have an insight-oriented therapy session with a kid. I don't know if you guys are familiar with the term anosognosia, but it's basically a word that means that the person with the illness doesn't realize how sick they are. It's a common phenomenon with people with schizophrenia. People with anorexia can have anosognosia, where they say "I'm fine, I don't know what's wrong. It's you guys that all have the problem." Therapy doesn't work when someone's in that place mentally, so the work with the family is really coaching the parents on the front end to help their kid with the core part of treatment for anorexia. The only treatment for anorexia is that the child has to gain weight, and bottom line, kids don't want to do that. They're terrified of it, so it's hard with the first couple of months of treatment being no fun at all.

Snyder: Right, these youth know all the tricks and all the things that are going to cause them to gain weight, even with medications that can help them manage their mental health.

Mack: It's really helping parents manage their own distress because when their kid is upset, and they have to make them do something that makes them very upset, that's really hard for parents. Our engagement with parents is a lot of validation for the parents, lots of education about behavioral theory like ignoring what you don't want to see repeated, labeled praise for when someone's doing something well.

Snyder: It seems like there are so many things to juggle. Where do you start? I know you said medical is the emphasis of treatment, but I'm wondering about family systems and the core family processes that we have a little more of a hand in shaping (we aren't medical providers, so we don't have a direct hand in that treatment). With family systems, guilt and blame can emerge from a very painful experience for a child and family. Is that or other particular types of psychoeducation that you start with families?

Mack: We come from the family-based treatment model which has a very agnostic view on causal factors, so we don't care, or it doesn't matter how someone got an eating disorder. We know that it's an energy imbalance within the body that activates a genetic vulnerability in the brain, so the old theory of an overbearing mom or a kid that wants control is not the present-day theory about the development of an eating disorder. Parents come in thinking those old theory things. There's a huge stigma around eating disorders because of those old views of what causes it, and it's a very misunderstood illness. People without the present-day understanding of it tend to say, "Well eat, it's simple." A lot of the psychoeducation around blame and parental thoughts like, "How did I miss this?" is really validating for the parent, that is that eating disorders are a pernicious illness that can come out of left field. You could be the most helicopter parent in the world and still miss this disorder. It's really helping parents to understand that there is no blame, nobody did something wrong or caused this to happen. Now, we're going to get ourselves out of it.

Snyder: That almost like other types of mental illness, where parents are asking themselves, "where did I go wrong?" and really, it's the developmental systems at play that produce these emotional problems for kids. It reminds me of what you said earlier; we don't have to worry about how the hole got in the boat, let's try to plug it up, get to the shore where it is safe, then take care of the details later.

Mack: It is remarkable how the brain is really healing, and this healing affects the rest of the body. The origin of it is in the brain, and once the brain is healing with restored nutrition, a lot of those why questions tend to subside. Once the crisis settles down, the parents may care less about wanting to figure out how it happened; the process of recovery resolves those questions for them. For some kids, once their weight is restored, their energy is restored, and they're bouncing back.

Snyder: How much do you engage with family together versus child and parents separately?

Treatment is weight restoration first and therapy later. Parents think, "Wait, that makes zero sense!" but there are neurobiological elements to anorexia.

Mack: The sessions are ideally with both caregivers, and we have to be mindful that people have jobs or family structures are different, and everyone cannot be there at all times. We don't do any individual therapy.

We have the kids present, but it is mostly geared toward supporting parents. Initially kids will have opportunities to talk and participate, but it's not unusual to hear screaming and crying and yelling from our patients because they're acutely ill, and the intervention is no fun for them. My goal as a clinician is to develop rapport with the whole family, and most often, I can get the kid to buy-in to liking me. Every once in a while, there's a kid that's says, "I freaking hate you," and that's fine, but having that rapport with the family unit is key. It's not until later in treatment that the kid become more involved. This may sound harsh, but their opinion doesn't matter early on because it's usually not in line with treatment goals, and we are talking about a very lethal disorder.

Snyder: The child wants to maintain starving themselves or intense exercising or whatever it is to maintain that dangerous weight.

Mack: Yes, and the child will say it's not fair. From a developmental standpoint, I talked about this with parents, that a family treatment model in which parents make decisions for them causes friction for a kid with an eating disorder that onsets during adolescence. This is a time where kids want independence and they don't want their parents telling them what to eat, but that's what you have to do in our intervention. The parents are going to run the show for a little while, and the bulk of the friction is kids feeling resentful that their parents are all up in their business.

Snyder: Eventually, there is the transition to the child becoming able to be in charge of their own eating, right?

Mack: There are three phases of family-based treatment. Phase one is weight restoration, where parents have autonomy over meal choices, activity choice, activity involvement, etc. When a patient's weight is restored either all the way or most of the way, we start shifting autonomy back to the kid to make age-appropriate, independent decisions around food. If the kid never made dinner, we're not going to now have the kid making dinner for the whole family, but they can chose their own snacks, chose their own breakfast, lunch, or whatever food with oversight by the parents. Phase Three is full transition to the pre-illness functioning, where the child can be age-appropriate and engage socially again. We want them in age appropriately managing their own self-care stuff. The course of this takes probably 12 months.

Snyder: It sounds like a gradual release of responsibility to get the child stable and giving the adequate level of support to the parents. And the course of an episode of care has different levels and types of supports (e.g., nutritionists, medical professionals like doctors or nurses). I'm interested now to learn more about how behavioral health fits into it all specifically, for instance, when you're doing your intakes. When you do your assessment, is it more from a family systems lens? Is it focused on symptomatology and functioning, considering that you do have one slice of this youth?

Mack: We have a very structured intake process which does include a medical/adolescent medicine piece, a dietitian piece, then we're the behavioral health piece, so we do a very standard biopsychosocial assessment. In the mental health diagnostic world, we would say someone has anorexia, whereas in the medical world, they get a malnutrition diagnosis. The anorexia diagnosis is the behavioral health piece, so we're assessing for the criteria that if it's in the DSM. I keep saying anorexia because the majority of our patients have anorexia, and we don't really treat bulimia or binge eating disorder. Most of the kids we see have a restrictive eating disorder.

In getting started with an assessment, I say to the kid, "I imagine you're not super psyched to be here today," and they will say, "Ugh, my mom made me come." Given that, I open up with, "Tell me in your words: what got us here?" What I love about family treatment is that there's always a story, and inevitably the family tag-teams the creation of it. There's a lot of very common stories there, like, "Well, I was in health class and the teacher was talking about sugar, so I wanted to cut out my sugar and then it spiraled from there." I had a very interesting case recently where the kid has a specific phobia of vomiting. Her fear of vomiting was causing her to restrict what she was eating. The brain doesn't know the difference; the brain doesn't know if you cut your sugar or if you're afraid of throw up or if you grew five inches and didn't gain any weight, the brain doesn't know the difference, and if you have the genetic vulnerability to developing the disorder, it doesn't matter how what led to the weight loss or the energy imbalance. It's that it happened, so we have to sift through the story.

A family treatment model in which parents make decisions for them causes friction for a kid with an eating disorder that onsets during adolescence. This is a time where kids want independence, and they don't want their parents telling them what to eat, but that's what you have to do in our intervention.

When it's clear that there's enough criteria for anorexia nervosa, then we know that this family team model is the gold standard in treatment. We try also to get a sense for family structure, family function, school. The visual in my head is school, family, friends. School because that is the natural setting for youth, friends because those who set social norms, and families because they are central to treatment. We need engaged caregivers that can work well together. Siblings matter as well because the whole system is affected by the illness.

It's important to note that fear of gaining weight is just a fear; having such thoughts doesn't mean anorexia, but you have to show through your behavior that you're not supporting your own growth and development. A kid could say I don't care about gaining weight, but if they're not eating enough at each meal, then that's the behavior that leads to disorder.

Snyder: I think you bring up the idea with the fear and the phobia. It's making me think of things that generally overlap with other conditions, and I'm thinking OCD. I've seen this with folks with anorexia; they'll do body checking behaviors. It's like a compulsion after the obsessional thought about their body image, so it almost seems like OCD. Or addictions even, features of repetitive behaviors that have a negative impact on the person.

Mack: There's a huge overlap. It's interesting sometimes parents will say I think my kid has OCD because of all the issues around eating. That's mainly anorexia, but OCD and anorexia overlap frequently. The perfectionist trait can be a psychological vulnerability. With substance use and eating disorder, it's worth noting that these both have genetic factors, so it's not surprising to see overlap in how the behaviors manifest.

Snyder: What about within race and ethnicity? Or socioeconomic status even? Do they affect the presentation of this disorder?

Mack: This illness does not discriminate across socioeconomic factors, across races ethnicities. What is particularly interesting is cultural expectations, values, standards, even ontologies. For example, I have had a couple Chinese American or Chinese students whose parents immigrated from China. One of these students came to Philadelphia to go to one of the private schools outside of Philly. They lived with a host family, and the child developed anorexia and was hospitalized. The parents flew from China to America to do a family-based treatment. Using an interpreter, I was trying to explain what anorexia is. Eating disorder is not a diagnosis in China; there's not even a word for it. So yes, there are some cultures that do not name eating disorders.

Regarding the aesthetics piece, there's a misunderstanding that social media or, in previous generations, looking at magazines causes eating disorders. It's certainly a systemic factor but those factors again don't cause eating disorders. The thin ideal and messaging is a social context, but again, at the end of the day, anorexia is caused by an energy imbalance in the brain.

Snyder: Culture as context for sure. What's interesting, though, that despite our knowledge of eating disorders in our culture, structured assessment tools seem few and far between. Does your team use specific tools or use certain progress tracking instruments?

Mack: We have an eating disorder behavior scale that our kids take at the beginning of treatment, and they take it once a week for six weeks. It's easy for kids to misrepresent themselves on that, so that's why we do it for six weeks to establish a baseline, then we do a treatment outcome rating too. We also look at depression scales because a lot of times kids that are malnourished have low mood symptoms. These can resolve with renourishment but also they may not which is whole other diagnosis. We also look at a parent accommodation, and that scale measures how much does a parent accommodate for the distress of the illness. We want to see that decrease over time, so the parents are involved in our measurements. It is critical to address accommodation behaviors by parents, because that is shown to be a driver of prolonged illness.

Part of our data tracking is to align with what research has established; if a kid can gain four pounds in the first four weeks of treatment, prognosis is better for full recovery. So, in addition to behavior, we track weight. We know that the physical body heals much more quickly than the brain; a youth can have their vital signs normalize very quickly, fortunately, but their brain lags behind in recovery. They may end up stabilizing medically in a very short period of time where we are able to avoid acute issues like cardiac arrest, but the youth is still showing a lot of eating disorder behaviors. That can be very frustrating for the kids who will mention, "Well, the doctor says I'm fine, why can't I go run five miles?" It's really our job to really manage the behavior piece, but obviously the physical piece matters and goes hand in hand.

Snyder: That's so interesting that the brain recovery lags behind and is not recovered as soon as the body is physically stable.

Mack: The reward center in the brain has misfired repeatedly, and we have to repair it through behavioral intervention which takes a long time.

Snyder: To recap, on the medical side, they're tracking with malnourishment, and anorexia is the behavioral component, so it makes sense to really focus on the behaviors themselves. That's what is going to lead to a fuller recovery on a holistic level.

Mack: I have this visual pie chart that I call the recovery pie, and every piece of the pie is equal in size, and the pieces include weight, vital signs, return of your period if you're female, decreases in anxiety around eating, increased flexibility with eating, decreased eating disorder behaviors (which could include breaking your food up into little pieces or hiding food) then return to activity while maintaining weight. and return to socially appropriate relationships. That's eight slices, and they're all equally as important as the other. Somebody can be weight restored and have their vital signs stable, but outside of the home it's too stressful. Just having vitals back to normal is not going to help you in the world, I always say to kids, "If you want to go eat pizza with your friends, if you want to go to college and live in a dorm and socialize (which tends to involve eating), we have to work on this stuff." It's all connected and impacts functioning on so many levels.

Snyder: Throughout all your responses, Amy, we have been getting a flavor of what intervention looks like. You showed us the phases of treatment, about family work like caregivers accommodation behaviors, the domains of intervention. Are there specific techniques that you use in working in the family-based model?

Mack: My systemic family therapy skills really take center stage. I'm picturing a scenario where you have a mom and a dad that don't get along, and each one is trying to align with you against the other. There's a lot of structural skills that you want to use, even so much as how you set up the room in person, where maybe the mom and dad have to sit next to each other and the kids sits next to you. In that instance, you're really trying to foster an alignment between the parents who are hierarchically over the kid for now. A lot of times you'll have families come in, and the kid plops themselves right between the two parents which literally splits them.

In terms of micro skills, it’s a lot of reflective listening; it’s a lot of validation. It’s a lot of being curious, with our reflections and statements “It seems like this; this is what it sounds like to me; am I hearing it correctly?” There’s a lot of sessions rife with troubleshooting around the intervention not seeming like its working, and it’s problem solving with the family; what should we do? It can be helping them dissect the problem and then helping them come to it themselves or sometimes they need direct direction. Most of the time, its’s helping them use their own strengths, too. Come up with ideas that work in their system. Problem clarification is huge so that the family can be empowered to understand what the problem means to them and can mobilize their own strengths to resolve it.

> *The visual in my head is school, family, friends. School because that is the natural setting for youth, friends because those set social norms, and families because they are central to treatment. We need engaged caregivers that can work well together. Siblings matter as well because the whole system is affected by the illness.*

There are times where you’re the expert (and I’m sensitive because these families have so many specialists working with them, and they receive that expert opinion) so you’re sharing the expertise of behavioral treatment for eating disorders. Being strength-focused is key, where it is the notion of recovery.

Snyder: The systems perspective is critical, because there can be feedback loops that the family can’t get out of or don’t know they are in. It’s a matter of clarifying that in a strength-based way to help get them unstuck.

Mack: Thinking of systems, people getting into the work of eating disorders and family work need to get comfortable with chaos. Our job isn’t to make things calm all the time; it’s to help the family reorganize patterns of behavior that work for them. That is not a neat and tidy process

Snyder: Now, I love CBT, but I’m thinking that this model is less about cognitive restructuring or purely teaching parent management skills. It is behavioral in the sense that if we change family behavior and restructure the family environment, change happens, but that really comes from a family systems approach. The thought processes change if we can change the family process, if the child can get medically stable as you mentioned, where the low mood resolves with renourishment.

Mack: There is definitely room for more traditional CBT or DBT, where you may teach skills. There's also something called cognitive remediation, which is a therapeutic approach that's addressing inflexibility. A lot of kids with anorexia innately are very rigid, so we have groups in our Intensive Outpatient Program called "Brain Gym," where we look at those drawings that have two images depending on how you view it (the vase or the faces example). I'm learning how to explain something in a different way, and we have them pretend that there's an alien here explaining how you make a Spotify playlist. Seems simple enough but sometimes they can be so detail focused that they miss the big picture, or vice versa, and we're trying to infuse some flexibility. So all in all, we have a multimodal approach to treating eating disorders

Snyder: It really does come back to that holistic pie you have in your head; we need to address these different aspects of recovery and our interventions need to match those needs.

We are nearing the end of our time, Amy; any parting words for our readers?

Mack: I would encourage clinicians to be confident. You are working on a multidisciplinary team with their own priorities for treatment; you're working with resistant children, and you have to manage chaos. So be confident in your training, in your protocol, and be that steadying force for the family. It can be scary for some of our young clinicians to manage all of those competing demands, but you learn by doing, and in order to do it, be confident and trust your clinical judgment and your supervision. You never know what's going to walk in the door, so we need to be in a good place in order to serve the families where they are at.

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15

Chapter

Psychosis in Children and Adolescents

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Randy is a 17-year-old Black cis-male. His caregivers stated that he was a “typical” child growing up; he enjoyed playing sports, had an interest in science, and had a good circle of friends. They noticed his behavior started to change shortly after his sixteenth birthday. He started to withdraw from his friends, stopped playing sports, and had no interest in his schoolwork, to the point that his grade in his favorite subject, science, had started to drop. Randy also had less interest in maintaining his appearance, whereas previously, the way he looked and the clothes he wore mattered to him. Randy’s family was worried that their son was depressed.

Randy was referred by his primary care doctor to a psychiatrist, as the physician noted that there seemed to be something more than what could be managed in primary care. Randy received a psychiatric evaluation, and the caregivers were shocked at the doctor’s news. The psychiatrist explained, “Randy told me that he recently started hearing voices. He doesn’t want you to be worried. He said that he is embarrassed that he is experiencing these voices, that’s why he never told you. I am really proud of him for sharing these experiences because this can be a very scary and confusing thing for a teenager. The good news is that we are catching this now and not in a few years."

Overview of Psychotic Disorders in Children and Adolescents*

Randy is experiencing the beginnings of the first episode of psychosis. Psychosis, broadly defined, is marked by a disconnect fom reality and impairment in reality testing, in which the person's thoughts, perceptions, and behaviors are impaired enough to impede daily functioning (Arciniegas, 2015). Schizophrenia is readily thought of when thinking of psychosis, but psychotic symptoms can be a part of depressive disorders, a feature of some bipolar disorder presentations, or associated with substance use (American Academy of Child and Adolescent Psychiatry, 2018). Of note, especially in children and adolescents, who are still developing, early psychosis-spectrum symptoms may be accompanied by mood disturbances (either depression or manic-type symptoms) and may eventually evolve into any of several disorders (e.g., a primary psychotic disorder like schizophrenia, or a primary mood disorder like bipolar). However, there can be a necessary lack of clarity in the earliest stages when the disorder has not fully developed (Hartmann et al., 2020).

Psychosis, broadly defined, is marked by a disconnect from reality and impairment in reality testing, in which the person's thoughts, perceptions, and behaviors are impaired enough to impede daily functioning.

Two of the most prominent features of psychosis include delusions, which are fixed false beliefs about reality, and hallucinations, or sensory perceptions that occur in the absence of a corresponding stimulus (Arciniegas, 2015). Often, a thought disorder accompanies psychotic symptoms and includes features such as disorganized thinking, derailment, or thought blocking. Formal psychotic disorders include schizophrenia, schizophreniform, schizoaffective, and brief psychotic disorder. For the purposes of this chapter, we will focus on early psychosis and early-onset schizophrenia.

Psychotic disorders in children are rare, but they cannot be overlooked because they can have detrimental effects if not detected early. Additionally,

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while threshold diagnoses are rare (Kelleher et al., 2012), 17% of children and 7.5% of adolescents report having psychotic-like experiences, such as illusions (Maijer et al., 2019). Hallucinations are different from illusions, which are misperceptions of a sensory stimulus. It is imperative to hold the possibility that a child may be experiencing an illusion and have difficulty interpreting this phenomenon. Furthermore, experiences of illusions in children are often overlooked as subthreshold psychotic experiences, which can be just as significant for prognosis as threshold psychosis-spectrum symptoms. Experiencing subthreshold psychotic symptoms earlier in life can increase a child's risk for developing more severe psychosis symptoms later in life, as well as increasing their odds for experiencing other psychiatric conditions such as depression, anxiety, behavioral disorders, substance use, and suicidal ideation (Calkins et al., 2015; Calkins et al., 2017).

The loss of reality testing and the functional impairment accompanying these experiences is what differentiates the clinically significant aspects of psychosis from the common experiences of a loss of touch with reality. Thus, clinicians should be sure to ask about the presence of psychosis-spectrum experiences in children, delve into context, and inquire if there is any related affective distress or impairment as a result of these subthreshold experiences. By doing so, a provider may be able to catch these early warning signs of psychosis, with the goal of intervening early to reduce the likelihood of developing a psychotic disorder later in life.

Prevalence of Psychotic Disorders

There are two forms of schizophrenia spectrum disorders that are diagnosed in children and adolescents: early-onset psychosis and childhood-onset schizophrenia. Early-onset psychosis is characterized by the onset of symptoms prior to the age of 18-years-old, with a global prevalence estimated to be 0.5% (Driver et al., 2013; Maloney et al., 2012). Childhood-onset schizophrenia is defined as an onset of threshold symptoms before the age of 12; it is extremely rare, with study samples showing a 0.04% prevalence (Maloney et al., 2012). About 1% of the population across the lifespan develops schizophrenia in their lifetime (Maloney et al., 2012) and usually the disorder is first diagnosed during late adolescence to early adulthood (late teens to early-to-mid-20s).

It is important to note that sociological factors have been linked to a disparity in diagnosis of psychotic disorders between White and non-White groups, with Latinx and Black individuals being diagnosed with psychosis at a rate of at least three times higher (Schwartz & Blankenship, 2014). Increased exposure to adverse neighborhood-level factors, individual and community-level trauma, and pre- and peri-natal complications have been cited as risk factors for psychosis that are elevated within Black and Latinx groups in the United States (Anglin et al., 2021). Diagnoses may also be given as a result of provider misunderstanding of cultural or spiritual experiences, interpreting client guardedness as delusional, or labeling a non-local as an Other, which is particularly true for immigrants seeking care (Schwartz & Blankenship, 2014). Waltman (2013) encourages providers to be mindful of a youth's cultural and religious background, and to keep this context in mind when determining clinical significance. Providers should also ask questions about the youth's conviction in their belief, or if they are experiencing any accompanying distress, impairment, or preoccupation, in order to evaluate the clinical significance of an experience (Waltman et al., 2013). Asking questions about whether they hold their belief more strongly than others in their community can also help determine how normative the experience. In the developmental systems focus, the macro system related to cultural attitudes and religious affiliation can also shape the individual's experience, which can also shape the provider's experience while working with clients with psychosis, as these labels can create stigma.

Causes of Psychosis in Children and Adolescents

Theories of psychosis tend to highlight the role of genetics, brain anatomy, neurotransmission, and stressful environmental factors. The neural-diathesis-stress model of psychosis explains that underlying vulnerability factors, such as a family history of psychosis, individual genetic abnormalities, or exposure to stress or trauma, interplay with neurodevelopmental alterations, thus increasing risk for psychosis onset or progression (Pruessner et al., 2017). Clinicians should be particularly mindful about elevated risk due to a family history of psychosis, especially first-degree relatives with schizophrenia, and should always inquire about this (Gottesman, 1991). Genetic studies are finding that schizophrenia is polygenic, or that there are many risk-variants at the allele/chromosomal level that contribute to the disorder (Owen et al., 2016). These studies have yet to translate to clinical application, but their effect on the knowledge base has been profound. Insel (2010) has called for a better neurodevelopmental understanding of psychosis, encouraging further neuroimaging and biomarker research to solidify our understanding of the neuropathology of psychosis. Neurodevelopmental factors that can lead to schizophrenia include maternal stress or infections or other complications occurring during or post pregnancy. Other physiological considerations include head trauma with loss of consciousness, seizures and epilepsy, and certain autoimmune diseases (Owen et al., 2016). Environmental factors span early childhood adversity, urbanicity, and substance use in adolescence (Owen et al., 2016).

Early-onset schizophrenia typically co-occurs with other symptom domains ranging from obsessive compulsive to mood symptoms, to neurodevelopmental problems such as language disorders, auditory processing problems, and executive functioning deficits (Driver et al., 2013). Cognitive decline is a critical marker for psychosis, and Driver et al. (2013) provide evidence to support the phenomenon of cognitive deficits leading to the development of a psychotic disorder. While the exact cause of psychosis onset from individual to individual may vary, psychotic disorders have many different predisposing factors (Driver et al., 2013).It is critical to note that especially in children and adolescents, who are still developing, early psychosis spectrum symptoms accompanied by mood disturbance (either depression or manic type symptoms, i.e., transdiagnostically) may eventually evolve into any of several disorders (e.g., a primary psychotic disorder like schizophrenia, or a primary mood disorder like bipolar). However, there can be a necessary lack of clarity in the earliest stages because the disorder has not fully developed (i.e., a pluripotential risk; see Hartmann et al, 2020).

Developmental Systems Considerations for Psychosis Related Problems in Children and Adolescents

Certain symptoms, including hallucinations, should be considered in the context of an individual’s developmental age (Maijer et al., 2019). Consider a child who is involved in the world of fantasies: believing in and interacting with imaginary friends is a common occurrence in early and middle childhood. If a teenager or emerging adult still discusses and strongly believes in imaginary friends, view this with skepticism. While this could be an eccentric personality trait or even a coping mechanism, the persistence of these phenomena could signal something more serious. After ruling out the developmental appropriateness of the context for a voice, consider that youth with mood disorders may interpret their internal dialogue as a voice (i.e., “the voice inside your head”). This can be related to their conscience talking to them, it could be the experience of their self-reflection, or, in the case of anxiety, it could be trauma reactions, depression, and “loud” negative self-talk.

Across all these manifestations, it is critical to understand how convinced the youth is in the externality of the thoughts or voice inside their head; in other words, determine how convinced they are that they are experiencing another voice distinct from their own versus their own thoughts. Furthermore, the clinician should evaluate whether there is any accompanying functional impairment or if they are experiencing any level of distress associated with the auditory perception. For example, a youth may be experiencing affective distress because of threats from the voice to harm a family member should the youth disclose their psychotic symptoms.

Certain symptoms, including hallucinations, should be considered in the context of an individual’s developmental age.

In terms of systems related influences, there are risk factors associated with adverse childhood experiences such as poverty, socioeconomic status, exposure to trauma, and discrimination-based stressors. Growing up with a family member with their own mental health challenges can also be stressful and may lead to a more adverse family environment, including more hostile interpersonal interactions. In fact, having a first-degree relative with schizophrenia increases a child's risk for psychosis (Walder et al., 2014). On the other hand, strong social supports and involved families can also serve as protective factors in a youth's life. So, while there can be a family history, the family can also be the medicine. Also, consider a youth's greater environment, including their neighborhood and the safety of that environment and the vulnerability it can generate. On the opposite end, consider the potential resilience-promoting role of a youth's schoolteachers, who could be helpful in identifying students with rapid cognitive decline or declines in academic or social functioning, and who could refer a child for evaluation for mental health services. Lastly, keep in mind ethnic and cultural contexts; religiosity has been suggested as a method of coping with hallucinations in children and adolescents (Maijer et al., 2019), and in adult populations, there have been differences in understanding of hallucinations comparing European and African samples (Furnham & Igboaka, 2007; Maijer et al., 2019).

Assessment of Psychotic Disorders in Children and Adolescents

Assessment of a psychotic disorder requires ruling out any other disorders that may better explain the presence of psychosis. The differential diagnosis process works through ruling out whether the presentation is related to the effects of a substance (e.g., synthetic cannabinoids) or a medical issue (e.g., head injury, viral meningitis), then understanding the specific primary disorder (e.g., is psychosis primary or is it secondary to a depressive disorder), which can be determined based on the timing of onset of the psychosis symptoms in relation to other psychiatric/medical symptoms. As with other diagnoses, differential diagnosis is critical to rule out malingering or a factitious disorder. Keep in mind that reports of psychotic experiences from youth can be accompanied by clinical features like being hesitant, confused, or embarrassed to disclose. Psychosis symptoms are typically not a readily shared experience, in part due to the stigma surrounding a diagnosis of schizophrenia. It is important for providers to develop good rapport with their clients and to be patient if a youth needs time to become comfortable and trust their provider before opening up.

Earlier in the chapter, psychosis was largely defined by the presence of hallucinations and delusions; however, this does not paint the entire picture. These are known as the positive symptoms of schizophrenia, due to the presence of experiences that are not ordinarily present. Hallucinations have different presentations, with auditory hallucinations such as hearing voices being most common. Other types of hallucinations include visual hallucinations, olfactory/gustatory hallucinations (related to smells and tastes), and tactile hallucinations (related to the sense of touch). A classic example of a tactile hallucination is the feeling that bugs are crawling on the skin, which is also a common phenomenon for people undergoing opioid withdrawal. Delusions are the other type of positive symptoms, and they span fixed false beliefs such as persecution (e.g., the government is out to get me; others are going to hurt or harm me) to grandiosity (e.g., I can jump off a building and not get injured; I have been chosen by God for a special role).

There is also a set of negative symptoms that may develop, which are deficits in behaviors that are experienced by a typical individual, and include affective flattening, anhedonia, avolition, and alogia (American Academy of Child and Adolescent Psychiatry, 2018). Though negative symptoms may appear like depressive symptoms, a key question that can help (though doesn't always) differentiate is to ask about the mood itself (e.g., "Do you feel sad, down, or blue?") Some individuals with negative symptoms will not endorse these questions. Additionally, individuals may experience disorganized speech or behavior. Individual presentations of psychosis are quite heterogeneous.

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In assessing a youth for psychosis-spectrum symptoms, while family members may be a valuable source of information for providing their observations on the effects of negative or disorganized symptoms on a youth's demeanor, they can often be unaware that their child is experiencing positive symptoms like hallucinations. Again, developing a good rapport with your client is of the utmost importance.

Clinicians should be aware of what is known as subthreshold or "prodromal" psychosis, which is the period of subthreshold signs and symptoms that precede the onset of threshold psychosis (Larson et al., 2010). A comprehensive assessment and ongoing monitoring of symptoms is crucial to catch this prodromal period in both newly established and well-established adolescent clients, as the duration of a prodromal period can last from a few weeks to several years (Larson et al., 2010). Some youth may never develop a psychotic disorder; that is, they may never cross the threshold and may continue to experience subthreshold symptoms for years, in which case a personality disorder diagnosis (e.g., schizotypal or paranoid) may eventually be considered in adulthood. Other youth may experience time-limited subthreshold psychosis symptoms that fully resolve. These symptoms may include disturbances in perception, cognition, language, motor function, and level of energy (Olsen & Rosenbaum, 2006), and while these can certainly be comorbid, they are not required according to current definitions of at-risk states.

Comorbid symptom domains may also be present during the prodromal period (Larson et al., 2010) including symptoms of depression, anxiety, or trauma. Prodromal symptoms may occur with less frequency, shorter duration, or reduced severity than clinically significant levels of psychotic symptoms (Yung et al., 2005), though they still may be worthy targets of treatments. Another way to conceptualize such presentations is through Attenuated Psychosis Syndrome (APS). This is defined by the presence of delusions, hallucinations, or disorganized speech in attenuated form; however, the severity and frequency warrants clinical attention (APA, 2022). APS features can occur for the first time in adolescence (Arango, 2011; Tsuang et al., 2013), and represent a large majority of clinical high-risk symptoms for individuals with psychosis (Fusar-Poli et al., 2016).

We saw with Randy that he reported hearing voices, or auditory hallucinations (i.e., positive symptoms), which aligns with what is experienced by many youths experiencing psychosis. It was also clear that Randy was experiencing negative symptoms, which his caregivers perceived as depressive symptoms. For example, we saw that he was becoming more socially isolated by withdrawing from his friends, not engaging in the activities he regularly enjoyed, and losing interest in his favorite subject, science. A key question that can help differentiate (though not always) is to ask about mood itself: “do you feel sad, down, blue?” Some individuals with negative symptoms will not say yes to these questions. Randy was also less interested in his appearance, which may be considered an early sign of disorganized behavior.

Common Assessment Tools for Psychotic Disorders

One of the most commonly used disorder-specific diagnostic instruments for assessing and diagnosing psychosis is the Structured Interview for Psychosis-risk Syndromes (SIPS) (McGlashan et al., 2001). This clinician administered semi-structured interview assesses the severity of 19 positive, negative, and disorganized symptoms on a 0-6 scale, including probing in detail about an individual’s experience, degree of conviction/meaning, degree of distress, interference with life, frequency/duration, age at which they first had the experience, and how the experience may have changed over time. Positive symptoms rated at level 6 indicate the presence of a psychotic disorder. Positive symptoms rated at levels 3, 4, or 5 l that began or worsened in the past year and occur at an average frequency of at least once per week in the past month may meet criteria for Lifetime Attenuated Positive Symptom Syndrome (APSS).

The Comprehensive Assessment of At-Risk Mental States (CAARMS), more commonly used outside the United States, also assesses for the presence of subthreshold and threshold psychosis symptoms (Yung et al., 2005). Two transdiagnostic assessment tools include the Kiddie Schedule for Affective Disorders and Schizophrenia (K-SADS) and the Structured Clinical Interview for DSM (SCID). After rigorous training on these diagnostic instruments, clinicians will be able to comprehensively assess for the presence of psychosis-spectrum symptoms; at the very least, they are invaluable tools for starting a conversation with a client to understand what their experiences are like for them.

Apart from conducting full-length diagnostic interviews, the Prevention through Risk Identification, Management, and Education (PRIME) Screen can also be a useful screening tool for quickly assessing the presence of positive symptoms (Miller, 2004). Based on the SIPS, this 12-item self-report measure asks individuals to rate on a scale from 0 (definitely disagree) to 6 (definitely agree) whether they have had a certain sensory, psychological, emotional, or social experience within the past year. For endorsed items, youth are then probed about the first time they had that thought or experience. Calkins et al. (2017) developed age-norms to accompany the PRIME Screen and have shown that younger community youth in a nontreatment seeking sample have higher total scores compared to older individuals.

Intervention with Psychotic Disorders

In their review of treatments for psychotic disorders in children, Hrdlicka and Dudova (2015) found that antipsychotic medication is the routine treatment, offering the following as medications shown to have efficacy: olanzapine, aripiprazole, quetiapine, risperidone, and lurasidone. These are known as second-generation antipsychotics (Hrdlicka & Dudova, 2015), as they were part of the second wave of medications developed to treat psychosis.

However, it is critical to understand the risks, benefits, and side effects of antipsychotic medications. Prescribing antipsychotics to a child is a serious treatment decision. There are known side effects with antipsychotic medication, particularly with the second-generation drugs. The following are common side effects: metabolic side effects such as weight gain, diabetes, and hyperlipidemia; akathisia, or the subjective feeling of restlessness and agitation; and tardive dyskinesia, which is characterized by jerking muscle movements, being "tongue-tied," or lips being pursed uncontrollably (Hrdlicka & Dudova, 2015). Monitoring is even more critical for medication treatment of psychosis, especially if the client is required to be adherent and committed to the treatment. If there are issues with commitment to the treatment plan, injectable medications can be an option, in which the patient would receive one administration of medication that can last 30-90 days (Maloney et al., 2015).

Psychosocial Interventions

While antipsychotic medication is a common treatment modality, not everyone may experience symptom reduction with medication treatment alone. Psychosocial treatments center on psychoeducation for clients and family members. Early identification and initiation of treatment can be preventative of severe psychosis and consequent disability (Armando et al., 2015; Maloney et al., 2012; Maijer et al., 2019). Social skills or coping skills can be introduced to cope with the initial distress of receiving a psychosis diagnosis and of the symptoms themselves (Maijer et al., 2019; Morrison et al., 2020). In another systematic review, Anagnostopoulos et al. (2019) reported that treatment recommendations for the psychosis population should center on cognitive-behavioral therapies (CBT) for psychosis and family-based interventions, both of which are aimed at limiting the distress related to experiencing psychotic symptoms and buffering against any consequent functional impairment. Two forms of CBT are specific to the treatment of psychosis: CBT for Psychosis (CBTp) and Recovery Oriented Cognitive Therapy (CT-R). The latter focuses on empowerment and resiliency, with a focus on how that person aspires to live a meaningful life (Beck Institute, 2020; Grant et al., 2012). It is also effective at addressing motivational issues surrounding engagement in treatment. CBTp emerged prior to CT-R and is more focused on symptom reduction to improve quality of life (Beck Institute, 2020; Sönmez et al., 2020). In a sense, one is thinking of adding something to improve quality of life, whereas the other considers taking away something to achieve the same end, resembling positive and negative modes of reinforcement.

With Randy, the first step in his treatment plan was considering the initial onset of symptoms and providing psychoeducation to him and his family about those symptoms, as well as instilling hope for his future. Early psychotherapy sessions focused on developing a plan to cope with his symptoms, understanding triggers, and subsequent emotion-driven behaviors. Because Randy was experiencing functional impairments, antipsychotic medication was offered to provide more immediate relief from symptoms. Family involvement also helped to support functional interventions. For instance, to help Randy with maintaining reality-based perceptions, the family was encouraged to communicate directly with Randy, in the same room, making eye contact in the hopes of trying to limit the distress of wondering whether or not the voices he was experiencing were based in reality or a product of psychosis. These functional interventions served as the basis for treatment. Goal setting included getting back to socializing and back into activities he enjoyed after stabilizing on medications and when he was functionally back on track.

In addition to learning to tolerate his symptoms, it was important to incorporate the recovery orientation of CT-R. With the help of a supported education specialist, Randy felt like he could get back on track with accomplishing his short- and long-term academic goals. Some motivational interviewing was also helpful to work through the ambivalence he felt as a result of feeling like he was "so far behind my classmates." His family and treatment team were committed to supporting Randy with getting back on track with his science class, and hopefully, his progress in that class could generalize to other courses. Randy was also introduced to a peer specialist, or someone with a lived experience of psychosis, who had already gone through the same CSC program and could be a model of hope for Randy, in addition to helping him reconnect with his friends and family. After two years of regular engagement with treatment, Randy was able to lead a life similar to what he led before the onset of his psychosis. He was not disorganized like he was before, and he no longer had the motivational deficits that kept him from pursuing the activities he liked to do. While positive symptoms like auditory hallucinations still presented at times, Randy was back in the driver's seat, knowing how to thrive and be well, and was on track towards recovery from psychosis.

Early intervention can be very protective for youth experiencing onset of a first episode of psychosis by providing them with the tools to challenge the reality of their beliefs. High rates of subthreshold psychosis have been found in community youth samples (Calkins et al., 2015), highlighting the need for referral to psychosis specialty services, which have been found to be more effective in treating psychosis symptoms compared to community care (Kane, 2016). In 2013, the United States Congress allocated funds to be distributed through the Substance Abuse and Mental Health Services Administration (SAMHSA) to fund evidence-based Coordinated Specialty Care (CSC) programs for individuals with early onset psychosis across the United States. By 2019, there were first-episode psychosis CSC programs in all 50 states. The Psychosis-Risk and Early Psychosis Program Network (PEPPNET) has an online interactive directory that individuals and families living in the United States can access in order to locate their nearest CSC program. The Early Psychosis Intervention Network (EPINET) has a similar interactive map on their website. The core components of the CSC model include psychotherapy, medication management (if warranted), in addition to family psychoeducation, supported education and employment services, cognitive remediation, and peer support.

The key to improved outcomes for youth is early detection and linkage to appropriate care.

Clinical Dialogues: Working with Psychosis in Children and Adolescents with R. Marie Wenzel, MSW

Ruth Marie Wenzel, LSW is the program director for the Peace Program, which is housed within Horizon House in Philadelphia. The Peace Program has been around since 2015. and Wenzel has been with the program since December 2016. The program itself is a first episode psychosis program for young people in Philadelphia County, age 15 to 30, who are Medicaid recipients or Medicaid eligible. The program targets young people who have developed psychosis within the last 18 months, and it serves as an early intervention right at the onset of psychotic symptoms and as the beginning of intensive wraparound services.

Sean E. Snyder, LCSW: Youth with psychosis is a population that can fall through the cracks, so I'm pleased to have our readers learn more about this population.

So, let's start from the beginning, with the engagement (i.e., the multidimensional commitment to treatment). When families come to you, how do you approach joining with them around their issues? There can be a lot of confusion or fear about what's happening, considering that psychosis does deal with reality testing: "What is this that am I experiencing? Is this a voice? Is this my thought?" How do you join with your clients when they initially meet you all?

R. Marie Wenzel, LSW: Each approach is tailored to the individual and their individual circumstances. We have a whole spectrum of people who come to the program with lots of family support, with no family support, who are in the foster care system, who are experiencing homelessness. It really depends on who that individual is and what their immediate needs are.

We approach the emergence of psychosis as an emergency situation that needs immediate attention. Given this, we really try not to have wait lists, which is really important so that we can directly call and get them connected to services right away. We do have a pretty rigorous intake process where we're really trying to define, "Is this psychosis? If it is, when did it start?" In that process, we're talking to everyone connected to that loved one. We're trying to talk to everyone in the very beginning to put together a timeline to really nail down when these things really started to happen. When did disruption in functioning happen? It's a lot of gathering history in that same context. Then we share with them what we're doing and why we're doing it and really explaining to them along the way about how our services are working. But we do it in a way where language really matters.

We don't really often talk about diagnoses with families or participants unless they're bringing it up, unless they really want to know for some reason, which often is not the case. We're talking more around goals and challenges, thinking through the strategies that have worked in the past with helping their loved one but then also recognizing that we're giving a lot of psychoeducation and information around what could be happening now. It's very general because we don't want to prescribe this idea that someone has schizophrenia if they don't, and because of the stigma related to psychosis specifically, we really try to really talk about their experience. For instance, "Do you hear a voice? What does it say? Or do you have a hallucination?" We're trying to change that language, change that narrative and help families. We try to ease the impact of what that feels like so that they can become a little bit more open to our services.

I should note that everyone in the general population experiences some psychosis at some point, not just those with a psychotic disorder, for example, if you've felt your phone vibrate in your pocket when it wasn't vibrating. We're on a spectrum. We have these moments where we may feel out of touch with reality, like the phone example.

Our biggest goal is to bolster as many social and natural supports that a person has that we can lean into. Then it's moving at the pace of the participant.

A lot of times they get a diagnosis of schizophrenia in the hospital setting, which then adds to the chaos and propels the family into this spiral of fear because of the stigma that most people have associated with that. That fear can often lead to denial, which can really impact our ability to engage a family or a participant if they're at the point where they're saying my son doesn't need your program because he doesn't have schizophrenia. We want to help figure out what's going on to get them back on track. So, you mentioned they haven't been going to school for a couple of weeks. What can we do to help you help them get back in school? We're shifting away from the diagnosis and experience and putting it back on how we can get you back on track.

Engagement looks really different. We have a little bit of flexibility, and I joke that we walk a fine line between assertive and aggressive engagement because we know by the nature of psychosis itself, engagement is one of the biggest challenges. We're working against negative symptoms, like the fact that people want to isolate and feel safe isolating. If we were talking about depression and anxiety, and you were saying, "Sam, your therapist is going to show up at your door, knock on the door and say you missed your appointment yesterday, what happened? I'm here to see you." That might be a little bizarre, but for us, that means it could be that somebody was sitting in their room for eight hours responding to internal stimuli, and they weren't able to answer the phone. That's why we're here.

Our biggest goal is to bolster as many social and natural supports that a person has that we can lean into. Then it's moving at the pace of the participant. I'm working with a 16-year-old who says, "Nothing is wrong with me; my mom's the problem, right?" Okay, how can we help you figure out how to work with your mom and live with your mom? It's really using their language, what they want to work on. In that process, we begin to work on managing psychosis, managing symptoms of psychosis, medication management, things like that.

Snyder: It sounds like it really is the infusion of the recovery orientation, like this thing happened to you, and it's "How can we respond to that?" It's really phenomenological, e.g., "This thing's happened. What can we do to support you to improve the quality of your life?" I love that you said natural supports, being in the community with people harnessing what's readily available to them as opposed to the complete opposite of when we think of psychosis. The other end is thinking about the stigmatizing, institutional approaches.

This might be part of the education, let's say. Are they interested in knowing more about why this is happening to me? Are they're asking you, "Why is this happening to me?" I know you tailor to individual cases, but on the whole, how do you explain that?

Wenzel: We usually explain psychosis in a way where it's your experience of reality is different than other people's experiences around you. Oftentimes, we don't necessarily know why it's happening, and we're comfortable in saying that we don't know and that why it's happening often really is not the most important thing. Now that it's happened or happening, it's what do we do with it? How do you live with it? How can we make it so it's not stressful?

I would be honest and say we don't get asked the "why" so much. The biggest challenge comes with getting people to understand the idea that intervention isn't, "Here's a pill, and it goes away, and you don't have any issues anymore." This is something that you might have to manage more long term, and we might have to change the approach several times in the process; it's not one size fits all.

It feels experimental, and it feels experimental to a person and their family. "What do you mean you don't know why that medication isn't working?" Things like that, where it's not a perfect science, it is a lot of trial and error. It's a fine line between not making someone feel that they have a chronic illness, and they're condemned for life, but also not something where you're going to be perfect tomorrow.

> *We usually explain psychosis in a way where it's your experience of reality is different than other people's experiences around you. Oftentimes, we don't necessarily know why it's happening, and we're comfortable in saying that we don't know.*

Snyder: You mentioned the timeline and how important that is to understand early on. And then you were connecting that with how you understand the context of the psychotic symptoms. Is that the critical reason that you are focused on making sure that you understand the timeline of events?

Wenzel: The research shows that the duration of untreated psychosis, or what we call DUP, has a huge impact on the efficacy and the outcomes of our programs. The sooner you intervene in somebody's psychotic experience, the better. Ideally, the World Health Organization says less than three months since onset. There's a switch that happens at the onset of someone's psychosis. They're still able to have what we call insight, that they can identify that something's not right. Once they externalize to thinking, "The government is stalking me," or someone else is following them, the work becomes harder and you're looking at a longer-term recovery. We can and have successfully intervened really early with people where then they have not had another psychotic experience again while in our program.

So, once you start getting into, like the two years plus of untreated psychosis, it becomes much more challenging. So that's why we're nailing down questions like when did they start having the positive symptoms? So, hearing a voice, having a hallucination, and then they might say, "Oh, that happened six months ago." But then they'll tell us in 10th grade they got into a lot of fights. They were agitated a lot. They stopped hanging out with their friends. So, we would start to then go back to 10th grade. What was happening then? Because as soon as we can start to see a change in someone's functioning—like hanging out with friends and family, participating in activities of enjoyment and pleasure, participating in school appropriately—once you start to see those things change, we can start to nail down that there were probably psychotic symptoms happening around that time. But sometimes the referral comes much later than the initial expression of symptoms.

Snyder: I also want to ask you, do you distinguish whether the psychotic symptoms that are now being identified were related to another diagnosis, like trauma and PTSD or even depression with psychotic features? Does that impact how you work with someone?

Wenzel: It's essentially nonaffective and affective psychosis, and at Peace, we treat everyone who has a psychotic experience. However, the research that created early intervention programs for psychosis was only targeting people who had schizophrenia specifically. So, the research body that informed the model for coordinated specialty care only included working with people with schizophrenia. We've built the program off of that research. We're now finding that it's challenging for us because we see people with many other presenting challenges other than psychosis, but we can target psychosis and work on other issues.

The development of CBT, and we use CT-R, which is recovery oriented cognitive therapy, was developed out of the Beck Institute here in Philadelphia. Those interventions, again, were developed using a cohort of people who had exclusively schizophrenia. When you add MDD to that or bipolar disorder to that, it changes the treatment. We're not just treating the psychosis, but we now have to adapt and treat some of the other challenging problems. But we do see everyone. Trauma related psychosis is really, really big in Philadelphia and is the least likely to respond to antipsychotic medications. A lot of times we're looking at how deep the trauma work is that needs to be done, because resolving the psychosis is based on resolving the trauma.

Snyder: It seems like it is a good point to juncture into with the assessment you mentioned about timelines and parsing out when what's happening. So, you get the youth and the families engaged to come for an assessment. Do you use any standardized scales, and if so, what's the rationale for using or not using them?

Wenzel: So, we're part of the HeadsUp network, which is the Pennsylvania Early Intervention Center out of the University of Pennsylvania, and we have a battery of assessments to use. We do a standard biopsychosocial and a psychiatric evaluation. Usually those happen once we've already determined that someone's eligible for the program. I want to say the only other exclusion criteria we have is IQ less than 70 and moderate to severe autism disorder because we're using a primarily cognitive intervention. We do the Global Functioning: Social and Role assessments, so that's an assessment done by the clinician once the biopsychosocial is done. Essentially it's like an old Global Assessment of Functioning (GAF), so we can assess changes in their social and role functioning over the past year prior to enrollment in our services.

We do the BPRS, which is the Brief Psychotic Rating Scale, which the psychiatrist completes. And that's also done based on the psychiatrist's interpretation of the person and formulation of the person. Then we have the GASS (Glasgow Antipsychotic Side Effect Scale). So that's measuring side effects of medications like involuntary muscle movements. Because of the antipsychotic medications, there are often a lot of really extreme side effects, and because we're working with young people, the more extreme the side effect, the less likely they are to use medication. We want to try to monitor and manage that as much as possible, so there's also a medical monitoring form that the nurse does for monitoring metabolic changes, again, because of the side effects of the medications. The population we're working with is at a higher risk for metabolic issues in general, then you add these antipsychotics. We're trying to manage that and manage physical health and wellness at the same time.

The participants complete self-report skills, so they do this independently or they do this with the support of their therapist, the peer specialists, the case manager, whoever they want support from. Then they do the Lehman Quality of Life Functional Assessment that's measuring happiness and how happy they are with their life. There's the Questionnaire About the Process of Recovery (QPR). We have the Mental Health Statistics Improvement Program (MHSIP) Youth Services Survey (YSS) that's measuring how satisfied young people are with the mental health treatment they're receiving and the services provided at the program. It's really trying to link the skills they learn with a progress measure for them, as well as keep it relevant and give appropriate feedback to us.

Snyder: It's interesting to see the different aspects with all the assessments. Of course, antipsychotic medication is very serious, seeing that you're monitoring the medical things and the side effects. I was really happy to hear about the overall quality of life and happiness questions because that's a very recovery-oriented approach where it isn't focusing on symptom reduction but keeping sight of the big picture and all these different systems in the individual's life.

Wenzel: We use a lot of scales, but we try to make it as personable as possible. It's not lost on us who the population is that we're working with. We're working with predominantly African American, adolescent males in Philadelphia. This group of people is often not included in the research and outcomes that are being measured. We carry the state that way in terms of being able to get what's happening in this urban environment with people in extreme poverty to be able to compare that against what's happening in the rural parts of Pennsylvania and what's happening with their young people.

For clients, we do have the ability to show the changes over time to them if they're interested, so the clinician is able to see the effectiveness of their therapeutic work over time. "Well, back in 2019 look at how isolated you were. But look at you now. Look at this change." And we are encouraging conversations about real life issues like trouble with their significant other or family, or even topics like erectile dysfunction after starting a medication. We need to be real with them.

Snyder: That's why I love measurement-based care. It shows the person you're working with that, “hey, this is working, or this isn’t really working. Let’s see what adjustments we can make.” Also, as clinicians, it’s nice to see that. We don’t get a lot of butterflies, or sometimes there’s so much compassion fatigue that when you measure it, you can hopefully see that you’re making a difference. I’m always a big fan of measurement-based care.

Wenzel: The data will show that about 80% of our participants report trauma, which is, again, really high. But I would argue that probably ninety-nine and a half percent of them have all experienced trauma. We’re talking tons of trauma and tons of poverty related challenges.

Snyder: You and I met because those same young people who are faced with lots of challenges every day in deciding a good choice or a bad choice and choices that have consequences or what they’re weighing out these issues, and they end up in juvenile detention.

Wenzel: A lot of times the psychosis is not the primary issue that we’re looking at. It’s just a complicating factor in an already very complicated system and life. So, what I would say is that we very rarely diagnose people with a schizophrenia diagnosis. Sometimes they come with that diagnosis, which might be what’s in the chart. But if our doctors are doing the diagnosis, they’re getting an unspecified psychosis diagnosis, that then might be changed later if it needs to be changed, but it often isn’t changed if it’s not required by insurance for medication or something like that. People who do have mood disorders with psychosis might get diagnosed with bipolar disorder. So, what we typically see is people who already have a bipolar disorder diagnosis before they develop psychosis. The psychosis symptoms developed a year or so after, maybe several years after. So, it’s figuring out what’s happening. Are they in a state of mania? Or is the issue a psychotic break. What’s going on there? I would say everyone has trauma, though. That’s definitely a thing with our population.

Another important topic is substance use. The drug of choice for people with psychosis in our program is marijuana. It affects dopamine receptors, so there’s the neural pathways there that are similar to psychosis. It’s tough for individuals because it’s such a normalized substance in our society today, so telling an 18-year-old kid to not smoke weed with his friends is really hard. We don’t see opiate abuse in this program. That’s also very interesting. We do see alcohol, we see an increase of alcohol use in the program over time, but we attribute that mostly to people turning twenty-one-years-old while in the program and being able to legally consume alcohol. There’s definitely a lot of tobacco use with people with psychosis, and a lot of that is related to their medications, oddly.

We're not just treating the psychosis, but we now have to adapt and treat some of the other challenging problems... A lot of times we're looking at how deep is the trauma work that needs to be done because managing the psychosis is based in resolving the trauma.

It goes beyond the purely clinical too. At Peace, I would say our biggest challenge is the trauma history, and then second to that is probably the challenges related to being in poverty. So, transportation, employment, food, heat, housing. For families who have a single mom with several children, often her 16-year-old who just developed psychosis is not her primary concern. It can become really complicated. We try to come in as a resource for that young person, but also as a resource for that family. We know that if we can help mom have heat and food to eat, that she's then able to support John and log into our virtual family therapy session on Wednesday. She's more willing to buy into us because she knows that we can help her, too. We identify small gifts that we can give, even if it's the gift of having a session with a loved one around some strategies on how to get their person to do the things they want them to do. They want them to get up and shower and eat breakfast. How can we give them some strategies to help do that in the home? Because they're really different specific things.

There are other functional things too. So, talking to a person with psychosis from behind them when they can't see you, for example, can make it sometimes difficult for them to decipher. "Is someone really talking to me or is this the voice in my head?" We suggest to mom that instead of yelling from the living room, come into the room, look and make eye contact and say the same thing. They're much more likely to respond to you because they can see you and know that you're talking directly to them. So, it can be something that small that I yell at my kids from rooms away and they can't see me. And that's a very normal, common thing to do. But that's not going to be effective to get someone who's maybe actively experiencing hallucinations or voices to get them to do that thing. So, some small things like that.

Snyder: That seems like a nice segue into the interventions. Can you talk about those functional things and how you can intervene with the family system or just the things that are in the person's life? It's not just cognitive restructuring, but we have to think about those everyday experiences, too.

Wenzel: Most of the interventions we use are more functionally based. We don't treat to symptom elimination; we treat the symptom management, with the least amount of medication possible to make sure that voice or hallucination is not distressing anymore. You can continue to do what you were doing. So that person might still hear the voice. But it's not shouting. It's lower. I can continue to log in to school and talk to my teacher or I can get myself up and go to work. If we medicated someone to symptom elimination, they wouldn't have anything left to function. They wouldn't have the motivation and ability to function because of how the medications work. So, because of that, then we have to come up with other ways. How can you tolerate the symptoms? So, we work with a stocker at Walmart whose voices were yelling at her while she was taking a break from stocking her shelves. She called her therapist and the therapist picked up to talk to her for ten minutes. She was able to do some grounding exercises, stop the voices and was able to return to her job instead of having a full crisis, and needing to go to the hospital or maybe even losing that job.

There are strategies we can confirm. We offer 24/7 on call support so families or participants can call, and they'll get a clinician twenty-four hours of the day to be able to intervene in an emergency situation like that, or help with medication management, things like that, whatever comes up. That's a big thing that we're really addressing now is how to safely support families in the community, and we avoid the gateway to hospitalization in Philadelphia, which is the police. How can we be the buffer between a family and a participant and the police when they're responding? So, we have all sorts of new strategies that we're using and trying and testing and trying to support our families because they don't want to call the police. Yet they're in situations at times where they really need help. For us, it's also making sure that families can trust us. We represent a system that often shouldn't be trusted or couldn't be trusted historically around an illness that people don't want to have and don't want their loved one to have. So, how can we make it as soft or as approachable as possible? We do as much as we can.

Snyder: I think you've covered a lot of what the recovery oriented cognitive therapy way is, where it's adding quality of life, versus CBT for psychosis, which is really about symptom reduction. And then talking about what does that look like in the community, like when you mentioned the client that called their therapist while they are at work. Really thinking about those functional things. I guess are there any other more direct clinical interventions, for the readers of our book that you would say are some core things to be mindful of?

Most of the interventions we use are more functionally based. We don't treat to symptom elimination; we treat the symptom management, with the least amount of medication possible to make sure that voice or hallucination is not distressing anymore.

Wenzel: We also use them. Especially around substance use and then other choices. So, there are definitely folks, again, who experience metabolic challenges and changes due to medications, so we use interventions around developing exercise routines or changing eating habits, things like that. We've been trained in a specific trauma intervention in our program as well that uses workbooks and things like that. With that foundation in trauma, we also use the CT-R and do have monthly consultations with Dr. Michael Garratt, who is trained in psychodynamic work. So, for the people who are at the point where they do want to process the meaning of their delusional content or they do want to process some more of the structure of their psychotic experience, there is an opportunity for that to happen as well through psychodynamic approaches. There are definitely people in our program who are much more interested in doing the psychodynamic talk therapy versus the activation and behavioral and functional interventions that we're using with some other folks. I have a lot of clinicians trained in psychodynamic work. It can be a learning curve for them to take a step back when we're talking about engagement work, which is what would happen in the CTR format. But it's a nice blend, and it's nice to be able to help people work through their experiences and make the connections in their psychotic experience. But not everyone's at the place where they can do that.

Snyder: There are power decisions made around medication, because it sounds like you're really trying to manage symptoms and not have a lot of overmedication or misuse of medication that really has so many side effects.

Wenzel: Our doctors follow a shared decision-making approach that comes out of Temple by Dr. Elizabeth Thomas and Yaara Zisman-Ilani. They're out of Mark Salzer's group. So, they developed the shared decision-making tool that we like. Their researchers did some research with our participants, and we use that now. So, the providers use that and it's not with everyone again. But for some people, it's nice to be able to weigh out their decisions and what's more important. But ultimately, the participant makes the decision for themselves. That can be really challenging because there are families who want their loved one on a specific medication, on a different medication, on a higher dose or on this, or they don't want them on medication and the person wants to be on medication.

It's always a dance. But ultimately the participant makes that decision, and they can tell us, "I don't want medications, I want that specific medication." I mentioned our process around 302s. What we're trying to do now is get more proactive in developing advanced directives when someone is well enough to be able to tell us, "OK, when I'm not well, this is the person I want to intervene. This is the hospital I want to go to. This is the medication I absolutely will not take. This is the medication I will take. I do want this is." I'm trying to get people to develop their plan in advance so we're ready to go if something happens. "OK, Mom, you're the one intervening." We give them control. How can we give them the control when they are not well enough to be able to make those decisions?

We represent a system that often shouldn't be trusted or couldn't be trusted historically around an illness that people don't want to have and don't want their loved one to have. So, how can we make it as soft as possible or as approachable as possible?

It's really hard because, again, people have advanced directives, and they think that we're talking about death. They get very like "I don't want to talk about that." So, again, language matters. I would say that's another thing on language matters. We are not saying that you have to come to therapy, that you have to see your therapist, that there's something wrong with you. We say we're a bunch of people who want to hang out with you. We have people who specialize in different things. If you need help with this, this one can help you. If you need help with that, that one can help you. But whatever you want to work on is what we're here for.

We use the term entourage, which flies with some folks, and we really try to use their language. If they're saying that I have a connection to spirits. Cool. You've got a connection to spirits. Who are we to tell you that that is something else? So, using the language that the participant is using to describe their own experience, working with families around reality testing, because a lot of times they want a reality test. You might as well bang your head against the wall, like try to convince someone who believes something happens, that they shouldn't believe that. Then you have families who are doing this all the time, and they're frustrated all the time.

Snyder: Like DBT skills like radical acceptance and teaching opposite action. That sounds like that's a tall task with working with families because there's so much going on. But it sounds like you do such great work and impactful work.

Wenzel: We keep people out of the hospital. The biggest goal of the program is to keep people out of the hospital. If they end up going to the hospital, have the length of stay be as short as possible. Also, to keep people at work, in school, volunteering, being active in some capacity in their community, social sphere, family, whatever that looks like. And ideally, staying off of Social Security because we're able to keep them working. So those are the main goals of the program.

Snyder: That may be a good place to end; when working with psychosis, we are working to help folks stay active in daily life, whatever that means to them. It is all about recovery and quality of life. To do that, we need the clinical awareness and techniques of ensuring the accuracy of the timeline to be as early and targeted with intervention as possible. It's organizing things with them, and that process needs always to keep the patient at the center of care, and focus on recovery, considering the lives that these clients want to live, and how to assist them in living a fulfilling and meaningful life.

Things Clinicians Should Know

Psychosis: a disconnect from reality and impairment in reality testing, in which the person's thoughts, perceptions, and behaviors impede daily functioning.

Delusion: a positive symptom of psychosis characterized by a fixed false belief such as grandiosity or persecutory beliefs.

Negative symptoms: symptoms that include avolition (lack of motivation), anhedonia (lack of anticipation or experience of pleasure), and social withdrawal.

Recovery-oriented cognitive therapy: an intervention approach that is a "strengths-based approach that focuses on activating adaptive modes of living, developing meaningful aspirations, and engaging in personally meaningful activities to bring about one's desired life" (Beck Institute, CT-R).

Common Elements Approaches

Psychoeducation: about psychosis, intervention options, and including the family in this process.

Family engagement: using strategies to facilitate family participation in treatment.

Cognitive coping: examining helpfulness of thoughts, working through reality testing.

Problem solving: in the context of treatment planning and in everyday decision making.

Open Access Assessment Tools

Structured Interview for Psychosis-Risk Syndromes (SIPS)

Mini- Structured Interview for Psychosis-risk Syndromes (Mini-SIPS)

Kiddie – Schedule for Affective Disorders and Schizophrenia – Present and Lifetime (K-SADS-PL)

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Chapter

Suicide and Self-Injurious Thoughts and Behaviors in Children and Adolescents

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"Kayla, one of your teachers asked for me to check in with you because they noticed you are quieter than usual in the classroom, and they also noticed some cuts in your arm. I care a lot about you, and I want to make sure you are okay." Kayla sunk a little in the seat in her school counselor's office and did not respond. After a long pause, she pushed up her sleeves. There were dozens of tiny red scratches on her forearms. "I see; it seems like you've had a lot of stress recently. In the past week, have you had thoughts of wishing you were dead, or falling asleep and not waking up?" Kayla didn't make eye contact but said "I've wanted to die ever since the kids made fun of the way I looked, made fun of my parents and family. I feel like I don't fit in here." Kayla recently transferred schools and was new to her high school. Her biology teacher had noticed the scratches and reached out to the school counselors. After finishing up with the suicide risk assessment, it was determined that Kayla was at a moderate risk. The counselor directly addressed the suicide risk, implemented suicide prevention strategies, and developed a safety plan. Kayla's parents were notified and involved with the safety planning to ensure that no lethal means were accessible at home. Finally, the counselor worked with the parents to ensure that Kayla had someone to pick her up and stay with her after school.

Overview about Suicide

Kayla was experiencing suicidal ideation and self-injurious behavior, two of the strongest predictors of suicide attempts. Suicide is defined as "death caused by self-directed injurious behavior with any intent to die as the result of the behavior" (CDC, 2013a). In a sense, it represents an outcome of several things going wrong all at the same time (Crosby et al., 2011). The Center for Disease Control and Prevention (2019) reports that suicide is the second leading cause of death for people ages 10-34 in the United States, and that 12 million American adults seriously thought about suicide, with 1.4 million people having a suicide attempt (CDC, 2021). Even more alarming, 19% of adolescents (high school age, 14 to 18) report suicide ideation in the previous year; 16% report making plans for a suicide attempt; and 9% report having a suicide attempt. (Ivey-Stephenson et al., 2020). This is quite literally a matter of life and death, and the most alarming part of this statistic is that suicide prevention is possible. Every life is precious. When we lose a child to suicide, we lose a family member, a classmate, and a community member. We lose a smile and the possibilities of that child's potential.

Suicide points to the various intersections of psychosocial distress, a capability to act towards suicide, and the means to take one's life.

One of the most relevant and frequent questions about suicide is why do people want to end their lives? Various theories explain the phenomenon of suicide. Emile Durkheim is credited with one of the first theories of suicide, and he focused on social influences such as social integration and social regulation (Durkheim, 2006). Suicide was the result of either not belonging in a community, being overwhelmed by a group's collective beliefs and expectations, lacking social direction, or wanting to escape a society that is not worth living in (Durkheim, 2006). With this theory, Durkheim tried to situate suicide in a social context to understand why people die by suicide and delve into the social functions suicide responds to and creates. What is interesting about this is that it is relationally driven and less about locating suicide as a purely internal, individual phenomenon.

Early psychological theories built on the concept of drives, such as Freud's sexual drive theory, and in this context, suicide would be contrary to the fundamental drive to life and mastery. More formal theories appear later in the 20th century, with Roy Baumeister's escape theory of suicide. His theory presents a sequential model where someone falls short of standards and internalizes those failures, and then a harsh self-concept is reified (Baumeister, 1990). From these early parts of the sequence, negative consequences such as depression arise from the reified negative self-concept, which can create tunnel vision through cognitive restriction and rejection of meaningful thoughts (Baumeister, 1990). Finally, maladaptive behaviors or affect become a daily norm, and suicide becomes the way out because death appears no worse than these negative patterns of behaviors (Baumeister, 1990). The ideas of the pain of depression and a cycle of negative affect previews the concept of psychache, the intense emotional pain rooted in shame, guilt, fear, and anguish (Shneidman, 1993) that arises a few years after Baumeister's theory. Similar to the escape theory of suicide, Shneidman's (1993) theory highlights how psychache can lead someone to have a suicide attempt not to die but to end the psychological pain and anguish of psychache. This pain becomes unbearable because of factors such as thwarted belonging, feeling of loss of control, negative self-image, and damaged relationships (Shneidman, 1993). The idea of thwarted belonging is a key element of another theory of suicide, Joiner's Interpersonal Theory of Suicide.

In Joiner's (2005) theory, three factors present the intersection of elevated risk conditions and the opportunity or means to act towards suicide. The desire for suicide is generated by two concepts: thwarted belonging, which is described as the lack of meaningful connections, and perceived burdensomeness, which is the sense that a person feels like a liability to others or creates an undue burden on others (Joiner, 2005). The means to act towards suicide are represented by the concept of acquired capability for suicide (Joiner, 2005). In the earlier referenced psychological theory, there is an assumed drive towards life and a fear of death that can condition people towards life-affirming activities and behaviors. Acquired capability for suicide occurs when a person becomes conditioned to lose that innate fear of death through experiences like traumatic exposure and self-injurious behavior (Joiner, 2005), thus making suicide appear feasible.

In addition, there are two theories that have connections to cognitive-behavioral therapies. Aaron Beck believes that hopelessness is what drives suicidal intent, even more so than depression (Weishaar & Beck, 1992). Marsha Linehan, the founder of the third-wave cognitive behavior therapy (CBT) model, Dialectical Behavioral Therapy (DBT), articulates a theory that relates to intense emotion dysregulation, invalidating environments, and the need to avoid these intense affective states (Brown, 2006). These theories have a direct clinical application, as clinicians would target hopelessness or the intensity of effect and dysregulation in respective clinical approaches.

These theories are not a de facto explanation of suicidal behavior, but the core concepts can guide the clinician to understand relevant risk and protective factors related to suicide, and present different understandings of how to tailor treatments to this phenomenon. Suicide is not a psychological disorder; rather, it points to the various intersections of psychosocial distress, a capability to act towards suicide, and the means to take one's life. As presented in the case vignette, Kayla's suicidal thoughts had a connection to not feeling like she fit in, and she was experiencing negative emotional states as a result. Thoughts, emotions, behaviors, and environments/contexts are interconnected to better understand her current situation and suicide risk.

> *The literature highlights the importance of assessing multiple risk factors across the individual and the contexts where they are embedded.*

Causes of Suicide and Self-Injurious Thoughts and Behaviors in Children and Adolescents

The CDC (2021) reports various risk factors for suicide, which includes having a prior suicide attempt, depression, substance abuse disorder, other mental health disorders, a family history of mental health disorders, a family history of suicide attempts, a family history of violence, being in prison or jail, medical illness, and access to lethal means. Exposure to adverse childhood experiences and bullying victimization are also seen as important relational risk factors. Lastly, social influences such as social and internalized stigma associated with help seeking pose as a risk factor that can increase the likelihood of suicide attempts.

For clinicians, consider clinical risk factors or warning signs of suicide including clients expressing wishes to die, reporting hopelessness, withdrawing and isolation from friends and family, and changes in eating or sleeping habits (CDC, 2021). Protective factors for suicide include clients having coping and problem-solving skills, social connectedness, accessibility and connection to care, and restricted access to lethal means, as well as religious/cultural beliefs that discourage suicide (CDC, 2021). Clinical protective factors include engagement in treatment (CDC, 2021), and, as we will see later in the chapter, clinicians conducting ongoing risk assessment, evidence-based intervention, and follow up (Stanley et al., 2018). However, over 50 years of research indicates that no single risk factor reliably predicts suicide attempts; this highlights the importance of assessing multiple risk factors across the individual and the contexts where they are embedded (Franklin et al., 2017). For Kayla, the clinical contact with her school counselor can be lifesaving; it is up to the counselor to continue meeting with Kayla, develop a therapeutic alliance, and work towards recovery.

Developmental Systems Considerations for Suicide and Self-Injurious Thoughts and Behaviors in Children and Adolescents

School is an immediate context where children and adolescents spend a significant amount of time. Considering the risk factors that lead to suicide, let's start with the natural settings of the child. Schools may be a primary setting where bullying victimization occurs, with approximately 5-20% of schoolchildren being victims of bullying (van Geel et al., 2014), but more and more, bullying can be present online via social media, also known as cyberbullying (van Geel et al., 2014). In children, peer victimization has a relationship with suicidal ideation and suicide attempts, with cyberbullying being more strongly related to suicidal ideation when compared with traditional bullying (van Geel et al., 2014). In our case illustration, we can see that Kayla was experiencing bullying. Considering the high use of social media by teens, the likelihood of cyberbullying is also high. Social media can foster some social networks that could be protective, so discussing emotional safety with social media is imperative.

Parental supervision of the child's online activity should account for the possibility of cyberbullying in hopes of intercepting potential bullying. This may require some education for parents and working with the parent-child dyad on developing a shared understanding of how to safely engage in online activities. The family system itself can be a clinical place of interest in relation to suicide. If we recall that family history of suicide attempts can be a risk factor for child suicide attempts, a risk assessment should include screening for family history. If there is such a history, consider how to support the parent in managing their own stress and to be a support for the child in the case of a crisis.

As noted in an earlier section, adolescents are at high risk for suicidal ideation and attempts (van Geel et al., 2014). In the context of developmental systems, while universal screening should take place across all age groups (as young as 5 years old, per recent recommendations), extra care should be taken with the adolescent age group. Part of the risk of suicide for adolescents is that their frontal lobes are still developing, which is the part of the brain that is responsible for executive functioning and impulse control. These ideas about adolescence should not cloud our judgment when we consider younger children, as we will see in the next section, as there has been an increase in suicide attempts in recent years.

Experiences Across Race and Ethnicity. Rates of suicide attempts for Black youth ages 5 to 12 are rising faster than any other racial and age group (Bridge et al., 2018; Plemmons et al., 2018). Another important context where we see significant racial/ethnic disparities is in the juvenile legal system (JLS). There is a 4.7 to 1 ratio of Black to White youth in the JLS, something known as the disproportionate minority contact (Development Services Group, 2014). Given this, it is important to consider the particular vulnerabilities created by the juvenile legal system. Reports indicate that youth that enter detention have 3-4 times higher likelihood of death by suicide than their counterparts without exposure to the JLS (National Action Alliance for Suicide Prevention, 2013). Two-thirds of detained youth have been diagnosed with at least one psychiatric disorder (Abram et al., 2015; Underwood & Washington, 2016). Furthermore, 90% of youth in detention have been exposed to a potentially traumatic event (Abram et al., 2015), with increased rates of polyvictimization than their peers without exposure to the JLS (Ford et al., 2013). A meta-analysis indicated that 19-32% of detained youth had suicidal ideation, with 12-15.5% reporting past-year attempts (Stokes et al., 2015). In addition, youth with deeper involvement in the system have higher rates of suicidal ideation and behavior, especially those who are either post-adjudicatory status or post-disposition and held in a secure facility (Stokes et al., 2015). Conditions in detention such as separation and sleeping in locked rooms may also serve as potential risk factors for suicide attempts in detention (Abram et al., 2014).

Higher perceived discrimination was associated with higher odds of suicidal ideation for Black adolescents.

A study by Assari et al. (2017) showed that higher perceived discrimination was associated with higher odds of suicidal ideation for Black adolescents. Brooks et al. (2020) report that for Black young adults, perceived discrimination can act as a painful and provocative experience that is associated with increased capability to overcome their own fear of death. This link was previously examined with black adolescents (Arshanapally et al., 2018). These studies call for clinicians to address the psychological consequences of perceived discrimination. Simply put, racism kills people in varied ways. Therefore, there is an ethical imperative for clinicians to provide the therapeutic space to discuss racism and discrimination (for further reading, consult the Racial Trauma chapter), and its impacts on suicide risk. Additionally, Opara et al. (2020) offer a theoretical framework for understanding how to integrate the interpersonal-psychological theories of suicide and intersectionality theory. A recent review on Black youth suicide also cited stigma as a significant factor driving disparities in youth suicide (Meza et al., 2022). In fact, Black students endorse the highest rates of stigma related to seeking/receiving mental health treatments, and these ratings of stigma are predictive of higher odds of past-year suicide (Goodwill et al., 2020).

Asian American youth are also a marginalized group that need to be centered in the discussion of youth suicide, specifically in terms of the myths and the realities of suicide. The lifespan perspective of the developmental systems can help us tease apart the realities of Asian youth experiencing suicide. There is a cultural phenomenon of hidden suicidal ideation that elevates the risk for suicide (Chu et at., 2018). Asian American students are more likely to have their internalizing mental health needs go unmet (Kim et al., 2018), and this can be related to problems with being screened for suicide risk in their school, to the likelihood that parents will decline mental health services, and to actually having services initiated after the assessment when compared to Latinx students (Kim et al., 2018). For Asian-American college students, rates of suicidal thoughts and likelihood to attempt suicide are higher than White American students (Wong et al., 2011). Could this point to a cumulative effect of not having their mental health needs met from their primary or secondary schools?

Overall, Black and Latinx adolescent girls have the highest rates of suicide attempts, with current rates indicating that White adolescent girls have a prevalence of suicide attempts of 9.4%, while Black and Latinx adolescent girls have rates of 15.2% and 11.9%, respectively (Ivey-Stephenson et al., 2019). Many culturally relevant risk factors among Latinx youth have been examined. For example, in a study of Latinx college students, lower levels of ethnic identity attachment were related to greater suicide risk (Oakey-Frost et al., 2021). Other studies focusing specifically on Latina adolescents found that large acculturation gaps with their parents/caregivers and immigration stress were significantly associated with suicide attempts (Cervantes et al., 2014). In a recent meta-analysis, discrimination was associated with increased suicidality among Latinx adolescents, and this association was stronger for girls versus boys (Vargas et al., 2021). However, there are culturally relevant protective factors that can mitigate suicide risk among Latinx adolescents. For example, one study of Latinx young adults found that higher affective ethnic identity (i.e., feelings of belongingness and evaluations of one's ethnic group, as well as preferences for ethnic behaviors and practices) reduced the odds of suicide attempts (Forster et al., 2019).

For clinicians, universal screening should be just that: universal, not overlooking any racial or ethnic groups. Clinicians may need to offer more psychoeducation (e.g., frequent outreach to parents) for ethnoracially minoritized groups in hopes of decreasing stigma or uncertainty of engaging in mental health care. Consider Kayla from an intersectional approach. What would you need to know about her family background and history, race/ethnicity, cultural upbringing, experiences of discrimination, or even immigration status? These factors are important for clinicians to consider especially when working with youth from ethnoracially minoritized backgrounds.

Experiences of LGBTQ Youth. Smith et al. (2020)'s review of the literature indicates that sexual and gender minority adolescents and young adults report higher rates of internalizing and externalizing symptoms, and these challenges lead to vulnerability to suicidal thoughts and behaviors. Specifically, in their article, Smith et al. (2020) tested how minority stress impacts this population and found that participants reported higher levels of discrimination and self-criticism than cis-gendered individuals, which in turn increases emotional dysregulation and maladaptive cognitive styles. Recent research suggests that transgender and gender-nonconforming youth experience more suicidal ideation than their cisgender peers (Perez-Brumer et al., 2017), and in a cohort study, over half of transgender and gender-nonconforming youth engaged in self-injurious behavior within a year of the study (Hatzenbuehler, 2017). As a result, clinicians must screen and assess for suicidality especially with these youth and know that targeting both emotional dysregulation and cognitive appraisal can be helpful in the prevention of suicide attempts. Clinicians need to have LGBTQ+ competence in this area and provide resources for their clients, whether online or in-person, which can provide affirmative support.

Assessment

Screening tools can be helpful to guide the clinician in using validated language to discuss suicide with a client, and suicide screening is an essential part of any clinical encounter. Clinicians should note that while screening is essential, any instruments or measures must be formulated into a suicide risk assessment.

With children, a few options emerge as appropriate for use. In their review of freely available measures for child suicidality, Becker-Haimes et al. (2019) found that most measures are designed for youth ages 5 and older. The Alexian Brothers Urge to Self-Injure Scale (ABUSI; Washburn et al., 2010) was rated as "excellent" with respect to its psychometrics, and the Columbia Suicide Severity Rating Scale (CSSR-S) had a "good" rating with respect to its psychometrics (Heise et al., 2016). The CSSR-S is a well-validated tool used to provide definitions of and quantify suicidal ideation and behavior, and it distinguishes between suicidal versus non-suicidal behavior (Posner et al., 2011). It also provides data and trends over time, making it ideal for guiding treatment for suicidal patients (Posner et al., 2011). The CSSR-S is known to have sensitivity to change over a six-week period (Becker-Haimes et al., 2019), which is a critical strength because suicide risk is elevated in the three months after suicidal behaviors. Furthermore, the Ask Suicide-Screening Questions (ASQ; Horowitz, 2012) was developed to use in pediatric emergency departments and has shown sensitivity and evidence for ruling out risk (Newtown et al., 2017). New computerized adaptive screening measures for suicide are emerging to facilitate (in terms of speed and accuracy) risk assessments (Gibbons et al., 2020), and have been validated across settings, including acute settings like Emergency Departments (O'Reilley et al., 2022).

You may have noticed in the case vignette that the counselor used one of the items from the CSSR-S. While Kayla didn't directly say yes, it was clear that she was experiencing some form of suicidal ideation. From there, the counselor would have proceeded to understand the extent of ideation, considering if there was intent or a plan, and clarifying the frequency, duration, and magnitude of her suicidal thoughts. The specificity of the spectrum of suicidal ideation helps build a risk formulation; the screening is not enough by itself. Please note that with suicidal ideation, "passive ideation" is not an accurate term. Passive could indicate the means by which to end their life (e.g., running into traffic). As a result, it is critical to use the distinction offered by the C-SSRS between a wish/desire to be dead and active ideation.

Intervention

Suicide attempts are the culmination of various stressors, so intervention and prevention efforts should recognize this complexity. The CDC (2021) offers a comprehensive public health approach to suicide prevention that spans economics to mental health systems to social domains. They recommend strengthening economic supports such as household financial security and housing security (CDC, 2021). From a social lens, the CDC (2021) advocates for creating protective environments through reduced access to lethal means among persons at risk for suicide and promoting connectedness through peer norm programs or community engagement activities. Formal mental health system-related recommendations include strengthening access and delivery of suicide care through reduced provider shortages, teaching coping and problem-solving skills through parenting programs and social-emotional learning programs and identifying and supporting people at risk via gatekeeper training and crisis intervention (CDC, 2021). Most effective treatments will focus on unique problems of the presenting client and consider how to support the client with problem-solving, regulation of intense emotions, and developing social connections.

The reviews for psychosocial intervention related to suicide are mixed. In terms of prevention, Calear et al. (2016) found 17 effective psychotherapeutic interventions, with over half of those interventions including CBT and problem-solving therapy. These programs show varying levels of impact on suicidal ideation, suicide attempts, and deliberate self-harm. The other half of identified programs had less formal psychosocial interventions such as social support and psychoeducation. However, the less formal interventions were reported to have a positive effect on suicidal ideation and suicide attempts.

> *Most effective treatments will focus on unique problems of the presenting client and consider how to support the client with problem-solving, regulation of intense emotions, and developing social connections.*

Nonetheless, there is promise in some interventions. In their evidence base update of psychosocial treatments related to suicidality, Glenn and colleagues (2019) report Dialectical Behavior Therapy for Adolescents (DBT-A) as a “Level 1: Well-Established” (i.e., demonstrated efficacy across two independent randomized controlled trials [RCTs]; Mehlum et al., 2014; Santamarina-Perez et al., 2020), intervention for reducing deliberate self-harm and suicidal ideation in youth. However, there currently are no Level 1: Well-Established interventions for the treatment of suicide attempts in youth, given that only one DBT RCT has demonstrated efficacy for suicide attempts in adolescents (McCauley et al., 2018). Still, the consistent support for DBT for reducing self-harm across the three RCTs is impressive, particularly considering that the three trials tested different variants of DBT, with different treatment manuals, formats for skills training (multi-family vs. separate youth and parent groups), treatment dosages, and comparator conditions (Individual and Group Supportive Therapy matched to DBT for dose offered in McCauley et al., 2018, versus treatment as usual in Mehlum et al., 2014, and Santamarina-Perez et al., 2020. The efficacy of DBT for reducing self-harm and suicide could be explained by the fact that it includes a wide range of skills training (i.e., emotion regulation, interpersonal effectiveness, distress tolerance, mindfulness, etc.) that are taught to both the youth and their caregivers/parents, and it includes weekly therapy homework to practice the skills at home/school, provides phone coaching for crisis management, and also includes separate individual and family therapy to supplement the skills training group. Although DBT is a comprehensive intervention that lasts about 6 months (and about 3-5 hours a week), new evidence also supports brief interventions.

Doupnik et al. (2020) identified that brief acute care suicide prevention interventions are associated with reduced subsequent suicide attempts. Furthermore, these brief interventions can increase the likelihood of linkage to follow-up care. The common elements of these interventions include care coordination, safety planning, brief follow-up contacts, and brief therapeutic interventions. One of the most studied of these brief interventions include the Safety Planning Intervention. The Safety Planning Intervention (SPI) is a brief intervention that grew out of CBT for suicide prevention (Stanley & Brown, 2012; Stanley et al., 2009). The SPI works most effectively after a comprehensive suicide risk assessment, for instance, the C-SSRS (Stanley et al., 2012; Posner et al., 2011).

The SPI intends to lower the risk for imminent suicidal behavior by improving coping skills, social support, and help-seeking behavior (Stanley & Brown, 2012). It includes the patient recognizing warning signs of an impending crisis, identifying internal coping strategies, using social support as a distraction, contacting family members who may help or mental health professionals, and lastly, reducing the potential use of lethal means by keeping the patient's environment safe (Stanley & Brown, 2012). SPI is recognized by the Suicide Prevention Resource Center/American Foundation for Suicide Prevention Best Practices Registry for Suicide Prevention as a best practice (Stanley & Brown, 2012). One of the prevailing myths for clinicians is the contract for safety, where a patient promises to not engage in self-injurious behaviors, including a suicide attempt, and affirms this through a contract with their provider. Reviews of this intervention show that such contracts are ineffective (Stanley et al., 2018) and from a theoretical perspective, this type of approach decreases the self-efficacy of a client. It lacks specific ways to manage a crisis, it does nothing to address isolation, and contracts are inconsistently created. The SPI has been known to be a systematic way to prevent future suicide attempts and is an acceptable, appropriate intervention (Stanley et al., 2018).

The SPI is grounded in a stress-diathesis model of suicidal behavior, in which stressors trigger suicidal crises for individuals with vulnerabilities to suicidal behavior (Glicksohn & Naor-Ziv, 2017; Stanley et al., 2009). In light of this model, SPI is intended to focus on acute need and risk reduction for suicidal behavior, not all the needs of a patient. While this intervention does not focus on long term needs, it is known to reduce suicidal behavior by patients by 50% after six months, as well as double the likelihood of the patient attending mental health treatment during the 6-month follow up period, compared to those who receive treatment as usual (Stanley et al., 2018). While the review in the previous paragraphs shows that there can be variance in outcomes among interventions, engagement in ongoing care is critical (Calear et al., 2016).

Fidelity, or keeping to the prescribed steps of the intervention, to the SPI is paramount for its effectiveness. Proper administration of SPI generally takes approximately 45 minutes to complete because it involves getting the crisis narrative, mapping it on a risk curve, and using the risk curve to brainstorm how to complete the safety plan steps. Anything on the SPI sheet should be specific and ready at hand. If a client has to deliberate on what adaptive steps to take in the midst of a crisis, the crisis itself can escalate more quickly, as opposed to proactively attempting to delay the onset of a crisis peak. The following are the steps to properly complete the Safety Planning Intervention (Stanley & Brown, 2019):

1. Identify and Assess Suicide Risk
2. Obtain Crisis Narrative
3. Psychoeducation and Introduce Safety Planning
4. Identify Warning Signs
5. Explain How to Follow the Steps
6. Complete Safety Plan
7. Implement Safety Plan
8. Follow-up

The videos available at https://vimeo.com/355995975 briefly summarize the proper implementation of the Safety Planning Intervention, as demonstrated by one of its developers, Dr. Gregory Brown.

Revisiting the case vignette, the counselor could have completed the Safety Planning Intervention with Kayla during the crisis session. Seeing that Kayla was engaging in self-injurious behavior, a DBT approach could be helpful to help Kayla with distress tolerance, mindfulness, interpersonal skills, and crisis management. Based on clinician judgment, it may be worthwhile to understand more about the thoughts Kayla was having. Safety is the priority across any type of intervention, and incorporating multiple social supports can help generalize safety. Safety is the foundation to increase the quality of life for Kayla so she can live the life she imagined.

Clinician Exercise

Consider you are the counselor at the school, and you would be completing the Safety Planning Intervention with Kayla.

- What contexts would you need to consider to increase protective factors?
- What are the things that would keep you up at night?
- How would you handle collateral conversations where others state "She just does that for attention" or "She really doesn't mean it when she does that"?

Clinical Dialogues: Suicide and Lived Experiences with Dese'Rae Lynn Stage, MSW

Dese'Rae L. Stage is an award-winning artist, suicide awareness activist, public speaker, and the creator of Live Through This. Live Through This is a collection of portraits and true stories of suicide attempt survivors. Live Through This re-imbues the topic of suicide with humanity by putting faces and names to the statistics that have been the only representation of attempt survivors in the past. Des has coauthored academic publications on suicide survivors.

Sean E. Snyder, LCSW: For this interview, I'm taking a different approach than other chapters. Suicide is one of those topics that can be hard to talk about, and there are evidence-based practices out there that can really help people.

Those best practices may not get to the people we help because either they do not have the training, or they do have the training and things get in the way of implementation, like our emotional responses or stress. Suicide can be one of those things that can create emotional reactions in clinicians; it can throw us for a loop.

And we have theories about suicide (discussed in the chapter), but suicide is not something to be wholly abstract about. So, for today's interview, I want readers to get a sense of lived experience of folks with suicide. This way, we can be grounded in our use of EBPs, knowing that our job is really to help, not hurt someone who is really suffering. I have Dese'Rae Lynn Stage with me to talk about suicide and the project she's been working on, Lived Through This. So, Des, can you tell me a little bit about your background?

Dese'Rae Lynn Stage, MSW: I've been working on a series of portraits and stories of suicide attempt survivors called Live Through This over the past 11 or so years. I've been doing research using the narratives of survivors, and I'm working on a grant right now about how researchers and people with lived experience can work better together. I consult a lot, I do speeches across the nation, and I run two podcasts. One is called "Suicide and Stuff," and it's really irreverent, but it's also kind of an amazing way to bring in people with various kinds of knowledge about suicide and to talk to them about their work, their experiences, and what they think needs to be changed.

Snyder: Thank you! To start, suicide can be a very uncomfortable topic for really anybody, even for professionals who are trained in how to respond to suicide or suicidal behavior ideations. Let's say from the experience of a client that someone is experiencing suicidal ideation or is having some sort of crisis, what's the best way to engage somebody from the client's perspective?

Stage: Well, I think there are a few things there. First, not enough providers are trained in-depth about working with suicide, where there seems to be a knowledge gap. In terms of engagement specifically, people can vary on the spectrum of suicidality, so really understand where they are on that spectrum. Suicidality isn't zero to crisis; there are places in between. As a person who experiences chronic suicidality, mostly I encounter the in-betweens. At this point, there are things that trigger my thoughts, and I know the ways that I cope with this. Maybe I just need to take a shower, go to sleep, and to distract myself. So first, you have to discern where this person is on that scale and their history of suicidality; they could have done some of their own work, and they just need reminding to work their own care plan.

With the thoughts, you ask specific questions about them: do they just wish to be dead, or is it they really want to kill themselves? With the history of suicide, we have to find out if they have a history of suicide attempts or a history of non-suicidal self-injury. There's a link between the two, but they are different. So that's where being specific is critical for the provider to know how to act but also to help the patient clarify their own experience. So, with engagement, everything here is nuanced, and we cannot treat people like we're all clones of one another. We're unique snowflakes, for better or for worse.

> *People can vary on the spectrum of suicidality, so really understand where they are on that spectrum. Suicidality isn't zero to crisis; there are places in between.*

For the providers or people in the helping role, it's scary every single time, but what I also think is that you have to run toward your fear because this can be life and death. It isn't always, but really, we are talking about life and quality of life. Especially as social workers (I complete my MSW in the coming year), we are tasked with treating people ethically. Whether or not we are fearful, we must act in accordance with our ethics regarding quality of life, self-determination, and the healing power of relationships. Really, it's just preserving the other person's dignity as you're attempting to help.

Snyder: There is a spirit of suicide prevention and care that really puts people at the center, not to sterilize it.

Stage: Right, so you start asking questions and try to actively engage the person, approach it with a kind of curiosity, asking, "What's going on with you? What do you mean when you say, 'I don't want to wake up anymore?' What's going on in your life that is making you feel that way? What do you need?" It all comes down to what do you need because as humans, we all need something. I think when we're working in suicide prevention or the mental health field, we really only get to the part where you ask the question and very rarely do we get beyond the question and the risk management response.

And what we've learned in my work is that this is not just a thing for people with mental health treatment histories; we need to go beyond suicide as just something for people that are already in therapy or whatever. The CDC released a report in 2018 (and you can tear apart the methodology, but I think it tells us something really important) that said 54% of people who died from suicide over a 17-year period did not have a mental health treatment history. This information came from police reports, coroner reports, and reports from the family right after the death happened. The factors that were coming into play were relationships, things were financial, medical things, basically just life things. I think this is a way that we are not thinking about suicide that would do us a lot of good to think about.

Snyder: This CDC Suicide Prevention approach takes a multi-faceted, public health approach, and considers domains such housing and how life stressors like eviction could precipitate a suicide attempt. Their prevention guidelines talk about increasing ways to be connected to somebody in your community. That more public health approach reframes suicide not as a personal character trait or something constitutional with the person.

Suicide is not just a thing for people with mental health treatment histories - we need to go beyond suicide as just something for people that are already in therapy.

Stage: The focus on suicide as something related to mental illness definitely has roots in the medical model, and I think with the way we do healthcare, suicide prevention clings to treating suicide as something that is mental health related, like an individual person that gets individual treatment. So, I think the way it's approached is limited and maybe even a way to keep medical providers in a position of power.

Snyder: Right, I just heard a talk about behavioral economics and implementation science, and when we think about changing paradigms or even just introducing a new intervention or way of doing a task, we would consider the role of loss aversion. Providers can be afraid of the idea that something else other than their clinical skill, or what they do, can be the answer for a suicidal problem. If a provider has to contend with approaches that have to do with things like social determinants or something that's a structural thing, it may feel uncomfortable because that may not be in the skill set. You may lose something in trying a new approach.

So, I'm not saying, blow up the model we have, because there are definitely things that are helpful. But we need to broaden our approach, and it requires a different response that could ultimately have providers give up some specialized knowledge about how to care for folks with suicidality.

Stage: And I think social workers are poised to change that because there's the idea that we are walking alongside the person we're serving, and we are not trying to locate the issue within the person. I will be willing to bet that most of those people who are looking at contexts are people with lived experience.

Snyder: That last point echoes what is most likely true with mental health providers, that providers probably have had some sort of lived experiences with mental health challenges. So, we can't ignore lived experience; mental health is interpersonal. To summarize where we are at, you mentioned with engagement that providers need to be exposed to more strategies or just given time in their training in regard to suicide. Clients have unique experiences, and engagement requires understanding that unique experience in terms of spectrum of ideation and of suicide history.

Stage: Something else to consider is the provider can experience a challenge by what policies they are working under. Are you working in private practice or are you working within an agency that has very stringent policies around suicide that are informed by liability? Understanding the policy context gives a guide with trying our best to maximize the self-determination of the person we are helping. The provider's aversion to screening to suicide may be the worry of the spillover effect of a positive screen; it could lead to having to clear out a schedule to follow a protocol to engage a crisis unit or whatever. Of course, though, we need to screen everyone, but sometimes the contextual pressure is there.

Snyder: Hmm, it's almost less a care conversation when we screen, it's more of a risk management conversation.

Stage: Right, and transparency from the start is key, giving the information up front, making a collaborative effort, and maybe just doing a wraparound or recovery action plan so you can get a sense from the client where it's joining with them to see what they need in particular moments. It is a matter, too, of being transparent, so a crisis doesn't catch the provider and client off guard, where it's scrambling to help and then falling back on things like the hospital. That's a place that could do more harm than good.

Transparency from the start, giving the information up front,... making a collaborative effort are all key.

Snyder: Well, we need to encourage care in natural settings, with natural supports and familiar resources.

Stage: The shame with hospitals is that people again are not trained, and people in mental health facilities may not have professional standards that go along with something like a medical credential. And they also are not paid enough. But thinking of the hospital as a suicide prevention strategy, what is it that we are really preventing? If we want to prevent that outcome of death, we have to be thinking of the long game, and not just prolonging life in a moment of crisis game.

Snyder: Sure, and that's where our system of care is oriented towards medicalizing stress and medicalizing wellness promotion, and segregating it from the everyday, natural experiences of people. Here's my mantra of natural settings again and less of a medicalized approach. The disclosure of suicide should not be met with a prescription or a hospital; we need to support recovery where people live, work, and play. Yes, adults play, too. Natural support can support someone's agency and also the agency of communities to care for each other. A hospital disrupts natural relationships. Relationships are critical when we look at the theories of suicide too.

Stage: Anybody who knows anything about suicide will tell you that isolation is huge risk factor. And yet, those same people will say, “Well, you got to get them hospitalized if that’s what’s going to keep people alive.” But they rarely talk about how hospitalization does interrupt those relationships and the natural setting, and it takes all your comforts and your safety. It can limit access to lethal means, but is that all the hospital does?

Snyder: Right, because it is focused on death, and while that’s super important, we need to also see what value we are adding to the person’s quality of life, what’s a positive approach where something meaningful is added. We’re not just delaying death in this way, rather, thinking of how can we add something so this person has a meaningful life.

Stage: Mainstream Suicide Prevention feels like it’s centered on the prevention of death versus how do we find quality of life for somebody, or how do we make them want to stay as opposed to just not die?

> *We’re not just delaying death in this way, rather, thinking of how we can add something so this person has a meaningful life.*

Snyder: Very much so. Now, I usually ask about screening questions in these interviews for the book. I think part of the equation here is that we have our instruments, and we need folks to be comfortable using them. Trust in their own skills and trust the instruments to guide the process. The key thing is just asking; what we need to do is ask people about these questions right and when we get that, then what do we do once we ask.

What we do should be in the context of a formulation; it’s not enough to get some checkboxes. Consider risk factors for attempting, get to know the person, get some collateral information, and the clinical decision making is based on the formulation.

Stage: I think that time can be a big constraint in formulation; consider what happens when you get a positive screen in a clinic setting where you have an hour. It’s probably still not enough, but that is a gift of time that maybe providers can be up against the clock in their clinic. So one client that expresses suicide can, like what was mentioned before, affect that clinic schedule.

And to take a step back, I probably sound really negative toward providers and science and everything, and it’s a negativity that is born of love because I want to learn how to help our colleagues doing the work.

Snyder: What have you seen with the people you’ve interviewed? What are the things that folks are hoping for from providers?

Stage: A lot of the time again, it’s wanting a feeling of control. People feel hopelessness; a lot of people feel backed into a corner. Preventing suicide in a crisis is about distraction, to get someone in the place to feel like that they have some sort of control.

Snyder: Right, as we see with some interventions, it is trying to ride out the stress.

Stage: It goes back to how you can retain self-determination.

Snyder: I like that you brought up self-determination, because I think that cuts across the provider perspective, the "why" of our interventions. Think about if you have that at the core of your approach when you do a safety planning intervention. Let's say you teach some coping skills, and you teach some distraction skills. It's different if you're just doing a mechanical scripting, "the patient says x, then I do y." Self-determination goes way down when stress goes very high, so a distraction skill created in the lens of self-determination realizes that we are trying to help the client be in a place to truly make an informed decision about whatever it is. I think what grinds my gears is seeing the Safety Plan as just a piece of paper, like an exit ticket to get out of a hospital. It really takes a connection, taking a deep dive into the client's situation when doing a safety planning intervention.

Stage: Yes, there's a self-advocacy piece there, too, that also doesn't get talked about enough. How do we create a space where clients can advocate for themselves, where the providers will listen. And it comes down to whether or not the provider feels comfortable and competent enough to have that kind of encounter. So, in wrapping up, I would say to providers, from the client perspective, run toward your fear, and it is okay to be afraid. It's okay to even acknowledge you're afraid of the person you're working with, because that can model "This scares me, but I want to help you. What can we do?" Because we're people. We're people and we care about the people we're working with. People are what live through the experience of suicide.

People are what live through the experience of suicide.

Things Clinicians Should Know

Remember that suicide is the second leading cause of death for children and adolescents. Do not be afraid to ask about suicide, and remember the common elements specific to suicide:

- Increasing social connection and support
- Working on affect modulation and distress tolerance
- Teaching problem-solving skills
- Making the environment safe

After you create a safety plan or intervene in any way with someone who is suicidal, it is important to revisit the safety plan during each follow-up visit.

Common Elements Approaches

Communication skills: the ability to communicate needs based on one's distress level.

Insight building: a concept used to achieve greater self-understanding, help with management the emotional consequences.

Problem solving: training in the use of techniques, discussions, or activities designed to bring about solutions to targeted problems related to suicide.

Maintenance: exercises and training designed to consolidate skills already developed to minimize the chance that gains will be lost in the future; these skills should be ready to use, like the "Stop, Drop, Roll" metaphor.

Open Access Assessment Tools

Ask Suicide-Screening Questions (ASQ) Toolkit

The Columbia Lighthouse Project/Columbia-Suicide Severity Rating Scale (C-SSRS)

Stanley-Brown Safety Planning Intervention (SPI)

Zero Suicide Toolkit

988 Suicide & Crisis Lifeline

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17

Chapter

Gender, Sexuality, and Psychosocial Care

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Two teens at a group home for dependent youth 13 to 18 were both exploring their sexuality and gender identity. Taylor, age 18, wanted to explore transitioning, so he and his child welfare worker went to the adolescent drop-in clinic in the area, and then he went a few times on his own after that. He told his child welfare worker that he wants breasts (not the word he used) and to keep his penis. In more recent years, she has physically and socially transitioned, living a healthy life with her partner. The other youth sometimes wanted to be Clifford and other times Trinity; they would get mad if you said, "Hi, Clifford" on a day they were Trinity. They had no desire to physically transition and wanted to express their gender in a way that validated their true self. In the following chapter, this youth will be referred to as Trinity.

An Overview of Sexuality

Taylor and Trinity represent different aspects of the gender and sexuality spectrum. Note that gender and sexuality are mentioned as separate, distinct concepts. There can be confusion with terms related to and within both concepts of sexuality and gender, so this section will provide a brief synopsis of key terms. Sexual orientation refers to someone's emotional and erotic attraction toward another individual (Forcier & Haddad, 2013; Spielman et al., 2020), and this may also be described as someone's "sexual preference," though the LGBTQ+ community has moved away from this terminology, as with the phrase "preferred pronouns." By labeling them as preferences, it implies a choice, rather than a person's truth or experience. For those with emotional and erotic attraction to members of the opposite sex, the term heterosexual is used (Forcier & Haddad, 2013). This is the basis for the terms "heteronormativity" or "heterosexism," which refers to certain cultures' bias towards heterosexual orientations. Homosexuality refers to emotional and erotic attraction towards an individual of the same sex, though again, many people in the community have moved away from this term due to its use as a diagnosis and consequential stigma. Bisexual people are attracted to people of their own sex and another sex; pansexual people experience attraction without regard to sex, sex identity, or sex expression; asexual people do not experience sexual attraction or have little or no interest in sexual activity (Forcier & Haddad, 2013; Spielman et al., 2020). Intersex refers to people whose bodies are not strictly male or female (Hughes et al., 2006).

Sexuality can be expansive. Research has made clear that sexual orientation is not a choice (Jenkins, 2010), but rather it is a relatively stable characteristic of a person that cannot be changed, despite claims of "conversion" treatments (Spielman et al., 2020). Not only is this type of "therapy" not effective, it is harmful. The position of the American Academy of Child and Adolescent Psychiatry (AACAP, 2018) articulates that such therapies lack scientific credibility, clinical utility, and suitability to the behavioral health treatment of children and adolescents. They instead say that clinicians should operate from a standard of care regarding the open exploration of gender and sexual identity without a predetermined outcome (AACAP, 2018).

An Overview of Gender

Sexual orientation can be confused with gender identity because of stereotypical attitudes that exist about gay and lesbian sexuality, and these issues, while related, are different. Gender identity is one's experience of their gender, internal to them. This is different from natal sex, or the sex assigned at birth based upon a physician's observance of particular genitalia/phenotype or through chromosomal testing (Forcier & Haddad, 2013; Spielman et al., 2020). Gender identity can correspond to natal sex, but it is not always the case.

Gender identity is psychologically rooted (Forcier & Haddad, 2013), and gender expression is described as the manner in which individuals communicate their gender identity within a given culture. As we saw with the example of Taylor, the development of her gender identity included phenotypic aspects (e.g., wanting breasts, keeping her penis) as well as social transitioning. We will discuss different aspects of transitioning later in the chapter. Taylor can serve as an example of gender nonconformity.

Gender non-conformity is defined by gender role behavior that does not conform to culturally defined norms (Adelson, 2012; Forcier & Haddad, 2013). As mentioned, some people communicate their internal sense of gender identity via gender expression, but this is not always the case. Transgender is an all-inclusive term for people for people who experience or convey gender nonconformity, gender discordance, and/or gender dysphoria. Not all gender-variant or non-conforming individuals identify as male or female, express their gender as exclusively masculine or feminine, or experience gender discordance or dysphoria. We saw this in the example of Trinity, whose gender expression was not confined to one particular identity or role.

Gender non-conformity is different from gender discordance, which is the discrepancy between anatomical sex and gender identity (Adelson, 2012; Forcier & Haddad, 2013). The experiences of folx with gender non-conformity are unique and represent a range of experiences; similarly, those who experience gender discordance have a broad range of experiences with that discordance. For those who experience affective distress, the psychological term gender dysphoria can be used. Not all those with gender discordance will experience affective distress, so gender dysphoria is not synonymous with gender discordance.

Transgender refers to non-conforming gender identities, where someone may identify as genderqueer, gender non-conforming, transgender, or genderfluid. Transexual is considered an outdated term, although this term is used by some to denote a change in their identified sex. This is different from identifying as transgender. When someone identifies as transgender, they can go through physical transitioning such as surgery or hormonal therapy to have the body match the person's gender expression (Forcier & Haddad, 2013), or they can go through social transitioning (Forcier & Haddad, 2013), in which the person performs and behaves as a way that resembles their expressed gender. These expressions of gender are not mutually exclusive, and it speaks to the overall move beyond a binary gender system.

Transitioning can be emotionally painful due to the external pressures of transphobia as one attempts to navigate social norms and culture and the expression of gender identity. The emotional problem of gender dysphoria occurs when affective distress related to gender discordance and the desire to be affirmed as a gender apart from their current gender identity.

Gender Development

Gender non-conformity is defined by gender role behavior that does not conform to culturally defined norms.

A child has a sense of gender identity by the age of three, with a lifelong identity consistent with their natal sex being formed by age five (Forcier & Haddad, 2013). Gender non-conforming children engage in cross-gender play, activities, and appearances in a way that is described as "consistent, persistent and insistent" (Forcier & Haddad, 2013).

For those experiencing gender dysphoria, the distress can alleviate with developmental progress typically during early adolescence, and oftentimes the affective distress was related to sexual orientation questioning (Adelson, 2012). Gender discordance and the potential for gender dysphoria can be precipitated by the physiological changes and changing phenotypic expressions of puberty (Adelson, 2012). During puberty, an adolescent will need to adjust to their changing body as well as adjust to what that bodily change means for them.

Around this developmental time, a desire to develop physical characteristics related to the other sex or gender can emerge. This desire can lead to seeking out medical interventions like surgeries on different areas of the body, hormonal therapy that can suppress the effects of puberty (Forcier & Haddad, 2013), and this represents only one part of that person's gender expression. Social transitioning can be another way to present as they desire to be presented through adopting different pronouns or gender-neutral words, changing their name, dressing in particular ways, requesting others to recognize their gender expression (Forcier & Haddad, 2013). Still, others may wish to have affirmation outside of a binary gender model. It is important to note that social transitioning is often the initial means through which individuals assert their gender identity. Gender affirming medical care, via hormone replacement therapy or surgical procedures, can only happen once an individual has an established process of social transitioning.

Across both gender identity development and sexual preferences data, epidemiological information is more readily available in regard to sexual orientation, with studies indicating that homosexuality emerges across cultures in about 10% of adolescents, and the variants of gender identity are less understood (Hill et al., 2012). Zucker (2017) notes that studies show a range of 0.5 to 1.3% of a self-reported transgender identity in children, adolescents, and adults. Rates of gender dysphoria are harder to establish because of the rise of gender clinics that can provide access to gender-affirming services, and there is more robust data for adult populations as opposed to children (Vance et al., 2014).

Developmental Systems Considerations with Sexuality and Gender

We could argue that issues around pathology and sexual and gender identity development reflect the macro pressures of culture and conformity. Culture and conformity play out across representations in mass media, as well as in our institutions. Take an institutional focus when considering the developmental systems approach and inventory these different institutions. What role do schools, employers, and governments play with the cultural reification of gender roles and heteronormative sexual orientations? How can these systems accept and promote non-conforming gender? Much of the distress that a child may feel comes from social norms and perceived expectations. As our interviewee Erica Smith indicated, how can youth feel safe at school, and how can they get their needs met without discrimination? Consider the negative effects of sexual and gender discrimination for children: lost social opportunities, potential development of mental health disorders like depression or anxiety, and lost learning. This may be a chapter where we turn the focus not on the child but on us as part of the systems in a child's life. What is the role of the behavioral health clinician then in a system of care?

Sexual orientation can be confused with gender identity because of stereotypical attitudes that exist about gay and lesbian sexuality, and these issues, while related, are different.

In terms of developmental stages and milestones, it would be appropriate here to mention the Tanner Stages (Tanner, 1962). These stages have become a routine part of the physical exam in pediatrics, with the stages spanning from 1 (no development) to 5 (adult development). Tanner's stages only capture the external signs of visible secondary sexual characteristics such as the development of breasts or of the genitals, or the appearance of pubic hair growth. Shirtcliff et al. (2009) note that researchers may have difficulty with doing physical examinations in non-clinical settings, so other methods are often used, such as the Pubertal Development Scale (PDS) (Peterson et al, 1988) or the Picture-Based Interview about Puberty (PBIP) (Dorn & Susman, 2002). What is relevant to us here is that these self-report measures were helpful for understanding youth development during puberty (Shirtcliff et al., 2009). These measures were compared against hormonal testing and were seen as adequate (Shirtcliff et al., 2009). In the context of a clinician assessment, these measures may have utility when understanding physical and sexual development. The brief mention of the Tanner Stages and related constructs are meant to be educational in the behavioral health context, not to be diagnostic of anything related to physical health, which is out of our scope of practice.

Gender Diversity in Other Cultures

Non-binary identities and diverse gender roles have existed in various forms across different cultures worldwide. Within these cultures, gender diversity and fluidity have been visible, accepted, and intact (Herdt, 1996; Nanda, 2014). Even with the globalized reinforcement of gender binaries, some cultures continue to honor the traditions and norms of gender diversity within their communities. Although there are many cultures worth mentioning that embrace multiple gender identities, we will describe a few. In some Native American tribes, two-spirited has become an all-encompassing term to describe gender-fluid roles and identities. Two-spirit is a term used to recognize gender diversity with various Native American tribes. In the Mojave (or Mohave) tribe, they accept the gender norms of Hwame (assigned female at birth, identifies as a man) and Alyha (assigned male at birth, identifies as a woman). Within indigenous communities of Mexico's Oaxaca Peninsula, they recognize Muxe (a person assigned male at birth who exhibits both qualities of a man and woman) as a third gender. Muxes emulate the femininity in their culture but do not identify as women. In the Bugi society within Indonesia, they recognize five genders. The five genders consist of the binary male and female, the Calalai (assigned female at birth, identifies as a man), the Calabai (assigned male at birth, identifies as a woman), and the Bissu (encompasses all gender identities).

Assessment of Emotional Challenges Related to Gender and Sexuality

Sexuality has had a controversial history within the various iterations of the DSM. Homosexuality was considered a mental disorder in the DSM III, then ego dystonic homosexuality was considered to be the source of sexual pathology, with the diagnostic label of disordered gender identity in the DSM-IV (Vance et al., 2014). The current diagnosis of gender dysphoria in the DSM-5 attempts to accept the nuances of sexuality and gender expression and the emotional challenges that accompany gender discordance. There are various criteria for a gender dysphoria diagnosis, but these potential criteria center on a reported marked incongruence between one's experienced/expressed gender and assigned gender, of at least 6 months' duration (APA, 2013; Vance et al., 2014).

Vance et al. (2014) note that in the DSM-IV, a cross-gender identity was considered to be pathologic, and with the updated DSM-5, this is no longer the case. The focus in the DSM-5 with gender dysphoria is the distress that arises from incongruence between assigned gender and affirmed gender identity (Vance et al., 2014). Children will express dissatisfaction or affective distress with birth-sex assignments (Vance et al., 2014).

Clinical Features of Gender Dysphoria

To stress the overarching theme of this chapter, there is nothing pathological regarding gender non-conformity or non-heterosexual orientations. In keeping with the current iteration of the DSM-5, there can be significant levels of affective distress that can interfere with the child's daily functioning, and this falls under the diagnosis of gender dysphoria.

There is some variance in the diagnosis for children versus adolescents (who share similar criteria as adults). Both must have an incongruence between one's experienced/expressed gender and their assigned gender. Adolescents may want to prevent the development of secondary sex characteristics. For children, criteria must include a "strong desire to be of the other gender or an insistence that one is the other gender (or some alternative gender different from one's assigned gender)" (APA, 2013). Other criteria span includes strong dislike of one's sexual anatomy among other behavioral criteria like cross-gendered play and fantasy.

Gender non-conforming children engage in cross-gender play, activities, and appearances in a way that is described as "consistent, persistent and insistent."

Let's revisit our case vignette. Would either Taylor or Trinity meet the criteria? At first glance, it is not evident. Taylor felt that breasts would affirm her true gender identity. She didn't necessarily want to rid herself of her penis. We would need to delve deeper into Taylor's presentation to see if criteria were present. You may ask, why does that even matter? Sometimes, the diagnosis could be needed in order to receive affirming treatments like hormone therapy or surgical intervention. For the behavioral health clinician, we need to focus on the impact on functioning; what can we do to support quality of life with Taylor? Gender dysphoria varies person to person, and some people may have dysphoria around certain body parts and not others. It may not necessarily be genitalia that's the source of dysphoria; it could be voice pitch, jawline, or facial hair. Folx from the trans community have cautioned us to move away from focusing on their genitals. In opening a nuanced discussion around this type of bodily dysphoria, it may be worth mentioning that vaginoplasty/phalloplasty, or "bottom surgeries," are multi-step surgical processes with lengthy recovery times. For some, though dysphoria may be present, the cost/benefit analysis of obtaining that type of surgery and the resources to do so can be a very complex decision.

Intervention with Emotional Challenges Related to Gender and Sexuality

Before speaking about gender dysphoria, clinicians working with issues related to sexuality should be guided by an affirmation approach. Affirmative approaches embrace positive views of sexual and gender minority identities and understand the negative influences that homophobia, transphobia, and heterosexism can have (Leibowitz et al., 2016). This approach recognizes that part of the therapeutic work will be on counseling about the feelings a person has towards their identity and how they relate to and from their identity (Leibowitz et al., 2016).

The affirmative approach is a necessary standard of care (Ehrbar & Gorton, 2011), as it is well-documented that sexual and gender minority persons experience higher rates of bias and discrimination in healthcare settings (Forcier & Haddad, 2013; (Leibowitz et al., 2016)), as well as experience increased risk for bullying, peer nonacceptance, and family rejection. They also experience suicidal ideation, non-suicidal self-injury, suicide attempts, mental health disorders, and health risk behaviors at a higher rate than the general population (Forcier & Haddad, 2013). This approach can come at odds with the systemic challenges related to the gatekeeper model. The gatekeeper model operates in a stepwise approach for medical interventions, in which patients must see a mental health clinician to obtain clearance for the initiation of medical interventions. An alternative model is the informed-consent model, where a mental health evaluation is not necessary for patients with the cognitive capacity to provide informed consent for treatment. Across both of these models and the potential for systems-level limitations, the practitioner should have an affirmative approach.

Evidence-based treatments have not been established specifically for gender dysphoria, but theoretical models indicate that reducing gender dysphoria would focus on targeting the affective distress of gender dysphoria (Leibowitz et al., 2016). For youth with gender nonconformity, intervention can span individual and family work, as well as parent guidance techniques (Malpas, 2011). Interventions can look to process the emotional aspects of the child and family navigating the child's gender expression, with some interventions focusing on social considerations about passing or not (Malpas, 2011). Behavioral techniques like setting limits on cross-gender behaviors, encouraging gender-normative play and preferences, and promoting same-sex peer relationships can provide important clinical information (Ehrensaft, 2012; Leibowitz et al., 2016). If the child is insistent on cross-gender behaviors, this can be indicative of gender discordance that would make transitional intervention appropriate (Ehrensaft, 2012; Leibowitz et al., 2016). The previously mentioned techniques are *not* meant to act like conversion therapy, where the heteronormative standards are reinforced; rather, it is meant to see how the child responds to such standards.

People of transgender, non-binary, and gender-expansive experience have highlighted the need to recognize the joy, strength, and diversity within the trans community.

There can be less intensive or hands-on approaches, such as a “wait and see” approach to understand how gender identity would unfold after the onset of puberty (Leibowitz et al., 2016; Menvielle, 2012). This is neither encouraging nor discouraging cross-gender expression, and this approach comes from a theoretical assumption that gender identity determination is unreliable in prepubertal children (Menvielle, 2012). Trinity can be an analogous example here, where a clinician can take a non-directive approach, opposed to encouraging the expression of one particular identity (e.g., direct towards Trinity only or towards Clifford only).

The other end of the intervention spectrum is the reinforcement of the opposite gender role through interventions such as prepubertal social gender transition (Ehrensaft, 2012; Leibowitz et al., 2016). This adoption of the affirmed gender can occur through the use of the child’s preferred name and gender pronouns in some or all contexts. This approach builds from the assumption that gender may be fluid and nonbinary, and that acceptance of the child’s gender now will lead to long-term beneficence (Ehrensaft, 2012). Medical intervention can be an option through pubertal suppression in which a child undergoes hormone therapy to suspend endogenous pubertal progression (Leibowitz et al., 2016). By suppressing puberty, the youth have additional time to explore their gender, and it is important to note that this hormonal therapy is “reversible.” The stopping of hormone therapy will allow endogenous pubertal development to resume (Leibowitz et al., 2016). For youth experiencing gender dysphoria, these transitions are not a matter of “sexual rebellion;” these are ways to correct what they feel is a mistake in nature (Spielman et al., 2020)

For the developmental systems guided practitioner, there are few key takeaways. Hold the space for the child to explore and integrate gender identity; address the mental and emotional impacts of minority stress; help the child and family to build a support network; plan for social and legal issues related to transition; help to develop problem-solving skills and flexibility for the child and family to make informed decisions about medical treatment options; increase well-being and quality of life for the caregivers and family members; and cultivate well-being for the child. So, with both Taylor and Trinity, what would affirming their gender expression look like? Given that they both are in the child welfare system, the clinician may need to take the role of advocate to ensure that any future placements are affirming homes, or education may need to be provided to the current group home parents about affirmative care. That home is also the most immediate space for any social transitioning, so then Trinity or Taylor's clinician would need to consider interpersonal skills development. In summary, the spirit of care is to affirm and not provide treatment for a disorder, and our developmental systems lens can lead to building connections across systems for these youth.

Liberatory Practices

As clinicians, we collaborate with clients to affirm and empower them in their deeply personal journeys of gender and sexuality identity development. While a clinician's role often focuses on addressing the internal response to stressors—experiences of dysphoria, rejection, internalized shame, and the subsequent impacts on one's mental health—we must also recognize that trans identities and LGBTQ+ rights have become highly politicized. Contextualizing affective distress within a sociopolitical climate of transphobia and homophobia, compounded by racism, ablism, and classism, is an important component of care and advocacy. Upholding liberatory practices in our clinical work can look like decolonizing our lens and finding space to challenge the heteronormative conceptions of gender and sexuality that permeate our systems and institutions. Trans folx, specifically trans people have color, have historically been at the forefront of LGBTQ+ liberation movements. Supporting activism and organizing efforts led by trans people is an important step in the pathway to liberation (Erickson-Schroth, 2022).

It is easy for anti-trans violence and legislation, as well as the very real struggles that trans people face, to dominate the discourse. People of transgender, non-binary, and gender-expansive experience have highlighted the need to recognize the joy, strength, and diversity within the trans community. The term gender euphoria has been increasingly used to celebrate the ways in which transness can liberating and affirming. Highlighting the positive emotions that trans people have around their gender identity is a necessary balance to the dysphoria that individuals may also experience (Austin et al., 2022). Trans people deserve to have all aspects of their identities and experiences validated in their fullness, with the necessary resources to live and thrive in authenticity and safety, both within the clinical environment and beyond.

Clinical Dialogues: Gender and Sexuality with Erica Smith, MEd

Erica Smith works with the Children's Hospital of Philadelphia's (CHOP's) gender and sexuality clinic, where she coordinates the support groups and support services for transgender children and youth and their families. She has worked with trans youth since 2002 and provided them and their families with lots of support, and she also does training for organizations on how to be more LGBTQ+ competent.

Sean E. Snyder, LCSW: What's the engagement process like when you work with a child, from when they first get referred to you and first come into your door?

Erica Smith, MEd: The CHOP gender clinic has been open for about six years now, and by the fifth anniversary, we had worked with over 700 children. We get a lot of referrals; oftentimes, there's a waiting list. During the initial encounter, the parent speaks to one of our intake folks who takes down all of the information about the kid; then they come in for a visit. Unfortunately, there is some wait time because there's a lot of demand for our services. We are the biggest gender clinic between Boston and Miami.

When a young person comes in, they have a very comprehensive assessment by one of our social workers and clinicians to assess the young person's situation: what they're experiencing and what's going on with them, what's going on with their family. We try to figure out how long they have expressed their gender dysphoria. That is really where everything starts; there's no medical stuff or anything. It's really understanding the many different facets of this child and their family.

Snyder: I wonder, are parents the ones reaching out or do you get physician referrals or other kinds of professional referrals? I wonder about the role that stigma can play with families or providers.

Smith: A lot to cover here. We do have tons of parents who call us and will say, "My child is exhibiting discomfort with their gender," or "I think my kid is trans" or "My kid came out to me as trans. I need you to help them." So, plenty of parents call us. The fact that a parent calls us means that they have some measure of acceptance with their child's gender. It might not mean that they are all the way there, but at least it means they are open to it, if they are bringing their kids to the CHOP gender clinic. We do get plenty of referrals from other doctors, though, but that usually also means the parent is somewhat onboard.

Snyder: What's it like to work with the parents of the kid in general? How do you work with parents that aren't really accepting of gender and sexual identity?

Smith: This is a big one. Our team at CHOP is a multidisciplinary team. It is not that we bring your kid into care, and we only address what's going on with the kid, then send them back out into the world. We have a comprehensive multidisciplinary team that also works with the families, including the siblings. And we also work with school personnel, depending on where your child goes to school. Once your kid is involved in the gender clinic, we are not only addressing their health needs but also their emotional needs and their therapeutic needs.

The fact that a parent calls us means that they have some measure of acceptance with their child's gender. It might not mean that they are all the way there, but at least it means they are open to it.

We are making space for the families, too. For a lot of parents, even parents who accept their child's gender identity, they kind of have a process that they go through. For some parents that is grief that their child is not the gender they thought they were. We find that it is important to give the parents space to experience and process that grief so that they're not putting it on their kid.

So, for example, if I had a trans child that was assigned male at birth and then came out as female, I may have feelings because I thought, "Oh, I thought I had a son, and I'm losing my son." I don't need to tell my kid all that stuff. I would process that with the clinicians at CHOP's gender clinic and also seek out my own therapy. We would recommend that the parents are talking to somebody, too, so that everyone in the family has their own process being addressed. That creates a better environment for the young person long term.

The support groups that I coordinate are also for the kids and their families. This massive support group meets once a month, and it's divided up into transgender children who are nine and under, transgender tweens who are 10 to 13, and young trans people who are 13 and up. We have a support group for parents of each different age group, and we have a support group for siblings of trans youth.

We have a support group for extended families, and we get a lot of grandparents, aunts and uncles, and other people who are caretakers of trans youth who can come and talk to other grandmas about what it's like to navigate having a trans grandchild and what it's like for them as grandparents. So, we really do a lot of work with the entire family.

Snyder: Are these groups typically an emotional processing group, or is it more focused on psychoeducation? What typically happens in these groups?

Smith: It's different, depending on the age of the kids. It is more like a play and social support for a lot of these children, as it's the only time they have around other trans people. Some of our gender clinic patients come from all over the tri-state area, and some folks drive as far as two hours to come to our group. It might be that in their regular life that they're the only trans kid in their whole school district who's out, but when they come to our groups, and they get to play with a whole bunch of other little kids and don't have to feel weird around their peers or explain themselves. Sometimes with the teens and tweens, they don't even talk about their gender; they're just there to be themselves with other kids and talk about things like memes or video games because they really want to be around other people like them.

The parents do a lot of talking about their emotions, and they receive some psychoeducation in the parents' group. For a lot of the parents, they want practical information like, "How can I change my child's gender identity marker; how can I change my child's name; what's the legal process?" A lot of that practical questioning happens in the parents' group. Or they want to know, "What's the process when my child gets prescribed hormones?" and sometimes they do talk just about their feelings.

It's often hard to get the parents to talk about their feelings because they really like to focus on the practical stuff. That way, they don't have to feel their feelings, and sometimes this support group coordinators probe with, "So let's talk about how that makes you feel," and that's when we have to tease it out of them. Regardless, there's space for all of it; it's a really beautiful group. On any given month, we have like 60 parents that attend, along with about 15 grandparents. 25 teens, 16 tweens, 16 little kids. It's a massive group of people who come together to seek support from each other.

Snyder: That openness seems like the social work approach of "meeting them where they're at." Sometimes all the kids need is just the opportunity to be themselves around other kids.

Some students are wondering about parental support and some of the technical aspects. What is the consent process like in order for kids to seek treatment? What about those kids that are faced with non-acceptance from family members? How can they get support?

> *Sometimes with the teens and tweens, they don't even talk about their gender; they're just there to be themselves with other kids and talk about things like memes or video games because they really want to be around other people like them.*

Smith: That question brings up a lot of things that I feel like I want to lay out beforehand. The idea of a trans youth or child getting medical care for transition is not something that every single trans person seeks out. I feel that in American culture, there is this idea that if you're trans, there's one way to do it: you transition from one binary gender to the other; you use hormones and surgery, and then there's an end you achieve. In reality, that's not how it works.

The experience of being trans is different for every single person and not everybody chooses to do the same interventions. There are a bunch of different surgeries that folks can have to affirm their gender and not everyone chooses to have them. For young people who want hormones, hormones are prescribed by their doctors after great consideration and a lot of evaluation that shows that their gender dysphoria has been persistent and over a long period of time and consistent.

When you're a tween, the first thing that can happen is being prescribed hormone blockers that block your natural puberty from happening. You do have to get the consent of at least one parent for that. When you are a teen, you may be prescribed either estrogen or testosterone depending on how you're transitioning. You need a parent's signature for that as well.

Surgical stuff is very different. The only surgery that is usually available to anyone under 18 to affirm their gender would be chest surgery. Very often, you have people who have breasts that want to remove their breasts via chest reconstruction, which we call top surgery. The youngest person we've had top surgery approved by insurance for was a 15-year-old. You can have top surgery when you're under 18; you do need approval. Each surgeon has a different approval process, and most of the time, the surgeon will require at least one parent's permission. Occasionally, a young person under 18 will get breast implants, but again, that depends on the surgeon's consent process.

The experience of being trans is different for every single person, not everybody chooses to do the same interventions.

I wanted to address the kind of method that there's one way to transition and that it's available to all people regardless of age, because it's not that simple. If we do have a young person (and I've run into this all the time in the juvenile justice system with you and with the young people we worked with together, Sean), a lot of them are trans youth that don't have family support. If you're a transgender person, and you really want to begin testosterone, and your family isn't supporting you, or maybe you're not even in contact with your family, or maybe you were in DHS, there are ways to address and bypass that. We've had success going to judges and getting a judge's order for a young person to begin hormone therapy. Hormone therapy can be incredibly important to a trans person that wants it. It can really be a therapeutic intervention. It doesn't just change your body, but if you're somebody that has gender dysphoria, getting the hormones that affirm your gender can have a massive impact on your wellbeing, on your mental health, and on your quality of life. So, we would get a letter from the director of our gender clinic that says, "X young person has been prescribed testosterone. It's our belief that it's going to give them all these good outcomes, and it's going to prevent certain negative mental health outcomes." When the judge approves it, we can then prescribe the kid hormones.

Snyder: And I'm wondering, what about the kids that can be left out for whatever reason (family refusal for consent, lack of resources). Are there open support groups for kids that don't require a parent's consent?

Smith: There are, and it depends on where you live. In order to go to the groups that I run, you have to either be a patient of the CHOP gender clinic or of Mazzoni Pediatric Trans Care Clinic. For folks that aren't familiar with Mazzoni, it's the LGBTQ+ health center in Philadelphia for general LGBTQ+ wellness. It's not just trans care, but they do trans care for adults and children. There are other places in the city that have support for trans youth, including the Attic Youth Center, which is an LGBTQ+ center for young people. A lot of the kids that go to the Attic are kids that don't have family support, and they really form community and form intentional family with each other through the Attic. In Bucks County, PA, there's a place called the Rainbow Room in Doylestown, PA, which is a great place for LGBTQ+ youth.

You kind of have to hear from word of mouth or from other people in the community about what's out there. There's also something called Mainline Youth Alliance, which is a queer kids organization on the mainline. There are resources, but this isn't going to be the case if you're a kid growing up in a rural area.

Snyder: Right, informal supports where available are very much connected by word of mouth. A lot of your responses have touched on engagement on a lot of different levels. One last area is the workplace.

One of the students asked about how you approach coworkers who have negative perceptions of gender dysphoria or gender non-conforming youth. How do you deal with those coworkers?

Smith: The lives and well-being of trans children are more important than the discomfort of a non-trans adult. If you're not familiar with the terms cis-gender, it just means a person that is not trans, a person whose gender identity corresponds with the sex they were assigned at birth. Cis-gender people can be uncomfortable. It's okay. I don't worry about offending cis-gender people by being an advocate for transgender youth. I think that there might be some people that need science. And there is science that trans identities are valid. From anthropology, they have existed in the beginning of recorded human history. Currently, we have more language now, so folks can put words to their identities in 2020 in a way they couldn't in 1920.

I would share with people that just because you don't understand someone's gender identity, it doesn't make it any less valid or real. If a person is telling you they're trans, they know themselves better than any person outside of them knows them. So, I know it can be a shock to some folks when a trans person comes out, but you can guarantee that the person that comes out has already thought long and hard about their gender identity. It is a real thing. It's not somebody being confused. It has nothing to do with religion or morality. Advocating for the person who is trans is far more important than like the discomfort of a cis-gender person.

> *If a person is telling you they're trans, they know themselves better than any person outside of them knows them.*

Snyder: Right, and, as you said, it's probably ignorance with lack of information or lack of comfort. And we have to hold firm with our views as advocates for these youth.

Things Clinicians Should Know

An open mind is the most important tool to have, and familiarity with terminology can be another foundational aspect of providing affirmative care. Here is a brief list of the terms we covered in this chapter:

- **Sexual orientation:** someone's emotional and erotic attraction toward another individual.
- **Gender identity:** one's experience of one's gender.
- **Natal sex or sex assigned at birth:** label based upon a physician's observance of particular genitalia/phenotype or through chromosomal testing.
- **Gender non-conformity:** gender role behavior that does not conform to culturally defined norms.
- **Gender discordance:** the discrepancy between anatomical sex and gender identity.
- **Transgender:** signifies non-conforming gender identities, which also

includes other terms such as genderqueer, gender non-conforming, or genderfluid.

Common Elements Approaches

Communication skills: communicating needs based on one’s sexual orientation or gender identity.

Insight building: used to achieve greater self-understanding, help with management the emotional consequences of transitioning, negotiating social spaces.

Psychoeducation: related to aspects of sexual orientation, gender identity for both the child and their families/caregivers.

Social skills training: may be helpful with social transitioning and navigating social spaces.

Open Access Assessment Tools

Guide to Being an Ally (Trevor Project)

The Gender Book (Gender 101)

Gender and Sexuality Development Program Resources (Gender/Sexuality Program)

Gender Affirming Care (Brief)

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PART III

ORGANIZATIONAL CONSIDERATIONS

18

Chapter

Clinical Supervision of Youth-Serving Clinicians

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Sean is a clinician in a community-based clinic, providing services to children and families. He has built up to a full caseload, and cases range from disruptive behavior disorders to depression to trauma and stressor related disorders. His supervisor started to notice that Sean's documentation quality was decreasing. He started to use sick time more frequently and was somewhat disengaged with coworkers. His supervisor brought this up in their individual check-in, and Sean reported, "To be honest, I feel like I'm swamped with cases. I know what to do with doing the evidence-based treatments, but I just can't get these cases done....I just can't keep up with the demands of the work. What can we do? I don't want to leave this job, I love it. I just need some help."

Overview of Supervision

As you can see, Sean needs supervision for various reasons: maintaining occupational wellness, balancing work demands, and helping to deliver quality evidence-based interventions for his caseload. Supervision encompasses the various ongoing clinical supports of individuals providing therapeutic services, ranging from activities that support quality of the clinical services rendered to clients to professional development of the clinician providing the service (Bearman et al., 2013; Falender et al., 2014; Bearman et al., 2017; Schriger et al., 2021). Supervision is a way to enhance clinician therapeutic skills and to understand the relational aspects of providing psychosocial interventions (Falender et al., 2014). There are various modalities of supervision, ranging from individual supervision (one-on-one), group supervision (one-supervisor to many supervisees), and peer supervision (peer-to-peer support without a senior professional). Supervision is one of key opportunities to make therapeutic concepts actionable (Bearman et al., 2013), and it has effects on patients, clinicians themselves, and organizations.

This chapter will cover the impact of supervision, the various roles and activities of the supervisor, and insights on how to use the valuable resource of time in a supervisory hour, based on the supervision literature.

Why is Supervision Important?

Clinical supervision has an impact on client outcomes, therapists, and organizations. Clinical supervision can produce benefits to patients and health organizations, typically when a working alliance is established between supervisor and supervisee (Martin & Milne, 2018). Leadership is required from a supervisor to provide direction and the supervisee to provide collaborative decision-making when faced with negotiating needs and self-evaluations (Martin & Milne, 2018). With clients' impact, clinical supervision is known to account for up to 16% of variance in client outcomes, evidenced in better numbers of symptom reduction and completed cases (Lyon et al., 2018; Rieck et al., 2015).

Supervision impacts therapist competence. Supervision itself can be more impactful than training as it promotes behavioral change in employees (Lyon et al., 2018). Structured supervision is not widely utilized because most supervision practice focuses on case conceptualization, interventions, and administrative tasks (Lyon et al., 2018). Supervision outcomes are typically not measured; however, it is known that quality supervision focuses some sort of standardization such as focus on session review, treatment model fidelity, and supervisee skill building (Lyon et al., 2018; Rieck et al., 2015).

Supervision itself can be more impactful than training as it promotes behavioral change in employees.

Quality supervision can reinforce practices that increase employee well-being. Making workplace detachment at home allows for recovery from work (Sonnentag & Fritz, 2015). A supervisor's promotion of work-life balance and relaxation can decrease emotional exhaustion, a core component of burnout (Hutchins, 2018). Supervisors who coach their employees to use active coping strategies opposed to avoidance coping can increase job satisfaction and organizational commitment (Hutchins, 2018). Quality supervision can increase employee job satisfaction, reduce turnover intention, and lead to increased organizational commitment (Mathieu et al., 2016). Perceived supervisor support increases employee social relations, which is protective against burnout (Arici, 2018). Employees who have higher levels of perceived supervisor support tend to have higher levels of perceived organizational support, a factor known to decrease burnout (Arici, 2018). Supervisors serve as a protective factor in this way; however, supervisors can also serve as a risk factor for burnout if employees focus on the negative aspects of their supervisor (Arici, 2018). When an employee experiences burnout or secondary traumatic stress, they are placed in a position in which they do not feel empowered. Supervision that has a leadership component (agenda setting, guiding the session, teaching and development of the supervisee) can be protective when a supervisee's ability to advocate, engage, and collaborate effectively is compromised (Martin & Milne, 2018).

Supervisors who provide frequent constructive feedback and direct, immediate support can affect employee engagement, job satisfaction, and organizational commitment (Shuck, et al., 2014). While not directly correlated with quality supervision, the effects of on work engagement can lead to decrease absenteeism, burnout, and turnover intention (Shuck et al., 2014). Supervisors can also provide feedback that enhances job embeddedness, which represents employee's skills and job fit; employee job embeddedness decreases turnover intention (Shuck et al., 2014). Clinical supervision does have an impact on coping; it serves as a supportive activity for coworkers, and it provides long-term influence on job satisfaction and competence (Hyrkas et al., 2005).

In addition, it may be helpful to understand the bi-directional impact of supervision on organizational climate (employees' perception of their workplace environment) and culture (norms and expectations in an organization) (Glisson, 2002). Supervisors often serve as middle managers, who supervise frontline employees and are supervised by top organization leaders (Birken et al., 2012). Middle managers play the important role of communicating and implementing the policies and practices established by organization leaders and are therefore essential in creating and maintaining organizational climate and culture conducive to employee performance and well-being (Birken et al., 2012). When particularly focusing clinician EBP use, supervision is theorized to increase EBP use through influencing EBP implementation climate, the perception that EBP use is expected, supported, and rewarded in one's organization. One study found that supervisors engage in four specific behaviors (diffusing, adapting, mediating, and selling) all related to communicating information about EBP use to clinicians in order to shape and improve implementation climate (Bunger et al., 2019). Another study found that when supervisors frequently engage in specific implementation leadership behaviors, organizational implementation climate improves, and clinician EBP use increases (Williams et al., 2020). However, implementation climate may also influence supervisor behaviors. One study found that implementation climate strongly predicted the amount of time supervisors spent discussing EBPs content, accounting for about 37% of supervisor-level variance (Dorsey et al., 2017). In this case, messaging from top organization leaders, through explicit communication or allocation of financial resources to EBPs, may be important in encouraging supervisors to engage in EBP specific supervision. Therefore, attending to this bi-directional relationship may help clinicians understand how and where they can best receive EBP support from within their workplaces.

Values and Principles of Supervision

When we think about the various roles of the supervisor, the value is not in a prescriptive description of what to do, but how to do it. In this section, we focus on the how of supervision. A critical first step in discussing supervision is grounding our practice in SAMHSA's Six Principles of Trauma-Informed Care (SAMHSA, 2014): safety; trustworthiness and transparency; peer support; collaboration and mutuality; empowerment, voice, and choice; and cultural, historical, and gender issues. Trauma-informed organizations infuse these principles in all their policies and practices. This section describes how these principles are implemented in supervision. By utilizing these principles in clinical supervision with a trauma-informed lens, we positively impact staff and improve the quality of care provided to clients. These principles not only apply to our clients but should be woven throughout all aspects of the organization.

> *It may be helpful to understand the bi-directional impact of supervision on organizational climate (employees' perception of their workplace environment) and culture (norms and expectations in an organization).*

Supervisory Value: Safety

As a supervisor, one of our primary goals is to increase safety for our staff. We must prioritize both physical and psychological safety. In thinking about physical safety, we must consider the physical space staff are working in (in homes, communities, office settings), their access to resources and safety plans in times of crisis, and their personal sense of safety working with certain populations. We must consider whether staff feel respected by clients and families that they work with as well as peers, colleagues, and administrators. It is important to have discussions with staff to better understand their sense of safety in their work.

Psychological safety is essential to the relationship between supervisor and supervisee. Supervision should be a place where staff can come to feel heard, respected, understood, and supported. Supervisors need to invest time and effort into trying to create spaces that are inviting and free of judgment. There are many ways to accomplish this, beginning with recognizing our staff as human beings who come to this work with their own personal feelings, beliefs, and histories. Infusing the importance of safety when we speak is paramount. It is our responsibility as supervisors to partner with staff to enhance their sense of safety and to implement policies and protocols to mitigate any safety issues.

Supervisory Value: Trustworthiness and Transparency

A positive relationship and connection between you and your supervisee create the foundation for trust and a strong professional relationship. By prioritizing the relationship, supervisees will begin to trust that we, as supervisors, will have their back. The goal of supervision is not to prevent staff from making mistakes but to allow staff to make mistakes, seek support, and learn from those mistakes. While we ask for our staff to trust us, and we work to build that trust, we must also trust our supervisees. We must trust that they

By utilizing these principles in clinical supervision with a trauma-informed lens, we positively impact staff and improve the quality of care provided to clients. These principles not only apply to our clients but should be woven throughout all aspects of the organization.

have the best intentions for their clients, which will allow space for supervisees to function independently without micro-management. It is critical that staff know that you, as a supervisor, believe in them, support them, and will stand by them when they're doing great work, as well as when they make mistakes. Our responsibility is not perfection, but it is to help supervisees learn and grow to provide the best care to clients.

Providing honest and clear feedback in a constructive, not punitive way, is another way to maintain transparency. In addition to being a source of support for staff, we must be consistent with that support. Holding our supervision time as scheduled, not frequently rescheduling, is one way to show consistency. We must also be accountable, following up on tasks and ensuring that staff have access to the information and resources to do their jobs. The supervision space should remain confidential, except when staff ask for assistance in advocating on their behalf. In addition to the trust and transparency between supervisor and staff, that transparency should also include openness about agency-level decisions, changes, or policy updates that impact staff and clients.

Supervisory Value: Peer Support

The supervisor is one of many forms of support to supervisees. As supervisors, it is important to encourage staff to seek out different forms of support. While supervisors must recognize their own impact on staff performance and wellness, they must also recognize the limits of individual supervision and the benefits of peer support. Catherall (1995, p. 86) states that "peer support can often clarify colleagues' insights, listen for and correct cognitive distortions, offer perspective/reframing, and relate to the emotional state of the therapist". In order to build a strong cohesive team, it is essential to recognize and create opportunities for staff to give and receive peer support and mutual aid. Similarly, supervisors should seek their own peer support, to learn from other supervisors and engage in collaborative learning.

Supervisory Value: Collaboration and Mutuality

As a trauma-informed supervisor, our goal is to reduce hierarchical structures to enhance mutuality and collaboration. It is essential that we, as supervisors, work to level the power differences in supervisory relationships. We must recognize our power and position and be mindful of that power and privilege in all the spaces we operate, as well as in the decisions we make. Our supervision time with staff should be collaborative in which the supervisor and staff join in sharing perspectives, problem solving, and making decisions. It is important for staff to model vulnerability at times and to be authentic when they may not have the solution to an issue. Just as we understand the impact of an authentic relationship between clinicians and clients, the context of relationships between supervisor and supervisee is the foundation for healing and empowerment.

Supervisory Value: Empowerment, Voice and Choice

Utilizing this pillar in the supervisory relationship helps us acknowledge that each supervisee has unique experiences, skills, and needs and will require different things from us as supervisors. Approaching supervision by using the strengths perspective will help us identify the assets of each individual staff member and be able to flex our style of supervision to meet their needs. While some staff may appreciate and utilize processing in the context of supervision, others may have alternate ways outside of supervision that allow them to process. Similarly, some supervisees are able to voice when they are struggling or need additional support, while other staff require the supervisor to create the opportunity for staff to feel safe enough to share it. It is important to have discussions to get to know what each staff needs from you as a supervisor. Supervisors should encourage staff to utilize multiple means of communication to share feedback, such as supervision meetings, email, or Slack.

Supervisory Value: Cultural, Historic, and Gender Issues

As supervisors, we must recognize our own biases. We must recognize the histories and experiences that our staff may have, including those related to race, gender, socioeconomic status, geography, sexual orientation, religion, and abilities; we must also recognize how these experiences impact their work and their relationship with us as supervisor. It is essential to recognize and acknowledge historical and present-day abuses of power and privilege and how these behaviors contribute to structural racism and discrimination that affect our clients, families, and staff. As a supervisor, it is imperative to hold space to acknowledge these experiences in the context of trauma in staff’s personal and professional lives. In addition, it is also essential to understand that staff often bring their individual cultural practices and ways of healing, and that is an asset and can improve care to clients.

SAMHSA’s Six Principles of Trauma-Informed Care provide the values and beliefs that can guide supervisors in how to create authentic professional relationships and safe spaces for their staff. In addition to these principles, it is also important to recognize the different roles that supervisors play within the organization. Supervisors can take on the roles of counselor, educator, consultant, wellness coach, and/or advocate. When we know our staff and their needs, it will help us know when we need to shift into these different roles to best support them and ultimately enhance the quality of care provided to clients.

Roles and Responsibilities of a Supervisor

The previous section gave the context of the approach to supervision, and this section will discuss the specific roles or implementation of those core policies. Supervisors may have different styles, such as a developmental approach that focuses on the continual growth areas; an integrated model that understands the eclectic approach to counseling and therapy; and an orientation specific model of supervision, like behavioral supervision or systemic therapy (Leddic, 1994). There are many other models and considerations for supervisory practice (Westefeld, 2009; Mitchell & Butler, 2021; Li & Peters, 2022), so we will glean common elements from these approaches. We start out considering the bigger picture for our supervisees, and then we will work towards the delivery of service.

Wellness Coach Role

Supervisors have an ethical imperative to discuss aspects of burnout or secondary traumatic stress with their direct reports. It is helpful to understand these concepts and how they can enter the supervisory relationship. Burnout comprises the specific cognitive, emotional, and behavioral changes an employee faces after cumulative stress, and its features include emotional exhaustion, depersonalization, cynicism, diminished sense of personal accomplishment, and the overwhelming feeling of increased difficulty to perform work tasks effectively (Stamm, 2010; Ahola, Toppinen-Tanner, Seppänen, 2017). Burnout can be seen through an organizational lens, in which burnout arises from the conflict of job demands and resources to meet demands; typically, this stress load is characterized by deficits in resources and surpluses of demands (Ahola et al., 2017). On an individual level, an employee’s appraisal of their stress also mediates the relationship of both the job-demands conflict and the resulting burnout (Ahola et al., 2017). This appraisal pattern can create a negative feedback loop that perpetuates and exacerbates burnout symptoms.

STS, if left untreated, can lead to problems for employees in both occupational and personal domains (e.g., employees can experience physical ailments, poor interpersonal relationships and diminished work quality, performance, and productivity.

Secondary traumatic stress results from the emotional responses when a helper is exposed to first-hand traumatic experiences of their clients (Stamm, 2010), and it often resembles the symptoms of post-traumatic stress disorder (PTSD). Employees can have intrusive thoughts about their clients' experience, undergo changes in mood and cognition, suffer sleep disruption, and, lastly, avoid their client or content related to their clients' experiences (Stamm, 2010; Osofsky et al., 2008; Figley, 1995). Secondary traumatic stress goes beyond burnout, as there can be drastic and lasting changes in a helper's belief system in which they feel helpless, detach from their work, and experience physical and psychological isolation (Stamm, 2010; Figley, 1995, 2002; Osofsky et al., 2008). STS, if left untreated, can lead to problems for employees in both occupational and personal domains (e.g., employees can experience physical ailments, and poor interpersonal relationships, along with diminished work quality, performance, and productivity) (Pryce et al., 2007). Both STS and burnout in their respective presentations of stress provide challenges for human service organizations with a seriousness that can signal an occupational hazard.

In addition to the negative sequela in individual workers, STS impacts the care provided to clients and families. Dutton and Rubinstein (1995) assert that defense mechanisms, such as detachment and non-empathic distancing used by workers to deal with client's traumatic experiences, lead to clients feeling emotionally isolated and detached from those workers who are trying to help them. STS also contributes to victim blaming and the disruption of empathic abilities (Pearlman & Saakvitne, 1995). Bride (2007) found that 31.6 % of workers endorsed client avoidance (reduced interactions or visits with clients) which was the second most frequently reported symptom. Bride's findings are particularly alarming considering how such symptoms not only affect workers but also directly impact the quality of care provided to clients. Compromised care may negatively impact vulnerable children and families and may also increase risks related to safety for staff, clients, and the organization (Vega, 2019).

STS also correlates with low rates of job satisfaction, retention, employee engagement, decreased agency efficiency, morale, quality of work, increase in staff turnover, and economic loss to the agency associated with hiring and training rates (Joyce et al., 2015). Mental health is an increasingly important topic in the workplace with common psychological disorders now recognized as the leading cause of sickness, absence, and long-term work disability in most developed countries (Cattrell et al., 2011; Moncrieff & Pomerleau, 2000). Stress-related health conditions contribute to substantial economic costs to employers and disruptions in quality services provided to vulnerable children and families.

The physical, psychological, cognitive, and behavioral manifestations of STS also interfere with worker productivity as workers perform their job duties, while also trying to address their own health needs. STS is pervasive and increases the risk for negative psychosocial and health outcomes for workers, negatively impacts client safety and wellbeing, and poses great economic strain on the organization. Abounding risk factors in multiple domains highlight the need for a holistic and comprehensive understanding of the interrelated factors that increase risk for STS.

One of the greatest protective factors that we can control organizationally to support staff and mitigate STS is the quality of supervision. Social support plays an essential role in the lives of individuals who work with clients who have experienced trauma. Kassam-Adams (1995) conducted a study on 100 psychotherapists who worked in outpatient mental health agencies. Approximately 50% of the participants reported STS symptoms, including symptoms of avoidance and intrusive thoughts. The participants' stress levels were found to be inversely related to the levels of social support they had in their personal and professional lives.

In addition, the use, availability, and quality of supervision has been shown to decrease the negative effects of STS and VT (Brady et al., 1999). Dalton (2001) found that the number of hours of supervision received but also the number of times a social worker received supervision were positively related to low levels of STS. Organizations seeking to prevent or reduce the impact of STS must employ interventions that focus on increasing peer, supervisor, and organizational support that can improve the quality of work and preserve the overall effectiveness of the organization (Dunkley & Whelan, 2006). STS is a serious work hazard, and administrators should pay more attention to the negative outcomes and implications of failing to address STS. Supervisors must understand that STS is a structural problem, and individual solutions may only buffer the negative outcomes. This can result in both physical and psychological impairment of staff, decreased quality of services to clients, and greater attrition rates and costs to the organization.

Advocate or Change Agent Role

As we have learned, the addition of supervisor support serves to reduce or alleviate concrete work stressors and/or workload. Ideally, the supervisor becomes a buffer to address the organizational and systemic factors that are increasing stress reactions (by diversifying tasks, reducing caseload, halting intakes, permitting time off, escalating client or organizational concerns, providing encouragement and recognition, etc.). The supervisor's role is to advocate for staff wellness (balancing that with client safety and needs) and think through creative solutions to mitigate the systemic sources of stress. Many of these organizational resolutions are often temporarily enacted to give staff enough time and space to cope effectively. This approach fosters the supervisory relationship as a protective factor to promote longevity of staff and quality care to clients.

Identification of STS as a systemic issue encourages those in the profession to reexamine the relationship between trauma and this type of employment stress. Evidence demonstrates the need for administrators and supervisors to implement organizational responses, such as reducing workloads, diversifying tasks, and increasing vacation or sick time to address employee health and safety. Other organizational responses, such as ongoing peer support, increased supervision, and creating a culture that acknowledges the potential for STS can serve to prevent or decrease symptoms (Vega, 2019).

Counselor Role

One of the roles that supervisors play is that of a counselor. While supervision is not therapy, a supervisee must feel that they can voice their concerns, ask for help, be vulnerable, and seek guidance. The counselor role resembles aspects of reflective supervision, where the supervisor utilizes active listening and thoughtful questioning to support the supervisee with decision-making. By providing space and silence in supervision, we allow supervisees to think and reflect before expressing their thoughts and feelings. In our role as counselors within the context of supervision, the goal is to try to create a safe space for our supervisees to feel supported and heard.

In this counselor role, we support our staff by helping them be able to process client experiences and the way those experiences impact them. In the same way a client may experience a persistent fight or flight response, there exists a parallel process in which staff can experience the same response as a result of their increased and chronic exposure to traumatic stress (Vega, 2019). It is important that staff are able to utilize supervision to receive social support and tips on how to manage this impact. The supervisor explores the thoughts, feelings, reaction(s) of the supervisee in this role as counselor. By engaging in reflective supervision, the supervisee can increase observational capacity and become more aware of their own reactions to the client and the change process. In addition, reflective supervision can help supervisees become aware of their own biases and thought processes which can, in turn, enhance the quality of therapy provided to clients.

Educator Role

Supervisors often function as educators within the supervisory relationship. Educational supervision helps supervisees better understand their role while refining their knowledge and skills. Supervisors provide skills development, share resources and deliver content. Within supervision, there may be activities that guide the supervisee to better understand assessment, treatment, intervention, and evaluation. In certain specializations or areas, supervisors may share specific skills related to job responsibilities or tasks to help the supervisee grow. Supervisors are responsible for helping to close gaps in knowledge from both a clinical and administrative perspective. While educational supervision can provide new skills related to clinical practice, supervisors as educators also provide education around employee benefits, stress relief, or self-care strategies.

Consultant Role

For more advanced clinicians, we may enter into the role of consultant. A clinician may feel competent in delivering an EBP, so the role may be less about teaching or reviewing aspects of the EBP and more about monitoring the fidelity of the model. In such cases, a supervisor should have a clearly laid out information system, such as a system of feedback loops that can guide a consultant's work to understand and maintain model fidelity. This work may feel less dyadic and more of a collaborative relationship that encourages a different type of problem-solving process in which advice and knowledge are shared. In the consultant role, a supervisor may have specialized knowledge, and this can be helpful to identify gaps/barriers to a therapist's knowledge. Supervisors often play the role of consultant when trying to enhance fidelity in delivering EBPs within a new setting or with a new population. The supervisor will be able to support staff in shifting expectations or trying new strategies while maintaining fidelity to the EBP model.

Architecture of a Supervisory Hour

Given the various roles of the supervisor, there are many things to consider in a supervisory session. Structuring supervision can maximize use of time and ensure that key treatment needs are being addressed. The supervisory hour has time constraints, and supervisors have a multifaceted role in supporting clinicians, facilitating implementation of EBP, and addressing other miscellaneous issues that arise. Because of this, it is important to be intentional in structuring the supervision hour. Doing so will maximize the utility of the supervision hour.

When considering how to best align supervision with gold standard recommendations, it is important to consider the supervision content (i.e., what is talked about), supervision process (i.e., how it is talked about), and the relationship between the supervisor and supervisee, particularly as it relates to cultural humility (Schriger et al., 2021; Hook et al., 2016; Patallo, 2019). Supervision content will ensure that clinicians have the content knowledge and skills they need to implement EBPs with fidelity. Supervision processes allow for supervisors to ascertain that supervisees have this knowledge; it also allows a supervisor to foster a clinician's growth and learning through strategies that promote their development. Finally, attention to the positionality of supervisors and supervisees allows supervisors to model cultural humility with supervisees, which can then be enacted with clients.

Supervision Content

The content that is discussed in supervision is highly related to what is discussed in therapy, and thus should be considered when carrying out supervision. This can be addressed using an agenda, much like what is done within therapy sessions. It is important that key evidence-based content areas are addressed during supervision to ensure that they are being brought into therapy. These core EBP elements should be prioritized during supervision to maximize the likelihood that they will be implemented with the client (Bearman et al., 2013). While the key EBP components will differ across interventions, there are many components that cut across interventions, such as psychoeducation (across most interventions), exposure (particularly for anxiety treatments), and behavioral activation (most often for treatments targeting depression).

Key active strategies include experiential learning techniques such as role playing, modeling, and direct observation of live or recorded therapy sessions. Direct observation (and subsequent feedback) is a particularly crucial element for increasing clinician competency and has been shown to be underutilized.

In addition to core EBP elements, there are often other content areas that may need to be addressed during supervision, including administrative tasks, case management, crisis assessment, and risk management. In some cases, it may also be important to briefly discuss each client and to review any questions that arose since the previous supervision meeting. However, spending even a few minutes of review on each client can quickly use up the supervision hour, and this breadth must be weighed against depth in other areas.

Content areas unrelated to EBP implementation are often addressed during supervision out of necessity, as there may not be an additional dedicated time to address them. However, time spent in these areas will diminish the time that can be spent addressing core EBP components, and thus, if possible, it is best to address them outside of the supervision hour. This will maximize supervision as a time to support clinicians in solidifying therapeutic technique and to facilitate EBP implementation. There are several creative strategies that can be used to retain individual supervision as a time for carrying out these goals, particularly through the use of group supervision and “drop in” supervision (Schriger et al., 2021).

Group Supervision. Recent work suggests that these administrative and logistical issues can be successfully addressed during group supervision, which maximizes efficiency by allowing multiple supervisees to gain information at the same time. Group supervision can create greater efficiency for common challenges that may arise across supervisees, and it has been shown to be as effective as individual supervision (Dorsey et al., 2013; Stirman et al., 2017). In addition to discussing administrative and regulatory content in group supervision, some studies have suggested that in-depth case reviews can be utilized to teach skills to supervisees that they can then use with their own clients (Dorsey et al., 2017).

Drop-in Supervision. Other alternative solutions include creating a drop-in supervision hour during which supervisees can ask non-clinical questions to supervisors during a designated hour, much like office hours. (Schriger et al., in press). Drop-in supervision may be optimized by using an online platform, as it allows supervisees to drop-in even when not in the office or when they have a quick question that would otherwise not warrant a full meeting.

Supervision Process

The strategies used within clinical supervision are essential in fostering high quality clinical care and ensuring that EBPs are implemented with fidelity. There are a number of supervisory strategies that can be used to carry this out, including strategies that are more active in nature and others that are more passive (Schriger et al., 2021). Though both sets of strategies are important, the active strategies are crucial in facilitating specific skill development (particularly around delivery of core EBP content areas) and are often underutilized (Schriger et al., 2021; Bailin et al., 2018). Key active strategies include experiential learning techniques such as role playing, modeling, and direct observation of live or recorded therapy sessions. Direct observation (and subsequent feedback) is a particularly crucial element for increasing clinician competency and has been shown to be underutilized (Milne, 2009; Schriger et al., 2021). Other core active strategies include agenda setting, feedback provision, and didactic skills training.

In addition to active supervision strategies, it is important to attend to the relationship between supervisor and supervisee to facilitate trust and honesty and, in turn, to maximize the utility and impact of the supervision hour. Passive supervision strategies include actively listening to the supervisee, receiving feedback from them, and validating their experience. Additionally, supervision should attend to cultural humility, which is one aspect of culturally responsive care (Hook et al., 2016; Patallo, 2019). Although the literature on cultural humility in the context of clinical supervision is relatively limited, strategies have been developed to best foster cultural humility and address issues pertaining to diversity within the supervisory relationship (Hook et al., 2016).

Bringing It All Together

Given the multidimensional nature of clinical supervision, it can be challenging to know how to structure the supervision hour. While each supervisor-supervisee relationship is different, and each supervisee’s caseload is different, below we provide a list of recommendations to maximize utility of the supervision hour.

1. Set an agenda at the start of the hour to provide a roadmap for what will be discussed.
2. Prioritize discussion of key EBP content areas (e.g., psychoeducation, exposure, behavioral activation) to facilitate clinician competency and EBP implementation.
3. Utilize active supervision strategies (e.g., direct observation, role-playing)

to bolster clinicians' experiential learning and to generate feedback for clinicians.

4. Leverage passive supervision strategies and enhance relationship with supervisee.
5. Adopt techniques (e.g., initiate invite instill approach described by Hook et al., 2016) used to model cultural humility to promote culturally responsive clinical care.
6. Whenever possible, free up the individual supervision hour by discussing administrative and regulatory issues that affect multiple supervisees in alternative settings, such as group supervision or drop-in supervision.
7. Encourage supervisees to come to supervision with questions to guide agenda setting and maximize usefulness.

This chapter shows the balance between the what and the how of supervision, as well as the technical aspects of supervision and the values and attitudes needed for a supervisor to effectively work alongside their supervisee. Our work is challenging, but it does not mean that it is not feasible or that there are not ways to mitigate those challenges. Quality supervision matters to clinicians, their clients, and their organizations, and there is an ethical responsibility for supervisors to ensure that their supervisees can be set up for success.

How to Structure the Supervision Hour: Example Agenda

While each supervision session will look different, below is an example agenda from a supervision session that incorporates several key supervision elements. Keep in mind that it is not possible to incorporate all gold-standard supervision content and process components within a single supervision session.

0-5: Check in and set agenda.

5-10: Discuss any urgent issues, including risk management issues that will not be discussed in another format (i.e., during group or drop-in supervision).

10-25: Review recording from clinician's session.

25-30: Provide initial feedback and elicit reflection from clinician.

30-35: Supervisor models area that clinician could improve upon.

35-45: Clinician role-plays, with supervisor as client.

45-55: Discuss content area(s) that clinician will be covering in coming week, and answer questions.

55-60: Discuss administrative or regulatory issues that will not be discussed in another format (i.e., during group supervision or drop-in supervision).

Clinical Dialogues: Talking About Stress in Supervision with Dr. Laura Vega, DSW and Caroline Glavin, MSW

Dr. Laura Vega, DSW is the Co-Director for Children's Hospital of Philadelphia (CHOP) Community Violence and Trauma Support Programs. She has more than 20 years of experience working with children and adolescents in community and hospital-based settings. She is a Licensed Clinical Social Worker and received her Doctorate in Social Work from the University of Pennsylvania's School of Social Policy and Practice. Dr. Vega has provided on-going leadership in establishing the CHOP Violence Intervention Program (VIP) policies and procedures. She provides supervision, training, and consultation to hospital staff and students.

Caroline Menapace Glavin, MSW, LCSW is a licensed clinical social worker who oversees the trauma-informed intensive case management services of the Family Advocacy and Support Program through the Growing Resilience in Teens program of the Healthier Together Initiative at CHOP. Caroline also oversees the GRIT Needs Assessments and provides outreach, trauma-informed needs assessments, and emotional support to families in order to connect them with appropriate support and services. Caroline collaborates with primary care providers and social workers as well as numerous community providers in order to ensure youth and families are connected with appropriate and timely support.

Sean E. Snyder, LCSW: Supervision is one of the most important ways that an organization can support clinicians to support patient care and to sustain therapeutic services. That requires us to juggle many different professional roles and tasks. So, starting with Laura, how do you view your role as a supervisor? And what types of roles do you occupy as a supervisor?

Laura Vega, LCSW: In my role as a supervisor, I first take a holistic approach to working with staff and view them first as human beings working with incredibly challenging settings with at times a challenging caseload. I look at the supervisor almost as a change agent or a buffer to those stressors, to advocate for policies and practices that both support wellbeing but also support the quality of services provided to our patients and clients. One of the roles is a supporter and an advocate. Another role is helping somebody grow professionally through sharing feedback or providing safe spaces for feedback, for staff to ask questions and admit if they make mistakes.

Snyder: I heard you say that it's a big picture thing with supervision, about connection to the organization locally and at large, about the person's development, their personal growth, and all those kinds of things that fit into that holistic perspective. Caroline, I'd love to hear your perspective on how you view your role supervisor, knowing that you've had a lot of clinical experience (Laura does, too) and supervising clinical folks recently for your program.

Caroline Glavin, LCSW: I have a lot of the same views as Laura, and I had the opportunity to learn from her about important aspects of supervision, especially from a traumainformed approach, from learning and understanding myself as a clinician. I strive to provide my supervisees with the understanding of how this work can impact us, and so, taking that holistic approach, acknowledging that the work that we do is so challenging, and that there are times that we may be impacted by it. As Laura said, creating the safe space for vulnerability to be shared and discussed, can help me to validate and normalize experiences for supervisees. The hope is that they do feel that they can turn to me for support when they are struggling with, secondary traumatic stress or compassion fatigue on top of their regular clinical activities. If we are not taking care of ourselves, or acknowledging how this work is affecting us, it's going to impact the service delivery, and the quality of work that we are engaging in and that we're able to provide to our clients and families.

Snyder: If you're burned out, if you're stressed, it is very easy to stray from the EBP you are delivering or the modality that has been shown to be helpful for your population. You can't even engage with a client if you're burned out yourself. All those things moderate the relationships we have with providing services. Knowing that's all in the background, how do you balance that with the delivery of the service, like providing trauma focused cognitive behavioral therapy intensive case management as well? How do you balance the clinician needs with the more direct clinical supervision tasks like case conceptualization, behavior rehearsal or other technical aspects of doing clinical supervision?

Vega: To be honest, once you prioritize somebody's wellness, as a person in supervision, the rest falls into place. I feel people carry so much with them. A lot of people come into this work with their own personal experiences of trauma. I do think that making it a priority to check in with how your staff is doing first in supervision because it does set the stage for the other parts of our job. People will be in a better place to have conversations about the other administrative or case-related things that need to get done, and staff can generalize those knowledge gains. But if that is absent, oftentimes, we're actually contributing more stress, and potentially, secondary trauma to our staff, if we're not responsive or creating spaces where people can share about how they're doing, both personally and professionally. So, it is helpful to enter into supervision with this. Let me meet you where you're at; let me see how I can support you with all the things you're doing. And let me try to advocate from an organizational standpoint if there are huge policies and practices that are going against your wellness and positive delivery of quality services to clients.

Snyder: If you think about when we deliver EBPs, we always go back to that rationale. For instance with trauma treatments, we consider how we are going to get the client to buy him into what we're doing when we know it's helpful for them in the long run (sorry if that seems paternalistic). What's our rationale? Why are we doing this, how can I get buy-in to provide the service? It's because we care about you as a person, and we care about you as the provider of services to the clients that you care about. Is that rationale of supervision? We keep tying it back to that. And then over time, our organizations will benefit. Systems benefit and patients benefit.

Now, Caroline, what's your perspective on this, especially because I know you've been trained in many different things like the Child and Family Traumatic Stress Intervention, Attachment-based Family Therapy, and TF CBT.

Glavin: I view the relationship between supervisor and supervisee similar to the way that I view relationship between a clinician and the patient, in that their relationship is the foundation, and there has to be a strong relationship between the two before you can make progress in other areas. So, setting the stage early on, having that strong foundation of that relationship where the other person feels safe is the priority and is something that is so important in both areas. The relationship isn't necessarily the intervention, but it's the context for the change to happen.

Snyder: Yes, relational intelligence is so key. So, in the chapter, we'll talk about how to structure and how to do the work in the clinical hour. I want to spend a little more time talking about the organizational context for supervision. It really does take an organizational approach, when we think about staff wellness and about supporting clinicians.

Laura, I know there's a backstory about the Stress Less Initiative you developed at Children's Hospital of Philadelphia. Could you tell us a little about what Stress Less is? It responds to that organizational piece.

Once you prioritize somebody's wellness, as a person in supervision, the rest falls into place. People carry so much with them...

Vega: The Stress Less Initiative is a trauma-informed group model for staff to enhance personal and team resilience and to reduce or prevent secondary traumatic stress. The overarching goal is to reduce the stigma associated with secondary trauma, to normalize our experiences as clinicians and social workers and researchers in the field that are working with trauma survivors, that this is normal experience. Secondary trauma is a normal thing that happens within our work settings, and so, the more we can come together and talk about those things, and validate and support one another, the more successful we'll be.

A lot of it came about, honestly, because of my own personal experience with vicarious trauma and also being in a supervisor role and seeing many of my own staff having trouble sleeping, having worries about their own safety, being hyper vigilant, having their own trauma symptoms. The model takes those insights into thinking about how hard it has been for me personally, but also for my staff. They were struggling in silos with these symptoms. The model aims to think about what it would look like organizationally to come together, to be authentic about these challenges, to talk about them and figure out how we can support each other. It was built out of an unmet need. We've been running it now for six years in our own program, which has been a great asset to both making sure that people have the support they need, but also that as an organization, we are being responsive to the wellness and the needs of staff.

Snyder: Later I'm going to ask you about the nuances of what it is, but I want to pivot back to something you mentioned about who this affects. The Center for Violence Prevention provides clinical services but there's also this research arm of the center. When you talked about staff and the people doing the work, you mentioned research staff. Can you tell me about that? That's an interesting piece, when we think about what about research staff and secondary trauma.

Vega: We've learned so much about trauma. We know it's subjective, and we know that it reaches everyone. There are researchers and research assistants on our team. You don't often think of researchers being impacted by secondary trauma. This reminds me of an example of when I was in my office one day, and there was a research project going on that required our research assistants to go through client encounter notes. It was a qualitative project and they had to read through notes, and one of the research assistants came into my office crying from being impacted by someone's story, one of the children who had extensive trauma history and had so many different challenges. We recognize that you don't have to be somebody who is in direct service or on the frontline to be impacted on hearing stories; seeing or hearing or witnessing the different aspects of our work can be challenging.

Snyder: I appreciate you sharing that because when we think about a trauma-informed organization, it's not only the clinicians; it's folks at the front desk of a clinic, or security officers in the building. Everybody can have exposure to this occupational hazard! Your example was a unique situation.

Ok, I'd love to hear how you developed it, as well as the nuances and what's happening now in Stress Less, I know the development of Stress Less was embedded in your coursework towards your Doctor of Social Work degree. A lot of thoughtful planning went into this, from reviewing the literature, getting expert consultation from child trauma experts at NCTSN or other research centers. What are some of the common elements you pulled from the literature for Stress Less?

Vega: The Stress Less model is 12 sessions, done over a year. We meet monthly for 90 minutes, and it's embedded within our staff meeting. The tone is important to set as a way for people to come together and have time and space for themselves to talk about how this work is impacting them both personally and professionally and then get support. I developed a logic model based on the risk and protective factors that I found in the literature on secondary trauma. There's a lot of research that still needs to be done on effective interventions for secondary trauma; there's a huge gap with what is currently out there. I pulled from that and from what has been working in trauma treatments, so, things like mindfulness, recognizing power and control issues and how we as providers often are faced with limitations and systems that can impede progress. The elements are meant to foster team resilience.

Another element is regular assessment, almost like measurement-based care. We start each Stress Less group by assessing where we are from a mind-body-behavior-cognition perspective, and that gives us a way to check in with ourselves regularly to stay connected to those four domains of stress. Awareness can help introduce our strategies for stress management, coping, and getting support sooner. The goal is that the more we become attuned with ourselves, the quicker we'll be able to use our tools in our toolbox or to reach out for support. A philosophical component of Stress Less is about the onus for care and support not being on the individual, but it's about the people around you. It's about having a culture where you can be able

The shared experience has been the most powerful for me: the opportunity to be with other people who truly understand not only the work but how this work can impact us, and being able to receive some validation about that or receive some comfort.

to ask for support when you need it, being able to help each other, being able to recognize any issues in each other when people are stressed and say, “Hey, what are concrete things that I can do to take off your plate?” There’s a lot of beautiful things that weren’t anticipated when I first developed it that are now happening, and that has been wonderful to see over the years. It’s building team morale, and team cohesion. It’s been a wonderful experience.

Snyder: It sounds like it’s a very iterative project, where it’s focused on really listening in and working with those core concepts, and then listening to folks to see what’s working, what’s not working, and what their lived experience is. People inform the model. You’ve made me think about your experience doing TF CBT and thinking of a wellness promotion mindset. There are so many things in our treatments where I think, “This stuff can benefit us too, not just the clients!” Mindfulness can help clinicians and affect regulation and interpersonal skills; it all helps.

There’s two parts to my next thought. One is that sometimes we need the skills, and we need to learn that as a group. But also, what are the things that get in the way of using those skills (for instance, stress)? So the group can cover both the learning problem or the problem with learning or about learning. Caroline, what was it like being on the receiving end of Stress Less and your trajectory as a supervisor? It’s so common; we start out as a direct service provider and then eventually become a supervisor. So, what was it on the receiving end, and what is it now being in that supervisory role?

Glavin: There are so many things that I’ve gained through experiencing Stress Less and that our team has gained. One of them that I never experienced in any other position was this connection between the work and how it impacts us, specifically with the symptoms we can experience. Laura talked about the frequent assessments, so checking in with our bodies, and acknowledging and recognizing if we have a headache every single day after work, that may be related to stress, or, if we’re having stomach problems, these very specific things that I never received any information or training around, this connection between the work and our bodies, and how our bodies can manifest stress.

The regular check-in is so important on those four different domains, but along with that, the normalization, the validation, and the opportunity to come together with people who truly understand what you do in that space to discuss that shared experience. It has been very challenging for me to have conversations about this work or how it impacts me outside of work, because with people who don’t do this work it’s a very particular conversation. I end up explaining all the different systems and definitions, and it’s not helpful for you or a very therapeutic experience to explain all those things to someone who doesn’t do the work. The shared experience has been the most powerful for me: the opportunity to be with other people who truly understand not only the work but how this work can impact us and being able to receive some validation about that or receive some comfort. That has been huge. That in turn has created an incredible culture among our team that Laura spoke of, this sense of trust and team cohesion.

Everybody on our team is always willing to pitch in and take something off someone else's plate if they're struggling. That is because of this foundation that we created with Stress Less and the normalization of having these conversations and that it's okay among our team to express when you're struggling. And so, there have been so many things that I've gained as a participant of Stress Less. And those are things that I hope to continue to instill in the new team members who joined Stress Less now that I am part of leading the group, creating that safe space for people to share, normalizing, validating and helping them understand the connections that can be between stress and our bodies and our minds and how this work can impact us.

Vega: Thank you Caroline, because that was so well said. Stress Less was designed to be a mitigation strategy for secondary trauma, the other side is that we come together to talk about the great things we're seeing. We're celebrating victories within the work because we wouldn't be doing this work if there wasn't both sides. This work with families is challenging, but because it is challenging, it's also powerful and wonderful. It provides the opportunity to be part of something so powerful and transforming when we see healing and recovery. So, we also share those experiences in Stress Less as well.

> *That pressure can create conditions that supervisors maybe want to micromanage or want to control more. My advice would be to do that less; trust your staff more and give people freedom and independence.*

Snyder: I come back to this notion in DBT, when we think about cultivating positive experiences. How do we cultivate positive experiences in the midst of a lot of stress, where it feels like climbing a metal ladder in a fire pit (that's the DBT metaphor)? What undercuts everything from both of what I heard you say is that stress is part of our work. It shouldn't be the thing that defines our work, so we should be celebrating those successes and putting the change that we influence at the center of it and not necessarily the stress that comes from the changes we try to make. Let's define our work through the change. I appreciate that idea of wellness promotion being at the center of all the things that we do, and your supervisory model does that.

Let's talk now about the implementation of your model. There are so many things to consider like organizational culture, organizational climate, internal leadership, and we know all of these things influence EBP implementation and also sustainability. That's the point of your model, to make our work sustainable. If we're all burned out, then no one's doing the work that our families need. So, there are two things in there: how do you try to sustain your model, and how has your model been able to keep your program at large sustainable?

Vega: The research shows how much turnover there is with clinicians. I know in Philadelphia currently, it's a huge issue, and we need to think about ways to respond. A lot of people leave prematurely, without feeling supported or getting the resources they need to feel better in their role. I do look at Stress Less definitely as a way to sustain people within the field and get the support that they need. As an example, too, of internal sustainability, Caroline has been a great advocate and champion of the work, and it has been great now to step aside and see other people facilitate Stress Less within our organization.

To help us with spread and scale, we had an opportunity recently to partner with the Netter Center, a wonderful organization, through University of Pennsylvania, that is a bridge between academic institutions and the community. They asked for some support in two after-school programs for two Philadelphia schools. They've been implementing Stress Less to their after-school teams, and that has been amazing to be part of this partnership. We are learning too about where we can do Stress Less. I wasn't thinking about educators with development of Stress Less. Teachers don't have a lot of support, especially with COVID and the impact of COVID, how much has that been the challenge for teachers to be there for children in the hybrid school model. So, we are learning and attempting to adapt beyond just organizations doing mental health treatment; it goes into anyone providing a therapeutic service.

Snyder: That's a great example of how an intermediary/purveyor organization can be a way to sustain things or get things to people. Also, I heard you say your team is tailoring Stress Less based on local knowledge, it's adapting to those local contexts, considering that lived experience. What are some other things with your pilot?

Vega: Effective implementation involves training, of course, but in our training we talk about secondary trauma, and then I do a second training for facilitators. The idea is that it needs to be somebody within the organization within the team that runs Stress Less. It's not me coming in or some other entity outside of the organization to have these sessions. The facilitator should be internal to the organization; often a supervisor is the one leading it. In that facilitator training, there's a whole section on being able to be vulnerable in front of people you supervise and how powerful that can be to set the stage for staff being able to share and being able to be a support and be authentic. The organization needs to own Stress Less, and the model gives them the space to take that on.

Snyder: When we lose people with turnover, the organization experiences knowledge loss; there's loss of resources because then orgs have to train new people. So, the start-up costs of doing an intervention like Stress Less, there is a return on investment if employees stay, if there's improved client outcomes.

Taking care of people is the best organizational medicine. Any parting words for us?

Vega: We're always growing and changing, and even as a supervisor, I see things new each day. The piece that is most powerful for supervisors is sometimes that we feel that we get pressure from above and from below. That pressure can create conditions that supervisors maybe want to micromanage or want to control more. My advice would be to do that less: trust your staff more and give people freedom and independence. Supervisors may try to control more, but actually, we need to let go more.

Snyder: It is constantly evolving and iterative. It's paying attention to that stress yourself because it is such a parallel process. Thanks for sharing all of your knowledge and wisdom!

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19

Chapter

Getting Evidence-Based Interventions to People: Implementation Science

Sean E. Snyder, MSW; Courtney Benjamin Wolk, PhD; John Armstrong, PhD

Caroline is supervising a team of clinicians who are receiving a deluge of referrals for trauma-based therapy in the wake of increased gun violence in the city. She received some training in TF-CBT. Her clinicians are hesitant to push their clients to talk about their trauma in the systematic, therapeutic way outlined in various EBP protocols for treating child trauma. The team feels they need some support but don't think that their agency has the resources to help them or the motivation to support therapies for child trauma exposure. Caroline knows that training only solves one part of the problem for her team, and she will look to implement best practices.

In the practice vignette, we are seeing an all-too-common issue: the demand for an evidence-based practice (EBP) outweighs the available supply of providers. This is what we call a problem of implementation. Implementation of an intervention requires more than just a clinical decision; it depends on a multitude of organizational contexts and factors related to the EBP itself (e.g., its adaptability, the service environment in which a clinician operates). In previous chapters we looked at the evidence-based selection process for clinicians treating their clients. This chapter will give an overview of the field of implementation science, the mechanics of implementation, and a practice example of translating research into practice.

Overview of Implementation

Implementation practice refers to the use of strategies to change people's behavior or organizational processes, which can include the roll out of an EBP. Implementation science is considered the scientific study of methods and strategies that facilitate the uptake of evidence-based practice in health care settings (Eccles & Mittman, 2006; Bauer et al., 2015). There is some overlap with quality improvement (QI), but there are differences between implementation science and quality improvement. QI is aimed at a developing a specific solution to a specific problem at the clinical or system level, whereas implementation science tends to start with an EBP that is seen as underutilized despite having an evidence base to support its use (Bauer et al., 2015). These differ from dissemination practice, the act of sharing information to increase awareness and knowledge of a "thing," and dissemination science, the scientific study of best practices to disseminate information across audiences and contexts (Bauer et al., 2015). In our vignette, Caroline's team did not necessarily have an issue related to dissemination; there was some knowledge of an EBP. The issue was getting that knowledge to practice and getting that practice to scale.

The Research Pipeline and Implementation

Our practice vignette with Caroline highlights aspects of the research pipeline. When an EBP is tested in a lab setting, we refer to that as efficacy research. Effectiveness research occurs when we move the EBP into a community setting after efficacy is established, and implementation research is the last phase of the research pipeline. Translating knowledge to practice can be a long process, and problems with implementation can contribute to the 17-year average wait before innovations can be used in practice (Bauer & Kirchner, 2020). We run into issues of impact and of efficiency with intervention science, with data showing that approximately 80% of medical research dollars do not make an impact on public health, largely because of lack of proper implementation (Chalmers & Glasziou, 2009). Designing for implementation does not lead to more cost in the long run. Studies of global health initiatives show that those designed for proper implementation are cost efficient compared to initiatives that did not plan for implementation (World Health Organization, 2009).

Implementation Research Outcomes

Implementation outcomes are different from more traditional clinical outcomes (i.e., did the patient/client get better after they received the innovation); they are concerned with the proximal effects of the implementation effort and include constructs of acceptability, appropriateness, feasibility, fidelity, penetration, and sustainability (see Table 19-1; Proctor et al., 2011). It is important to attend to implementation outcomes because they can help clinicians and administrators understand why an EBP did or did not achieve the intended outcome when implemented in their setting. Without this information, one may falsely conclude that an EBP does not work for a particular population or in a particular context. Rather, it may be that the desired outcomes were not achieved because clinicians were not trained and supervised in implementing the EBP with fidelity to the core intervention components.

Caroline's leadership team is at a crossroads: how can they meet the needs of their clients under time, capacity, and resource constraints. We will discuss how her team will work through those in the coming sections. Before taking a dive into the process, let's look at the key concepts within implementation.

Table 19.1. Implementation Outcomes

Implementation Outcome	Conceptual Meaning	Related Questions
Acceptability	The degree to which stakeholders agree with aspects of the EBP	Does the content of this EBP match our situation? Is the EBP too simple or complex? Is it meant to be delivered to our intended audience?
Appropriateness	The degree to which stakeholders view the EBP as relevant to their need	Do we *believe* this EBP will address our needs? Do we *think* it is practical to reach our intended goal?
Feasibility	The degree to which the EBP is *actually* relevant to stakeholder's needs	Is this EBP *truly* suitable for us? Can we *realistically* implement this to create meaningful change?
Fidelity	The degree to which the EBP is implemented as intended	Are we adhering to the methods this EBP requires? If we're modifying the EBP in any way, what effects might that have on outcomes?
Penetration	The degree to which a practice is used within a service setting and its subsystems	Do clinicians trained in the EBP deliver the EBP with eligible clients?
Sustainability	The degree to which an EBP can be implemented over time	How much maintenance does this EBP require? Do we have the necessary resources to maintain its use? How easily can implementation be incorporated into organizational and clinical routines?

The Mechanics of Implementation

It may be helpful to unpack some of the overlapping terms in the field of implementation. To keep it simple, what we are implementing can be loosely called "the thing," and the implementation strategies are considered "the how" (Curran, 2020).

Implementing “the Thing”

Implementation science can appear convoluted, with its many terms and over 61 identified dissemination and/or implementation theories, frameworks, and models (Tabek et al., 2012), each with its own particular language or overlapping concepts. A common practice in communicating scientific knowledge to lay persons or non-specialists is to use nonscientific language. Geoffrey Curran, an often-cited implementation researcher, offers the model of simplicity to explain implementation science. He defines the intervention/practice/innovation as the *thing*. Effectiveness research attempts to see if the thing works, and implementation research attempts to understand how to best do the thing. Implementation strategies are referred to as the *stuff we do* to help people and settings do the thing. Defining the thing can be one of the most difficult aspects of implementation work. Oftentimes, our things can fit into the 7-Ps defined by Brown and colleagues (2017): programs, practices, principles, procedures, products, pills, and policies. In this chapter, the thing Caroline’s team wants to roll out is the practice of trauma-focused cognitive behavioral therapy (TF-CBT). The stuff Caroline’s implementation support team will do to help her clinicians do TF-CBT will be the implementation strategies discussed later in this chapter.

> *Implementation outcomes can help clinicians and administrators understand why an EBP did or did not achieve the intended outcome when implemented in their setting.*

It is important to note that there isn’t always one perfect EBP, or thing, to implement in a particular scenario. The available efficacy and effectiveness research may not directly map onto your exact client population or setting. However, EBPs can be delivered flexibly, while maintaining fidelity, to allow for personalization to client needs (Kendall, 2022). See, for example, Chorpita et al., (2011) for information on how to select EBPs to meet client needs.

Implementation Frameworks

Frameworks are outlines, overviews, and systems of thinking; they are descriptive and not explanatory. They do not outline the process; rather, they provide the context and architecture around any process or theory (Nilsen, 2015). As mentioned previously, there are numerous dissemination and implementation theories, frameworks, and models. This chapter will highlight those that are readily actionable for readers and have open access supports for implementers to utilize. Some frameworks are determinant frameworks, that is, they help us understand the relevant contextual aspects of implementation.

There are also process models, which describe the steps for putting the research into practice; these tend to not have the same degree of explanatory qualities as theories (Nilsen, 2015).

The Consolidated Framework for Implementation Research. The consolidated framework for implementation research (CFIR). described by Damschroder and colleagues (2009), represents an effort to synthesize the health services implementation literature. It provides "an overarching typology – a list of constructs to promote theory development and verification about what works where and why across multiple contexts." The five major domains described by CFIR include intervention characteristics, outer setting, inner setting, characteristics of individuals involved, and the implementation process. Intervention characteristics are the features of an intervention being implemented into a particular organization; they involve considerations such as whether there is the need to adapt an existing intervention to improve fit. The outer setting includes the economic, political, and social context within which an organization exists, for example what policies drive the practices selected for implementation and what are the characteristics of the community the organization serves. The inner setting includes the structures, organizational norms, and cultural processes implementation occurs within. The fourth domain relates to the individuals involved with implementing the intervention, including the impact of individual choices and influence on implementation. The final domain is the implementation process; successful implementation requires an active change process to achieve widespread use of interventions with fidelity. The CFIR website includes more information about these constructs and helpful, free, tools and resources.

> *The intervention /practice /innovation is referred as "the thing." Effectiveness research attempts to see if the "thing" works, and implementation research attempts to understand how to best do the "thing."*

EPIS Framework. One of the most widely used implementation science frameworks is known as the exploration, preparation, implementation, and sustainment (EPIS) framework (Aarons et al., 2011). The EPIS model has been applied to juvenile justice settings (Knight et al., 2015), public mental health, and child-welfare service settings (Moullin et al., 2019). The EPIS framework covers the different phases of implementation as well as the contextual factors that can organize implementation activities. These include outer contexts, inner contexts, innovation factors, and bridging factors. The outer context spans factors external to the organization such as the service environment, funding/ contracting factors, networks and interorganizational relationships, and client characteristics. (Aarons, 2011) The inner context considers determinants such as organizational characteristics that span leadership, organizational culture and climate, readiness for change, and quality and fidelity monitoring (Aarons, 2011; Moulin et al., 2019), as well as individual characteristics of the organization that span staff and leader attitudes, skills, and demographics. Bridging contextual factors reach across both the outer and inner contexts; intermediaries like purveyor organizations or community-academic partnerships often serve in these roles (Aarons et al., 2011). The innovation factors are related to the EBP that is to be implemented in the organization and the fit and adaptability of the EBP to the organization, provider, and client. We will explore how this process model is used at the end of the chapter.

Theoretical Models

Theories describe and explain how individuals, organizations, and systems change (Nilsen, 2015), and there can be abstract ways to show how specific relationships lead to specific events (Nilsen, 2015).

Theory of Planned Behavior. The theory of planned behavior (Ajzen, 1991) asserts that motivational factors and perceived behavioral control influence one's intention to perform a behavior, and this intention will become actual behavior if given the opportunity. Motivational factors include constructs such as attitudes, subjective norms, and social norms. For example, if a person is motivated to use an EBP, believes other clinicians like them use the EBP, believes use of the EBP would be appreciated and rewarded in their organization, and believes they have the requisite knowledge and skill to use the EBP, they will use the EBP if given the opportunity. In the context of implementation, implementation strategies may look to capitalize on available motivation or address its absence.

Theoretical Domains Framework. Building on the work of Michie and colleagues (2005) and Cane and colleagues (2012), the theoretical domains framework (TDF) aims to group constructs from implementation theories into domains to inform the identification of determinants of behavior. Atkins et al. (2017) also present a guide to using the TDF. The TDF can be helpful in informing the theoretical basis for implementation studies, understanding the scope of potential reasons for slow diffusion of knowledge to practice, and offering methods to make knowledge actionable. The domains discussed the TDF include knowledge; skills; social/professional role and identity; beliefs about capabilities; optimism; beliefs about consequences; reinforcement; intentions; goals; memory, attention, and decision processes; environmental contexts and resources; social influences; emotion; and behavioral regulation. To view the constructs within these domains, consult the table from the guide offered by Atkins and colleagues (2017). These domains and constructs cue us into what can facilitate or get in the way of implementing an EBP.

Implementation Strategies

Implementation strategies are, as discussed earlier, the *stuff we do* to help people and settings do the *thing* (Curran, 2020). That is, implementation strategies are the methods used to help increase adoption of an EBP, to support the implementation of an EBP in an organization, and/or to promote sustainment of the EBP (Proctor, Powell, & McMillen, 2013). There are at least 73 recognized implementation strategies (Powell et al., 2015), including strategies to support dissemination of information about the EBP, strategies that aim to improve the implementation process (e.g., by engaging stakeholders, adapting the EBP), strategies to help integrate the EBP into the context (e.g., through modifying record keeping and supervision), strategies to build capacity for the EBP through technical assistance and support, for example; and strategies to support scale-up (e.g., training, developing toolkits; see Leeman et al., 2017). In social work organizations, commonly utilized implementation strategies include training/workshops, supervision, policy mandates to use the EBP, and financial strategies (e.g., an enhanced reimbursement rate). The complete list can be found online in Powell et al.'s (2015) supplementary material and tables. As Powell and colleagues discuss, these strategies do not constitute a checklist required for any implementation effort; they merely present the breadth of strategies that can be packaged together in an implementation plan. On the CFIR website, you can find a tool for matching implementation strategies to barriers identified at different CFIR domains (i.e., the CFIR-ERIC matching tool; see also Waltz et al., 2015).

Clinician Exercise

- Think of a current service problem in your practice setting
- Is there a practice gap that requires a new intervention roll-out?
- Or do you have something that works but it's difficult to sustain and scale?
- What beyond training would you need to do to improve your practice setting?

Example: EPIS Process

Let's look at the practice vignette and consider how Caroline's team may attempt to approach their problem. We will look at the process of implementing TF-CBT in a community mental health clinic through the lens of the EPIS Model and Framework. Note that while we use TF-CBT as the example here for illustrative purposes and continuity throughout this chapter, the same process can be applied to other situations and EBPs. For example, a community clinic that is increasingly receiving referrals for preschoolers with behavioral challenges could apply this process to their implementation of parent-child interaction therapy (PCIT) (Funderburk & Eyberg, 2011). Or a school seeing an increase in aggression and conduct problems may apply the same process to the implementation of the Coping Power program (Larson & Lochman, 2002).

Exploration Phase

Exploration begins when implementers and an organization identify a need. Following the identification of the need, various EBPs are evaluated to determine those most likely to achieve the desired outcomes. While doing so, implementers and relevant stakeholders consider systemic, organizational, and individual levels of adaptation that may be required to ensure the EBP represents the best possible fit for their organization (Moullin et al., 2019). The exploration phase ends when implementers and stakeholders choose an EBP and outline the initial expected adaptations necessary to ensure effective implementation.

As a leader, Caroline knew that that TF-CBT was efficacious and had been widely implemented in different settings. So, the thing itself seemed appropriate, but Caroline had to consider exploring aspects of the outer sociopolitical context and funding availability. Would insurance and managed care organizations support the rollout of TF-CBT with an enhanced rate? How would she cover the cost of training? She knew that there was a network in her local department of behavioral health that could offer training and used direct networking to get to the right administrators in that department. She knew this partnership could take time, but it was worth the effort of reaching out and taking things slow.

What about the inner context? Caroline was a champion for this intervention and thought that she could lead the charge. The main barrier in her organization was the climate: folks were feeling burned out and potential individual adopters had little perceived need to change. They felt comfortable with their usual treatment. Caroline had to consider organizational readiness before moving into preparing for potential implementation.

Preparation Phase

Preparation involves a deeper consideration of the systemic, organizational, and systems-level needs prior to implementation. Implementers and relevant stakeholders collaborate to determine potential barriers and facilitators to implementation. The implementation team also plans for expected implementation support (e.g., training, coaching, audit, and feedback) to create an environment where the EBP is valued and supported at all levels within the organization (Moullin et al., 2019).

Caroline's networking resulted in a meeting with a key administrator in her public mental health system. They were open to training her team but needed to apply for an internal grant. This process forced Caroline to consider the steps for preparation. She needed to determine the funding stream for the service (continued billing), set up the actual training, identifying other champions of the intervention to support group supervision in TF-CBT, build out a fidelity checklist for use in supervision of clinicians, consider appropriate staffing patterns to continue to offer non-trauma psychotherapy services, determine how youth would be referred for TF-CBT, and prepare to evaluate the outcomes of rolling out the service.

Implementation Phase

Implementation occurs when the use of the EBP begins within the organization. Implementers and relevant stakeholders engage in an iterative monitoring of the use of the EBP to assess for unforeseen challenges or needs. Where necessary, adjustments are made to implementation strategies and supports to meet expectations for effective implementation (Moullin et al., 2019).

To support the roll out of TF-CBT, Caroline consulted the go-live checklist. This ensured she was covering all aspects of implementing TF-CBT at her clinic. She made sure there were adequate monitoring and feedback systems in place and planned to pilot cases as a way to get iterative feedback.

Sustainment Phase

Sustainment consists of continuous monitoring of implementation, as well as internal and external factors that affect implementation (Moullin et al., 2019). Successful sustainment occurs when the EBP is properly adapted and ingrained within the organization to achieve the desired impact upon its intended need.

Six months into implementing, Caroline was seeing some success. The main problem was continued staffing. One trained clinician transferred within the clinic, another was promoted to supervisor, and a third left the agency. Caroline had planned for some turnover and was able to work in a second cohort of trainees later in the year. She allocated money in her grant for ongoing consultation with a TF-CBT master trainer for support and generalizable learning from the original workshop training. “If I went back and did it all over again, I wouldn’t change a thing,” Caroline said. “It was a lot of up-front work to make sure we were ready, that it was something we could continue to do; ultimately, we want youth to get access to care and for care to be there for the next family that needs it.”

Clinical Voices: Implementation Science with Dr. Courtney Benjamin Wolk, PhD

Courtney Benjamin Wolk, PhD is an Assistant Professor at the Penn Center for Mental Health at the Perelman School of Medicine. She is a licensed clinical psychologist and an implementation scientist. The long-term goal of her research is to develop and evaluate strategies to promote the uptake of evidence-based care into routine practice, with the ultimate goal of improving the effectiveness of mental health services for children and adults in non-specialty mental health settings. She completed both her MA and PhD in Clinical Psychology at Temple University, where she focused on the development and evaluation of cognitive-behavioral therapies (CBT) for child and adolescent anxiety. She completed an APA-accredited pre-doctoral internship in clinical psychology at Children’s National Medical Center in Washington, D.C.

Sean E. Snyder, LCSW: This clinical dialogue is going to focus on implementation science. Dr. Wolk, could you give a little bit of background about yourself to start.

Courtney Wolk, PhD: I’m a clinical psychologist by training, and I identify as an implementation science researcher. I’m currently an Assistant Professor at the Penn Center for Mental Health, which is in the psychiatry department at the University of Pennsylvania’s Perelman School of Medicine. Most of the work that I do right now is focused on how to implement and integrate evidence-based mental health interventions into settings where mental health is not traditionally a part of the service model. I’m really interested in non-specialty mental health settings and some of the implementation challenges that arise in those settings that are unique compared to more traditional behavioral health settings. A lot of the work that I do is situated in either schools or primary care clinics.

Snyder: Wonderful. Now the big word of the day, implementation. The formal chapter will explain the technical definitions related to implementations science, so I would love to hear how you would explain what implementation science is to a layperson who doesn't know anything about it.

Wolk: Great question. Implementation science is really the scientific study of methods to support the implementation or the use/uptake of evidence-based interventions in real-world settings. We in the field are really interested in how we take practices that we know are effective through established research and help spread them so that people in the community can access those treatments when they need them. We focus on different strategies to help support clinicians and organizations to use evidence based or best practices.

Snyder: I know from your experience as a clinical psychologist that it's all too familiar a case where a smart clinician like yourself gets trained in an EBP, then you see that there's a problem with that EBP not getting to the kids. I want to hear more about your particular story. How did you get into implementation science? When we hear about the career dreams and aspirations of children, we hear them say they want to be a psychologist when they grow up or be an astronaut or a pop star. You don't hear kids saying they want to be an implementation scientist. How did you get there?

Implementation science is a relatively new field. It builds upon many established fields, from social psychology, to organizational management, to other areas like quality improvement.

Wolk: It's actually a lot of what you started to describe about training and the gap you see in practice. As part of my graduate training and my internship, I got trained in all these best-practices and evidence-based interventions for kids, such as CBT for anxiety and PCIT. I saw how effective these treatments were through the research, but more importantly, in the kids that I was working with. I was always struck by hearing from families, time and time again, about how long it had taken them to find an effective treatment for their child. It was pretty common for families to say, "You are the third therapist that we've come to," or "My child's been on medication for this for three years and nothing has helped us so far." Then they got to us and in 12 weeks or 16 weeks of working through an evidence-based program with them we could see really dramatic changes in their child's symptoms, behavior, and their overall functioning. Families were thrilled and would often say, “Why hasn’t anyone done this before, why did it take us so long to find this particular program?” I saw this over and over again and it was often luck that they happened upon an EBP. Or maybe the child had a parent who had some medical training or health education, where they knew what to look for and found their way to the right place.

I was so frustrated that so many of these kids and families were struggling for so long, when we had these treatments that work and that could really help their kids. It was so hard for them to get EBPs and as I thought about what were the next steps in my training, I really wanted to get training to address the questions, “How do we actually help clinicians and systems use these best practices? How do we make sure that people are getting trained in them? How do we make sure that when a family shows up at their local community clinic there’s someone there who is trained in these best practices and that the child can get help right away, instead of having parents spend years searching for someone who can best help their kid?”

That’s how I stumbled into implementation science, which at the time was and still is a relatively new field. It builds upon many established fields, from social psychology to organizational management, to other areas like quality improvement. Implementation science was this new way of thinking about evidence-based practice implementation in community health settings. I got really excited about potentially having some actual tools and methods to guide bringing these practices to families who needed them.

> *I was so frustrated that so many of these kids and families were struggling for so long, when we had these treatments that work and that could really help their kids.*

Snyder: I heard you say that it almost came from a place of empathy and sympathy. When you are a community clinician, you can really empathize with the families about what they’re going through because they want the best care for their kids, and we know about the faults of our systems of care. There’s always this constant parity issue between medical care and behavioral health. Here it is more about disparity in the access and actionability of our knowledge. This makes me ask, does implementation science have an inherent social justice spirit?

Wolk: I think that’s absolutely true; I think every child and family and individual deserves to get the best that we have to offer as clinicians. They shouldn’t have to work so hard to find effective treatments when they exist, and we see this, as you mentioned, in other areas of healthcare as well, where there’s this real gap between the development of evidence-based practices and when they actually are diffused widely in the community. This access and actionability is not unique to mental health, but it is particularly problematic for behavioral health. Many of our psychosocial interventions are pretty complex and many of our clinicians in the community don't have a lot of exposure to them as part of their training. Clinicians want to do what's best for their clients, but they don't always have the right tools in their toolkit in terms of some of these particular evidence-based practices.

And so I think we need to do a better job of preparing the workforce, and most importantly, preparing organizations to support and sustain these practices. The hope is that a sustainable model can provide better access to families. Everyone deserves and should have access to effective treatments when they exist.

Snyder: The point of this book as an open access resource is to get people access to evidence-based information and hopefully prepare our workforce a little better. But we know what happens in textbooks needs to be tailored to the clinician's reality on the ground. And reading this book isn't enough. There are a lot more steps that go into adopting an EBP. In your practice working with organizations, what do you see as the biggest barriers or challenges for organizations when adopting or sustaining use of an EBP?

Wolk: These are often challenging jobs, where there are really high productivity demands on clinicians in the community, where they have very large caseloads and often have many administrative responsibilities like paperwork and billing. There's not a lot of time for extra training or extra supervision in these practices, and there's often not a lot of extra money in these clinics to invest in training or to protect clinician time for the extra supervision needed to learn a new practice. It's really hard for anyone to absorb a new EBP into their workflow when there's not a lot of extra time or money to support that.

> *If you really want people to change their behavior and start integrating evidence-based practices more into their work, you need to go beyond just training and think about ongoing consultation or supervision.*

Snyder: There are different contexts, from the outer context where it is something about funding and contracting— Are they getting reimbursed differently? Is there money available for this? — and intercontextual factors like the organizational culture and staffing patterns. Those contexts are from the EPIS model. Are there other things from that model that pop out to you in regard to key implementation factors?

Wolk: Leadership is also something that we find time and time again is critically important. With implementation, it is critical to know if there is a champion or a leader in that organization, who believes in evidence-based practice and will help their staff carve out the time to really develop their expertise in these practices and make sure they have the time and flexibility they need to implement them. Another thing that happens a lot is policy mandates about using a specific practice. And it might not always be the right fit at that moment for that particular organization or for the skill set of the clinicians who are working there. Sometimes there's a mismatch with something that needs to happen or there's not a lot of time to really develop the infrastructure and to do the trainings that are needed to do it well. Everyone does their best, but these are sometimes complicated interventions to learn and master. We don't always give people enough time and support to really take that on.

Snyder: And maybe that's where capacity issues could be addressed through community-academic partnerships or other types of arrangements. I would be interested to hear from your experience with the University of Pennsylvania as your academic home and Philadelphia as the home for your service contexts, do organizations in Philadelphia reach out to your team? Or is it your team reaching out to organizations? How do these partnerships typically develop?

Wolk: It happens in different ways. Sometimes we have a particular program that we're really interested in helping to support or spread into the community, and we approach different potential clinics or partner sites to see if they're interested and if they have the ability to take that on and partner with us. Then we go about figuring out a plan for how to how to bring it to their site.

Other times it's more system driven, in that the system has identified a particular need or gap or there's a mandate that has come down from a funder or other organization that has identified a need to do something different. They might find us and seek our support or our advice about how they could do that. Over the years, our Center has developed some pretty long-standing relationships with school districts and with behavioral health payers in the area, and because we've established those relationships and been able to help support some of their previous EBP efforts, they may come to us for advice or support when they have something new that they want to roll out or when they've identified that there's a gap and they want someone to help them work through what some potential solutions might be.

So sometimes we try to push into sites to see if we can help bring something to them, but oftentimes it works well when they have already identified a need and then we're able to be there to help support them in making a change.

Snyder: Could you share about a project to give us a sense of what that looks like?

Wolk: I can tell you about our efforts in partnership with Community Behavioral Health in Philadelphia to bring BRIDGE, an evidence-based teacher consultation model, to public schools in Philadelphia. This arose a couple of years ago out of an identified need in the system and the school district to bring some new evidence-based practices to the clinical training of the community providers who are working in schools. BRIDGE was selected by key stakeholders involved with school mental health services in the city. At that time, a payer organization, Community Behavioral Health, wanted to invest in BRIDGE.

Our team at Penn has a history of doing a lot of teacher consultation work in autism support classrooms and had an existing relationship with the developer of BRIDGE, and so we were able to work with them to develop a plan to build capacity. It's been something we've been working towards for a couple of years now, in partnership with them, to implement it system wide.

Once BRIDGE was identified as something helpful and acceptable for Community Behavioral Health and the schools, our team worked with the intervention developer, Lisa Capella at NYU, to make sure we were well trained in BRIDGE, and worked together with her to make some adaptations to the model in our training and implementation plan to really fit the context in Philadelphia. We think it's really important that we work closely with the developer on that because we don't want to make any adaptations that would compromise the fidelity of this existing model, which is effective. On the other side, our team has a lot of experience working in the system and in the school district, and so we want to make sure that we customize BRIDGE as much as possible so that it's a good fit for the clinicians who will be working in the schools.

> *With implementation, it is critical to know if there is a champion or a leader in that organization, who believes in evidence-based practice and will help their staff carve out the time to really develop their expertise in these practices and make sure they have the time and flexibility they need to implement them.*

We're gearing up in a couple of months to start training clinicians. We'll be doing a couple days of workshops with them and a lot of consultation and coaching both live in the schools, and as they develop mastery, we will continue to work with them by phone over the course of this whole year. The ongoing consultation is to help them really build their confidence and their comfort with using the BRIDGE intervention strategies to support teachers in the schools that the clinicians are working with. We'll be starting small with about 15 or 20 clinicians this fall and the hope is that we'll learn and iterate and continue to refine things in collaboration with the developer. Then we would be able to continue to scale this up over the next few years, with all the clinicians who are in the system, working in K-8 schools in the school district.

Snyder: Everything is iterative! What was really nice to hear in your response is the idea of designing for implementation. Designing for implementation takes time, it is not something where you look up an intervention on the California Clearinghouse, then it happens in a couple of weeks. Designing for implementation requires steps like organizational preparation, considering ongoing supports in the actual implementation stage. Or for instance, with the EPIS model, there is exploration phase (to make sure the thing is appropriate), the preparation phase (to prep to do the thing), and the implementation phase (where we do the thing). All of that preplanning leads to sustainability, which is the ideal. We want to spread and scale interventions and sustain them to ensure continued access to treatments that work. It's also attempting to ensure the cost effectiveness of implementation when you design for it.

Looking ahead, implementation science has a bright and varied future, because it's not only related to behavioral health. In fact, a lot of the work of implementation science has been in public health or health care settings. Considering the breadth of implementation science in settings, what's the future look like for the field?

It's really important that we work closely with the developer on that because we don't want to make any adaptations that would compromise the fidelity of this existing model, which is effective.

Wolk: It does cut across many different disciplines. I think there are a lot of opportunities in implementation science to think about how we can develop generalizable knowledge that will work across clinical conditions across different types of sites. That could help streamline the implementation process; right now, the best practice for implementation is to tailor and customize a lot to the particular site, to the population. That can be quite effective, but it also is extremely time and resource intensive. There's a lot of interest in developing and harnessing rapid approaches for developing and testing and iterating on potential strategies to support implementation, and from there, we can better understand what things need to be customized and tailored. It's differentiating between where you need to spend that intensive time and what you can streamline. There could be go-to strategies for particular things that you're trying to implement or strategies for particular settings or challenges. As a field, we're starting to develop some of that knowledge, but I think we have a long way to go. We want our work to continually be effective, but we do want to streamline things so that it's feasible to embark on this work with more and more sites and to bring more things to scale. That is where we can really have a big impact.

Snyder: For the novice implementor or someone who now has caught the fire of implementation, where can they go to learn more?

Wolk: There are some great institutes and resources that are available both for people who want to develop expertise in implementation science and for people who want to practically understand some of the principles and practices to support implementation in the setting that they work in.

The Society for Implementation Research Collaborative website has some nice resources organized, which is a good place to start. There are some websites that are more geared towards practical implementation and some sites for more advanced learning. There are week-long institutes, or certain training institutes, for example, the Implementation Science Institute that runs every year at Penn. It's a weeklong course that will give you a much more in depth understanding of the field, which may be more appropriate if you're in a leadership role or if you're overseeing your organization or system's efforts to bring evidence-based practices to your setting.

Snyder: Great resources all around. Any last parting words or nuggets of wisdom?

Wolk: A lot of times when people think about implementing an evidence-based practice, they think about training for their staff in that practice. And we know that this is a really important foundational thing that needs to happen. People have to get trained in the practice, but training alone is not sufficient. If you really want people to change their behavior and start integrating evidence-based practices more into their work, you need to go beyond just training and think about ongoing consultation or supervision. You need to think about other ways that the organization can support the use of best practices, so that people are motivated to use them and they have the support and resources that they need to implement them. There's not an easy fix; a workshop is not a typically enough because these efforts really require an investment to make sure that you are doing it right and that you can sustain the practice.

Snyder: Yes, that harkens back to designing for implementation, doing things the right way so that people can get the treatments they need and that more and more people can continue to have access to quality care. To wrap up, implementation science really is a social justice vehicle. We need to get things to people who need them and who ultimately deserve them.

Things Clinicians Should Know

Implementation practice: the use of strategies to change people's behavior or organizational processes.

Implementation science: the scientific study of methods and strategies that facilitate the uptake of evidence-based practice in health care settings.

Quality improvement: the process of developing a specific solution to a specific problem at the clinical or system level.

Implementation frameworks: outlines, overviews, and systems of thinking that are descriptive and not explanatory.

Implementation theories: describe and explain how individuals, organizations, and systems change.

Implementation strategies: ways to help people and settings do an evidence-based practice or innovation.

Open Access Tools

The Consolidated Framework for Implementation Research (CFIR)

EPIS Framework (EPIS)

Orientation to the Science of Dissemination and Implementation (Intro Series)

Society for Implementation Research Collaboration (SIRC)

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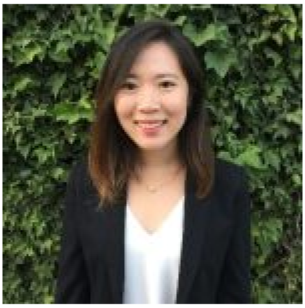

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Lourah Kelly earned her doctorate in Clinical Psychology at Suffolk University. Lourah has assisted with a number of NIMH and NIDA grants, and particularly enjoyed assisting with several NIH-funded projects, including a longitudinal study testing an HIV, substance use, and suicide prevention program for adolescents, and adaptations to cognitive-behavioral therapy for depression in adolescents with concurrent weight problems, concurrent suicidality, and comorbid behavioral disorders. Her research interests include comorbidity among mood disorders and substance use, pathways of social-cognitive factors in suicide and non-suicidal self-injury, and the importance of family and peer relationships among adolescents and emerging adults. Twitter: @LourahKellyPhD, @DLourah

Amy Mack, MSW, LCSW is a clinical social worker in the Department of Child and Adolescent Psychiatry and Behavioral Sciences at The Children's Hospital of Philadelphia. Her area of expertise involves the treatment of eating disorders across various levels of care.

Dr. Jocelyn Meza is an Assistant Professor In-Residence in the Department of Psychiatry and Biobehavioral Sciences and a bilingual licensed clinical psychologist at UCLA. Currently she is the Associate Director of the Youth Stress and Mood (YSAM) Program and the Principal Investigator of the Health Equity and Access Research and Treatment (HEART) lab at UCLA. Her research interests include studying socio-ecological risk and protective factors for suicide and self-harming behaviors among Black and Latinx youth. She aims to integrate psychological, cognitive, and sociocultural influences to predict suicide and self-harm behaviors and, importantly, to identify therapeutic targets for culturally responsive interventions for ethnoracially minoritized youth. In addition, Dr. Meza is expanding her research to adapt evidence-based psychosocial interventions for ethnoracailly diverse youth, particularly Black and Latinx youth and systems–involved youth (i.e., dually involved youth in the child welfare and juvenile justice systems).

Bernie Newman, PhD is an Associate Professor in the Temple University School of Social Work, where she teaches theory, practice, and research courses. Her research has focused on intimate–partner violence, sexual abuse of children, and social work education regarding sexual orientation and gender identity. She engages in program evaluation in a variety of community settings and is a licensed clinician working with children, families, and adults in behavioral health and child welfare settings.

Julie K Ngyuen is a Clinical Community Psychology PhD Student at the University of South Carolina who is interested in in trauma, racism, intervention, and health equity. She has previous research experience working with Dr. Isha Metzger at the University of Georgia and with Dr. Shannon Dorsey at the University of Washington, exploring topics such as trauma-focused intervention for children and racial trauma.

Silvia Nishioka, PhD earned her doctoral degree in Counseling Psychology at Teachers College, Columbia University, where she also received her master's degree in Clinical Psychology. As a psychologist in Brazil, she specialized in Health Psychology and worked as a psychologist in a pediatric hospital. As a clinician, she works with children and families to support their well-being and reduce psychopathology through culturally sensitive assessments and interventions. Silvia is also engaged in research that focuses on evaluation, implementation, and adaptation of prevention interventions for diverse youth and their families in community settings.

Victor Pereira-Sanchez, MD, PhD is a child, adolescent, and adult psychiatrist based in New York. He conducts research in local and international global mental health projects as a Fundación Alicia Koplowitz Fellow at the Department of Child and Adolescent Psychiatry, New York University Grossman School of Medicine. His past research focused on the neuroimaging of attention-deficit/hyperactivity disorder, and he is a prominent emerging leader in international psychiatry and global mental health research. His research portfolio includes more than 50 peer-reviewed publications and more than 860 accumulated citations, and he is recognized as one of the most distinguished Spanish investigators in the fields of psychiatry and mental health (SEPSM). Twitter: @victorpsanchez

Mary Phan is a third-year student in the School Psychology PhD Program at Utah State University. She is interested in implementing mindfulness-based interventions with underserved youth in public schools as well as promoting social justice through policy changes. She received her BA in psychology at Temple University. Mary is also a Health Policy Research Scholar, supported by the Robert Wood Johnson Foundation and led by the Johns Hopkins Bloomberg School of Public Health. Twitter: @marylyndphan

Dr. Stephon Proctor is a clinical child psychologist specializing in the evaluation and treatment of attention-deficit hyperactivity disorder (ADHD), disruptive behavior disorders, and anxiety disorders. He has experience treating children through various interventions, including cognitive behavioral therapy (CBT), parent management training (PMT), and exposure and response prevention (ERP). Dr. Proctor uses empirically supported interventions and works closely with children's caregivers and teachers to improve children's functioning at home and school. Dr. Proctor is board certified by the American Board of Professional Psychology with a specialization in Clinical Child and Adolescent Psychology.

Dr. Barbara Robles-Ramamurthy is a physician, scholar, mental health equity expert, organizational consultant, and entrepreneur. She is a triple-board–certified Adult, Child and Adolescent, and Forensic Psychiatrist and the Founder and CEO of Saagara PLLC, a consulting firm assisting child- and family-serving organizations to center justice, equity, and healing in their services. She brings passion and expertise in medical education, advocacy, and leadership in child and family mental health, along with experience in providing and leading collaborative and integrative care, to youth and families in community clinical settings.

Dr. Jessica S. Reinhardt (she/her) is a nationally certified school psychologist and licensed psychologist. She is the Coordinator of the School Psychology Program at Temple University. Her overarching professional interests include mental health of children and adolescents, culturally responsive counseling in schools, trauma-conscious teaching and consultation, and assessment of neurodevelopmental disorders.

Natalie Rodriguez-Quintana, PhD, MPH, LP (she/her/ella) is the Senior Director of Clinical Science at TRAILS (Transforming Research into Action to Improve the Lives of Students). Natalie received a PhD in Clinical Psychology from Indiana University, Bloomington and completed her clinical internship at The University of Texas Health Science Center in Houston, TX. She also holds an MPH in Biostatistics from the University of Puerto Rico, Medical Sciences Campus and a BA in Psychology from the University of Puerto Rico, Rio Piedras Campus. Natalie's work is focused on improving equitable access and delivery of effective mental health services for youth through dissemination and implementation of science and practice. Twitter: @ Natalie_RQ

Simone Schriger, MA is a doctoral candidate in Clinical Psychology at the University of Pennsylvania, where she received her master's degree. Her work focuses on increasing access to evidence-based mental health treatments in resource-limited contexts. Simone's master's thesis focused on characterizing clinical supervision in community mental health settings. In graduate school, Simone was awarded an F31 NRSA Fellowship from the NIH.

Erica Smith, MSEd (she/her) is an award-winning sexuality educator and consultant with over 20 years of experience working with LGBTQ+ youth. She has provided comprehensive sex education and advocacy to young people in Philadelphia's juvenile justice system and currently supports transgender adolescents and their families through The Children's Hospital of Philadelphia Gender and Sexuality Development Clinic. Erica received her Master of Education from Widener University's Center for Human Sexuality Studies. You can find her on Instagram at @ericasmith.sex.ed or at purityculturedropout.com

Sean E. Snyder, MSW, LCSW is a Licensed Clinical Social Worker whose work focuses on providing evidence-based treatments to systems-involved youth. His area of expertise centers on treatments for youth with emotional challenges after trauma exposure. He is nationally certified in Trauma-Focused Cognitive Behavioral Therapy and has received intensive training in Cognitive Behavioral Interventions for Trauma in Schools (CBITS), the Child and Family Traumatic Stress Intervention (CFTSI), and Prolonged Exposure (PE). His future work will investigate the intersection of trauma exposure and suicide risk for youth. He has taught courses on child emotional challenges at Temple University and Thomas Jefferson University and has lectured at the University of Pennsylvania.

Dese'Rae L. Stage, MSW is a writer and self-taught photographer with experience in music journalism. She has an academic background in psychology and suicidology and is trained in crisis intervention. She is a certified QPR trainer and has lived experience with chronic suicidal ideation, suicide attempts, and suicide loss, which she centers in her work. Dese'Rae ties threads together with Live Through This, a multimedia storytelling series that aims to reduce prejudice and discrimination against suicide attempt survivors. It reminds us that suicide is a human issue by elevating and amplifying survivors' voices through raw, honest stories of survival, and pairing them with portraits—putting faces and names to statistics that have been the only representation of attempt survivors in the past. She has interviewed and photographed 188 attempt survivors in 36 US cities since 2010.

R. Marie Wenzel, MSW earned her BA in Sociology and her MSW from Temple University. Since that time, she has worked in child welfare, housing and homelessness, chronic illness/HIV prevention, and serious mental illness. Marie is passionate about social justice and creating a more equitable and healthy community. For the past six years, Marie has been the director of the PEACE program of Horizon House, the largest First Episode Psychosis program in Philadelphia. The PEACE program is designed to help people in the early stages of psychosis learn how to manage their symptoms and meet their life's goals. PEACE provides multidisciplinary evidence-based services to adolescents with Medicaid and who have been experiencing psychosis for the first time. Marie and her team have mastered early intervention in psychosis. She is using this experience to help transform psychosis services to include long-term, specialized treatment for individuals in Philadelphia living with psychosis.

Brian Wiley is a doctoral student who graduated with his master's degree in school and mental health counseling from the University of Pennsylvania in 2017. Since then, Brian has been practicing family-based therapy, utilizing Ecosystemic Structural Family Therapy, in southeastern Pennsylvania and southern Florida. His primary clients are children and adolescents who have been self-referred, or court mandated to therapy for Emotional/Behavioral disorders or truancy. Brian is researching the effects of trauma on an individual's emotional and mental development, and how a caregiver's trauma can impact a child or adolescent. Brian's goal is to start a group home for children who have experienced trauma and provide therapeutic services that help them to process and heal from the pain they have experienced.

Courtney Benjamin Wolk, PhD is an Assistant Professor at the Penn Center for Mental Health in the Department of Psychiatry, Perelman School of Medicine at the University of Pennsylvania. She is a licensed clinical psychologist and an implementation scientist. She received her BA in Psychology from The Ohio State University and completed both her MA and PhD in Clinical Psychology at Temple University, where she focused on the development and evaluation of cognitive-behavioral therapies (CBT) for children and adolescents. She completed an APA-accredited pre-doctoral internship in Clinical Psychology at Children's National Medical Center in Washington, DC and an NRSA postdoctoral fellowship at the University of Pennsylvania. The long-term goal of her research is to develop and evaluate strategies to promote the uptake of evidence-based care into routine practice, with the ultimate goal of improving the effectiveness of mental health services for children and adults in non-specialty mental health settings. Twitter: @CourtneyWolk

Stephanie H. Yu, MA is a doctoral student in Clinical Psychology at the University of California, Los Angeles. She received her BA in Psychology and Social Welfare from the University of California, Berkeley with minors in Asian American Studies and Education. She is passionate about mental health equity and community-based research aiming to reduce mental health disparities for racial/ethnic marginalized groups. Her research focuses on culturally responsive adaptation and implementation of evidence-based practices (EBPs) in public systems of care serving marginalized communities and the cultivation of community partnerships to foster EBP implementation and sustainment. She is also interested in how individual and systemic conditions, such as those stemming from racism and discrimination, can be addressed to improve well-being outcomes for racial/ethnic marginalized communities.

Arturo Zinny, LPC, MA is the Program Director of Healing Hurt People (HHP) at the Center for Nonviolence and Social Justice, Drexel University Dornsife School of Public Health. HHP is a hospital and community-based violence intervention program that provides trauma-focused therapy, peer support, and case management to people ages 8 to 35 impacted by violence. Before his current role, Mr. Zinny served as Project Director for the Philadelphia Alliance for Child Trauma Services (PACTS) at Community Behavioral Health (CBH), a SAMHSA/NCTSI Cat 3 grantee. He also served as Director of Behavioral Health Services at Congreso de Latinos Unidos in Philadelphia and as Adjunct Faculty at Chestnut Hill College School of Graduate Studies. Mr. Zinny is a former chair of the National Child Traumatic Stress Network's (NCTSN) Lesbian Gay Bisexual Transgender and Questioning (LGBTQ) Youth Sub-Committee. He is an advanced doctoral student at Drexel's Dornisfe School of Public Health, Community Health and Prevention concentration. His dissertation focuses on researching the impact of evidence-based practices on the mental health of violently injured marginalized youth.

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