

# Pediatric Mental Health for Primary Care Providers

A Clinician's Guide

Sarah Y. Vinson  
Ebony S. Vinson  
*Editors*



Springer

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Sarah Y. Vinson  
Lorio Psych Group  
Atlanta, GA  
USA

Ebony S. Vinson  
Lorio Psych Group  
Atlanta, GA  
USA

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*To the wonderful Dr. Donna M. Parker and  
all of the pediatric primary care providers  
serving children and families in excellence.*

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## Preface

Pediatric primary care providers (PCPs) have been drafted into the mental health workforce. Even before integrated care per se became a buzzword in medical professional communities, a steady stream of pediatric patients and families were bringing their mental health needs to their PCPs. It makes sense. In the vast majority of cases, PCPs are not only more accessible than mental health care specialists, but they are also, more importantly, already trusted and respected by families. In a perfect world, the mental health care system and/or a seamlessly integrated medical/mental health care system would be optimally configured and funded to efficiently and equitably provide excellent mental health care to all children and families who need it. The reality is that our systems fall far short.

A shift is needed, and in some respects is underway, to better equip and support the clinicians bridging the gap out of a sense of clinical duty and beneficence. That said, we have a lot of catching up to do. Training in mental health during pediatric residency programs is variable in depth and breadth. While there are some billing codes that support screening, care coordination, and collaboration, they are often inadequately reimbursed, if at all. When screening for mental health identifies issues requiring further treatment, wait times for mental health care providers are too often too long. In this practice environment, PCPs could use a practical, easily referenced clinical resource intentionally designed and written with the realities of their practice environment in mind. Of note, while the term PCP is used throughout this text for brevity, many of the recommendations can be implemented by other clinicians or staff operating under the supervision and direction of the PCP.

From its conception, this project was informed by the co-editors' experiences of teaching pediatric interns and residents; treating children and adolescents from diverse backgrounds in both private and public settings; serving as a curb-side resource to pediatric colleagues; consulting, doing collaborative care, and seeing patients in primary care settings; and engaging with local pediatric professional organizations in providing continuing medical education. When the search for a book such as this one to recommend to our colleagues yielded nothing, we took it upon ourselves to create one. While no single text can bridge the gaps between need and access to mental health interventions for children and adolescents, a tool that supports the process of earlier identification and, in some cases, initial interventions, in the medical settings where kids and families feel most comfortable, and are already going, is an important contribution.

The goals of broad applicability, clinical relevance, and practicality guided the development of every chapter. PCPs in rural, urban, public sector, private, resource-rich and resource-poor environments can all find some benefit from this text. Additionally, content was not included just for the sake of being interesting, it had to have clear clinical utility. Eloquent discussion of policy and in-depth examinations of neuroanatomy have their place, but not here. There is, instead, an emphasis on clinical pearls such as questions to aid in the diagnostic process and key points for parental/family education. Finally, it was written with the cost and time limitations of a busy outpatient practice in mind. For example, recommended screening tools are public domain and/or free, and chapters include tables and charts for quick reference.

The book is divided into two parts. The first includes overarching topics that can inform any pediatric encounter involving mental health issues. These topics include resilience, cultural humility, trauma, suicide and self-injurious behavior, mental health assessment, medico-legal considerations, measurement-based care, and interfacing with the mental health care and school systems. The second part includes diagnosis specific information for the psychiatric conditions most commonly seen and possibly managed (at least initially) in primary care settings. These topics include depression, anxiety, attention deficit hyperactivity disorder (ADHD), oppositional defiant disorder, autism spectrum disorder, and substance use disorder. The reader will notice that there is greater emphasis on more advanced management in the ADHD chapter, which was an editorial decision informed by PCPs' relative clinical comfort managing uncomplicated ADHD in the primary care setting.

Of note, as a clinical handbook, this text is not meant to be a stand-alone resource regarding pediatric mental health and was written with the presumption that more comprehensive resources would be accessed when needed. For example, the diagnosis chapters include discussion of the most common and/or concerning potential side effects of relevant psychiatric medication classes; however, the FDA package insert for each medication will include a comprehensive list of adverse effects. Additionally, though our authors summarize diagnostic criteria, the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) will include a complete description and the exact verbiage.

While we are pleased to provide this resource and hope that it is of benefit to your practice, we appreciate the need for a forum where easily referenced, clinically informed, up-to-date information and practice support tools can be shared. The website [pedsmmentalhealth.com](http://pedsmmentalhealth.com) will be a dynamic resource from the editors of this text that will build upon the work started here.

Atlanta, GA, USA

Sarah Y. Vinson, MD

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# Acknowledgments

We would like to sincerely thank all of our exceptional contributing authors for their amazing work and diligence in creating this book.

We would like to acknowledge the support and assistance of Springer Staff (Nadina Persaud, Johnson Manasseh). We are deeply grateful for your guidance, patience, and support.

Completion of this book often took us away from our families and loved ones and required a lot of dedicated time away from other important areas in our lives. We are eternally grateful for all of the love, support, and encouragement of our support network as we have embarked on this journey. To Lotta and Theriot Vinson, we love you immensely and we thank you for all of your sacrifice and hard work to instill the values of service and humility.

Finally, we want to appreciate each other. Our collaboration as sisters first and as an editorial team second has been stimulating and rewarding. As mental health professionals with different training backgrounds and unique perspectives, we worked together in an efficient and supportive way which ultimately led to a focused product of great purpose and clinical utility. Thank you for being you, sister.

Atlanta, GA, USA

Ebony S. Vinson



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## About the Editors

**Ebony S. Vinson, PhD** received her B.S. in Psychology from Florida A&M University. She earned her Ph.D. in Clinical Psychology in 2014 from the University of Kentucky and completed a Clinical Health Psychology Postdoctoral Fellowship in the Department of Psychiatry at Virginia Commonwealth University. During the fellowship, Dr. Vinson developed advanced clinical skills in the field of health psychology and broadened her experience with integrated primary care models and psychological evaluation. Her research interests and areas of publication include mental illness stigma, consequences of traumatic stress in African American women, racism-related coping, and cross-cultural factors in assessment. Dr. Vinson is a licensed clinical psychologist.

**Sarah Y. Vinson, MD** is a triple-board certified Child & Adolescent, Adult and Forensic psychiatrist who began her post-secondary education at Florida A&M University earning a B.S. in Chemistry. In 2007, she received her medical degree from the University of Florida College of Medicine with Research Honors and as an Inductee in the Chapman Humanism Honors Society. She completed her general psychiatry training at Cambridge Health Alliance/Harvard Medical School followed by fellowships in both child & adolescent and forensic psychiatry at Emory University School of Medicine. Dr. Vinson is currently an Associate Clinical Professor of Psychiatry and Pediatrics at Morehouse School of Medicine and Adjunct Faculty at Emory University School of Medicine. In addition to her academic work, she provides mental health care services such as psychotherapy, consultation, and psychopharmacology through her private practice in Atlanta, Georgia. Dr. Vinson is the founder and CEO of [Pedsmentalhealth.com](http://Pedsmentalhealth.com).

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## Contributors

**Peter Ash, MD** Forensic Psychiatry, Atlanta, GA, USA

Department of Psychiatry and Behavioral Sciences, Emory University, Atlanta, GA, USA

**Hasani Baharanyi, MD** Lorio Psych Group, Atlanta, GA, USA

Morehouse School of Medicine Adjunct Faculty, Atlanta, GA, USA

**L. Kevin Chapman, PhD** Independent Practice, Louisville, KY, USA

**Nicole Cotton, MD** Department of Psychiatry and Behavioral Sciences, Morehouse School of Medicine, Atlanta, GA, USA

**Arden Dingle, MD** UT Rio Grande Valley School of Medicine, Harlingen, TX, USA

**Michelle P. Durham, MD, MPH, FAPA** Department of Psychiatry, Boston Medical Center, Boston University School of Medicine, Boston, MA, USA

Department of Psychiatry, Boston Medical Center, Global and Local Center for Mental Health Disparities, Boston, MA, USA

**Michael A. Ellis, DO** Mercer University School of Medicine, Macon, GA, USA  
Philadelphia College of Osteopathic Medicine (PCOM)—GA Campus, Suwanee, GA, USA

Child and Adolescent Psychiatry, The Bradley Center, St. Francis Hospital, Columbus, GA, USA

**Mark S. Gold, MD** Department of Psychiatry, Washington University School of Medicine, Saint Louis, MO, USA

**Yolanda Graham, MD** Mental Health Services, Devereux Advanced Behavioral Health, Kennesaw, GA, USA

**Steven L. Jaffe, MD** Department of Psychiatry, Emory University School of Medicine, Atlanta, GA, USA

**Deborah Kulick, MD** School Based Programs, Cambridge Health Alliance, Cambridge, MA, USA

Harvard Medical School, Cambridge, MA, USA

---

**Amber J. Landers, PhD** California School of Professional Psychology, Alliant International University, San Francisco, CA, USA

**Howard J. Lloyd, EdS, PhD** Lorio Psych Group, Atlanta, GA, USA

**Courtney L. McMickens, MD, MPH** Boston Medical Center, Boston University School of Medicine, Boston, MA, USA

**Phillip Murray, MD, MPH** Behavioral Health, Atrium Health, Charlotte, NC, USA

**Alphonso Nichols, MD** Independent Practice, Louisville, KY, USA

**Nancy Rappaport, MD** Harvard Medical School, Cambridge, MA, USA  
Cambridge Health Alliance, Cambridge, MA, USA

**Matthew R. Salmon, DO** Georgetown University School of Medicine, Washington, DC, USA

**Kevin M. Simon, MD** Department of Psychiatry and Behavioral Sciences, Morehouse School of Medicine, Atlanta, GA, USA

**A. Benjamin Srivastava, MD** Department of Psychiatry, Washington University School of Medicine, Saint Louis, MO, USA

**Colin E. Stewart, MD** Georgetown University School of Medicine, Washington, DC, USA

**Aditi Vijay, EdM, PhD** Georgetown University School of Medicine, Washington, DC, USA

**Ebony S. Vinson, PhD** Lorio Psych Group, Atlanta, GA, USA

**Sarah Y. Vinson, MD** Lorio Psych Group, Atlanta, GA, USA  
Department of Psychiatry and Behavioral Sciences and Department of Pediatrics, Morehouse School of Medicine, Atlanta, GA, USA

**Glenda L. Wrenn, MD, MSHP, FAPA** Department of Psychiatry and Behavioral Sciences, Morehouse School of Medicine, Atlanta, GA, USA  
Kennedy Satcher Center for Mental Health Equity, Satcher Health Leadership Institute, Atlanta, GA, USA

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## Part I

# Over-Arching Topics



# Considerations on Resilience in At-Risk Youth

1

Sarah Y. Vinson

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## Introduction

All people, including children and adolescents, operate on a multidimensional continuum between mental health and mental illness. In a number of ways, sociocultural factors, be they in the home, community, or larger society, influence where each youth falls on this continuum. The overall organization of this text reflects an emphasis on diagnosing and treating illness in an individual, which is reflective of the medical model under which practitioners provide care. This model, however, has limitations, especially as it pertains to pediatric mental health. Many youth exposed to challenging events and/or environments endure and display a psychological impact from their adversities. Though potentially significant, this impact does not always meet criteria as a diagnosable mental illness. These patients may benefit from early identification and intervention by their primary care provider (PCP) and/or other trained clinicians operating under their PCP's supervision.

While such a practice could be conceptualized as mental illness prevention in at-risk youth, it is also an opportunity to foster resilience and promote mental wellness. This chapter will include information regarding risk and protective factors, guidance on how to use this text to assist at-risk youth and their families, a brief description of select mental health promotion strategies with broad applicability, and a short list of relevant, recommended resources.

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S. Y. Vinson  
Lorio Psych Group, Atlanta, GA, USA

Department of Psychiatry and Behavioral Sciences and Department of Pediatrics,  
Morehouse School of Medicine, Atlanta, GA, USA  
e-mail: [DrVinson@LorioPsychGroup.com](mailto:DrVinson@LorioPsychGroup.com)

## Identification of Risk and Protective Factors

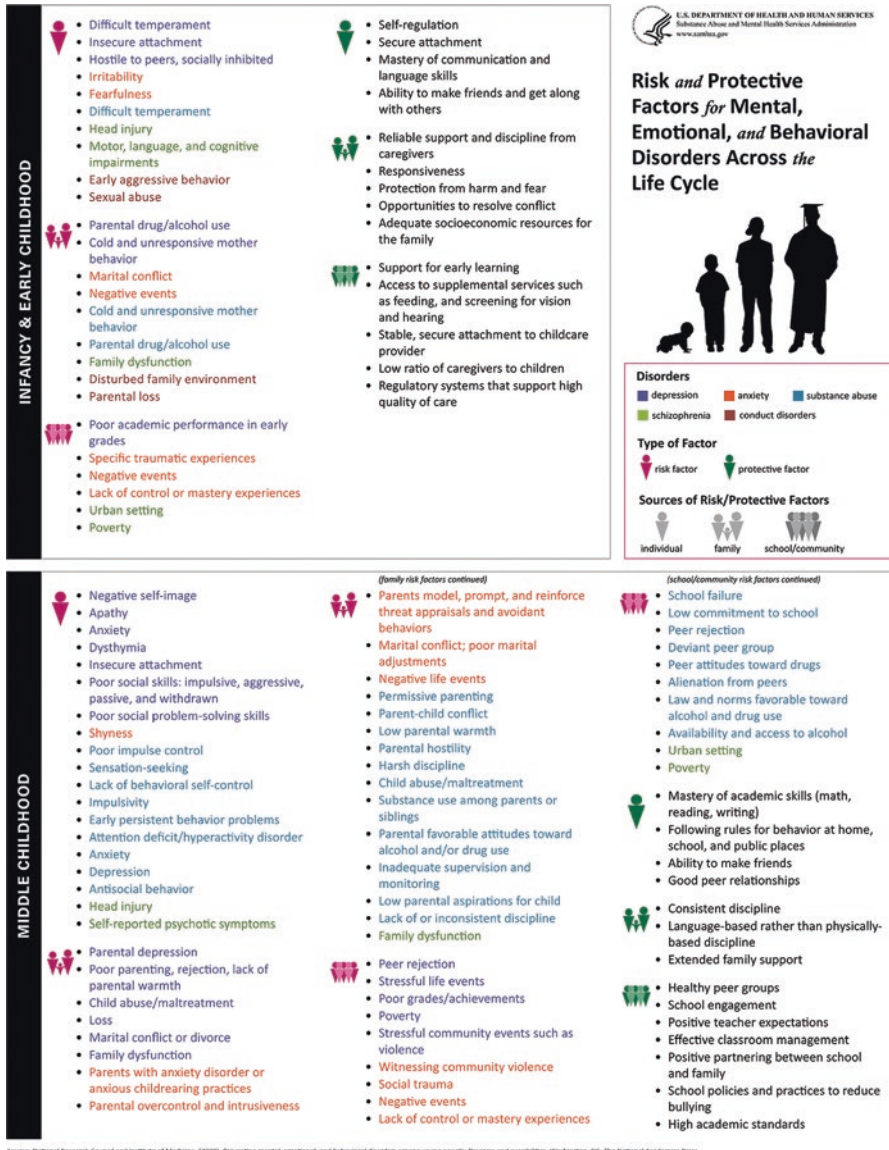
For pediatric primary care providers, the goal for patients is not merely the absence of illness but the promotion and preservation of wellness and healthy development. The World Health Organization defines mental health as “a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community” [1]. For mentally healthy youth, this definition could be extrapolated into some of the following attributes:

1. Youth who are able to develop healthy emotional, intellectual, and social functioning
2. Youth who are able to explore, practice, and implement a growing repertoire of adaptive coping skills for handling difficult emotions and stressful situations
3. Youth who are able to advance academically and occupationally to the best of their ability
4. Youth who are able to play a positive, developmentally appropriate role in their families and communities

Life is stressful, and the scientific literature is clear that adverse childhood experiences are not only common, but they also increase the risk for emotional and mental health problems in children and adults [2–5]. This risk is not deterministic, however, as the child can also have protective factors in place that promote resilience. The PCP’s appreciation of these protective factors has the potential to mitigate risk, as it can inform interventions for youth who have known risk factors and are either currently asymptomatic or have subclinical symptoms of mental illness. Youth are tasked with figuring out who they are, learning about their feelings and how to regulate them, identifying ways to handle stressors, navigating expanding social circles, and coming up with their own framework for understanding the world around them. As if this work is not hard enough, they are tackling it with a brain that is still a work in progress. Additionally, unlike adults, they have little to no control over the people in their household, the place where they spend most of their daytime hours (school), or their neighborhood.

For PCPs, each interaction with youth and their families presents an opportunity to help families decrease risk factors and enhance protective factors. Familiarity with these factors is a necessary first step in doing so. While not exhaustive, (Fig. 1.1), Risk and Protective Factors for Mental, Emotional, and Behavioral Disorders Across the Life Cycle, from [samhsa.gov](https://www.samhsa.gov) is a useful quick reference tool.





**Fig. 1.1** Risk and Protective Factors for Mental, Emotional, and Behavioral Disorders Across the Life Cycle

Risk and Protective Factors for Mental, Emotional, and Behavioral Disorders Across the Life Cycle (continued)

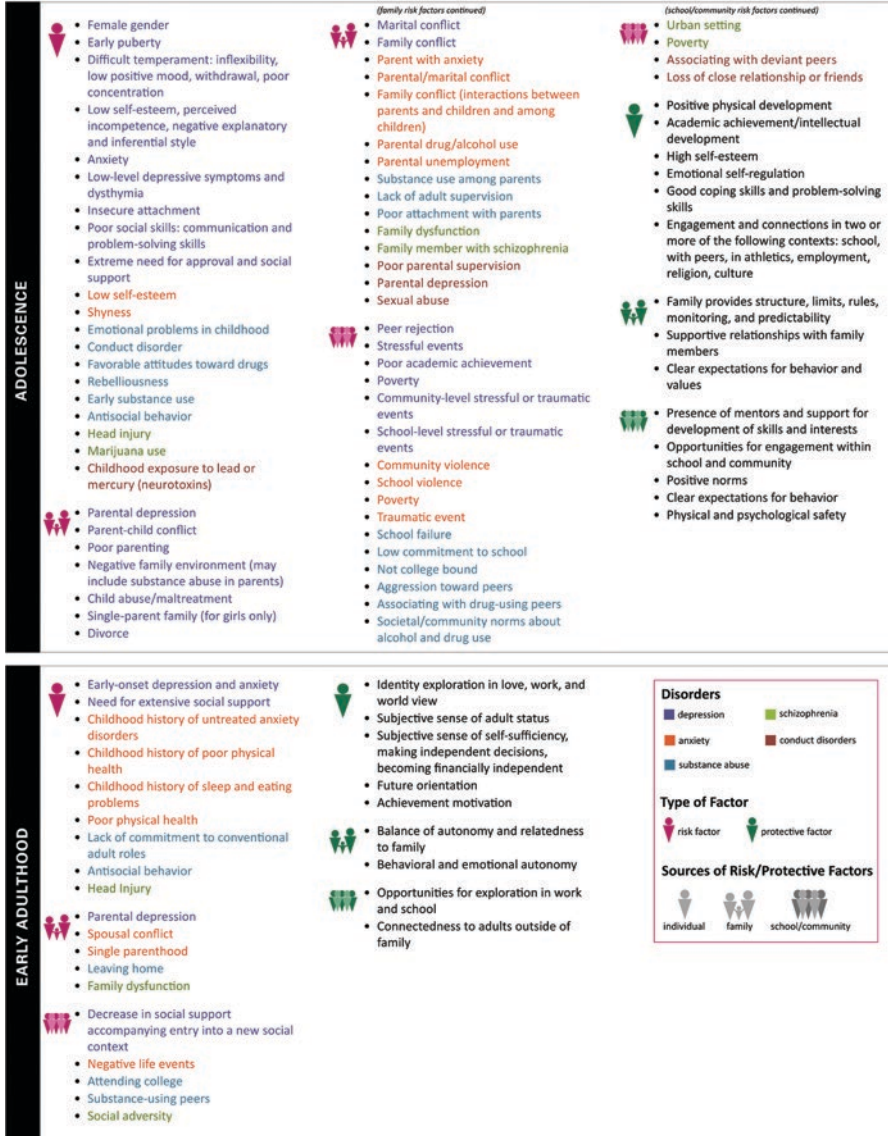


Fig. 11.1 (continued)

Use of This Text in At-Risk Youth

This text’s trauma chapter can serve as a helpful resource for children whose risk factors include those that cause real or perceived fear regarding the safety of the youth or loved ones. Additionally, each diagnosis chapter includes behavioral interventions and tips for family education that are written with protective factors in

mind. Acting on these tips could provide benefit not only for youth who meet criteria for the illness but also for youth who are showing subclinical signs or have known risk factors for it.

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## Ten Evidence-Based Interventions to Promote Resilience

While an exhaustive discussion of strategies to promote resilience is beyond the scope of this text, select, evidence-based, parental educational tips with broad relevance are introduced and briefly discussed below.

### 1. *Safety and Security First*

There is a dose response effect when it comes to the impact of stressors on mental well-being. Chronicity matters, too. In other words, if a child is showing signs of distress or has known exposures to risk factors, helping him/her feel safe and secure in the aftermath is vitally important. If at all possible, at-risk youth need to trust that they will not be harmed and that their basic needs will be met consistently. This is where screening about issues such as violent exposures, housing instability, and food insecurity can be helpful. A key accompaniment is a list of up-to-date resources for directing families to help when unmet needs are identified. This list need not be compiled by the primary care provider but can be updated and maintained by other staff or clinicians under the provider's supervision.

### 2. *You Are What Your Kids Need Most*

Parents need to understand resilience and their critical role in supporting it, simply by being there. Often families are pulled in many different directions, and quality time between parent and child must be consistent and planned intentionally. Youth feeling a strong connection to a stable, responsive, consistent, loving adult is key to resilience. And, yes, this applies to teens, too. Research findings across age ranges and a myriad of demographics demonstrate the importance of a relationship with a reliable, responsive adult as a protective factor [6–8]. While this role does not have to be filled by the youth's primary caregiver, the parent is certainly well positioned to function in it.

Parents may feel so pressured to provide their children with things that they underestimate how much their child needs *them*. Additionally, parents who have been unable to provide the sort of home, neighborhood, or academic experience that they wanted for their child may feel as if they have failed them. PCPs can provide some valuable perspective and motivation to parents by helping them understand that the environment does not have to have the final say. It is important for parents to know that they are the most important person in the world to their child's success.

It is also worth noting that parents who have a good baseline for their child's affect and behavior will be better at catching signs of emerging mental illness earlier. Also, when a child trusts that a parent knows them and cares about them, it makes it easier for them to be receptive to discipline and boundary setting.

Quality time is important and can take various forms from bedtime stories to making meals together, from hikes in the woods to screen- or headphone-free car rides. The key here is consistency and that parents are truly present. The distractions of taking work home or getting wrapped up in screens can draw parents away even though they and their children share physical proximity.

### 3. *Catch Them Being (or Doing) Good*

Caregivers should be encouraged to catch the child being good and to redirect unwanted behaviors, specifically telling the child what *to* do not just what not to do. Negative emotions get people's attention. It is easy for parents, even those who recognize their children's strengths, to fall into a routine of voicing their anxieties or frustrations over what they perceive their child is doing wrong. This can lead to children underestimating the things that they are doing right in their parents' eyes, which can impact not only the parent-child relationships but how children think of themselves. Youth benefit when parents are diligent at "catching" them being or doing good, verbalizing this recognition, and rewarding it.

When children engage in problematic behaviors, it is important to understand why. Telling a kid to stop goofing around in class probably won't work unless the root of the behavior is addressed, and the child is helped with problem-solving to address it. Rather than simply telling youth what not to do, parents have to be intentional about helping them identify, initiate, and sustain preferred behaviors.

### 4. *And then, Praise Like a Pro*

People notice things they look for. As parents intentionally look for things their children are doing right, there will be more opportunities for praise. Research shows benefits of praise that is specific and that recognizes effort and a child's process [9, 10]. As noted above, the attention of a caring adult matters. The right kind of praise shows youth that parents are paying attention and is also powerfully reinforcing. In other words, when they get it right and are praised for it, they are likely to get it right again. It is important that praise is specific and not over-the-top. This helps the child to receive it as genuine. Additionally, praise should focus on effort, not the end result. We do not want to send children the message that it's not worth trying if their best is a B+.

### 5. *Know Your Limits, and Make Sure the Kid Does, Too*

Sometimes adults assume that youth know what they should be doing. While it may be common sense through the lens of an adult, for a youth with a developing brain, a relative lack of life experience, plus or minus the capacity to think abstractly, it helps if things are spelled out. Having rules gives children the opportunity to live up to expectations. Additionally, there are benefits to having predetermined consequences for not following rules. Such consequences are thought through rather than made in the heat of the moment, so they are more likely to be fair and consistently enforced. Of the four commonly studied kinds of parenting, one has most consistently showed favorable outcomes, authoritative [8, 11–13]. This approach combines high parental responsiveness (see Tips 1, 2, and 3) with fair discipline.

## 6. *Supervision, Structure, Schedule, Repeat*

It sounds so simple, yet supervision, structure, and consistent schedules are protective factors that have been demonstrated repeatedly, especially for adolescents. For working parents, this may involve the exploration of available community programs or engaging more intentionally and regularly with extended family or informal supports such as neighbors or members of a faith community.

## 7. *Count Screens, then Sheep*

Resting well is good for everyone but is especially beneficial for kids who have any difficulty with emotional regulation. Both the quality and quantity of sleep are important, and both are reinforced by sleep hygiene: avoiding stressful or excitatory activities in bed or near bedtime, having a regular bedtime, regularly engaging in a relaxing pre-bedtime routine, and exercising earlier in the day but not too close to bedtime.

In this culture, screens in their various forms often present one of the biggest threats to resting well. Screens should be turned in and accounted for as part of the bedtime routine. One study showed that youth aged 8–18 years spend an average of 7 hours and 38 minutes using entertainment media, a number driven in large part by the use of mobile media [14]. Media and devices are designed to keep people engaged and stimulated. Additionally, social media and interactions with peers can be excitatory if pleasant, and incredibly stressful for youth if not. Also there is some evidence that the light from these devices affects children's sleep-wake cycles [15]. In other words, media use at night can rev up the brain when it should be slowing down, and it can confuse the body about when it should be winding down.

## 8. *Keep It Moving, and Practice Being Still*

While the benefits of exercise to physical health may be obvious to parents and are a routine part of PCP guidance to children and families, there is also a strong evidence base for the benefits of exercise for anxiety, mood, attention, and sleep in children [16–18]. The key here is to find an activity that the youth enjoys and that the parent and youth agree on a way to incorporate it into the weekly routine. Mindfulness and deep-breathing exercises have also been shown to have mental health benefits for at-risk youth [19]. The great thing about these interventions is that they are easily accessible and teachable, and there are free apps for it.

## 9. *Secure Your Oxygen Mask First*

Parenting is hard work. For those raising at-risk youth, the demands can be even greater. Meeting the challenge is difficult, if not impossible, to do when caregivers are not mentally healthy themselves or do not have adequate support. Parents may not understand how critical their well-being is to that of their children. Sometimes they may feel that if they were a good parent, they would be focused on the child's needs rather than their own for support or mental health interventions. Primary care providers can introduce and reinforce the notion that caregiver mental health is a key to protecting the child's mental health. Additionally, sometimes families have informal supports that they are not fully utilizing that can provide helpful respite.

The resource list mentioned above in tip 1 should include referral sources for adult mental health agencies that parents can be referred to if a primary



caregiver reports or is showing signs of depression or anxiety (as all too often adult and child mental health systems are not integrated). If there is need for assistance with managing the household, interacting with their children more productively, or adaptively coping with stressors at home, professional assistance in the form of individual, parenting, or family therapy can be helpful. In populations where there is a high proportion of uninsured adults, particularly if the latter two are relevant issues and the child has insurance, the parent can often receive family therapy services with the child as the identified patient.

10. *Get the Kid's Input*

While parents are ultimately the limit-setters, the creation of the rules, structure, household routines, and environmental interventions for stressors can and should be informed by youth's perspectives. This supports their growth in problem-solving, gives them a stake in the outcome, models collaboration, and reinforces their sense of self-efficacy, all of which can bolster resilience.

---

## Recommended Resources

### *Books*

Building Resilience in Children and Teens. Kenneth R. Ginsburg MD MSed FAAP, (2011)

Raising Cain: Protecting the Emotional Life of Boys, by Dan Kindlon, PhD and Michael Thompson, PhD (2000)

### *Journal Articles*

Traub F and Boynton-Jarrett R. Modifiable Resilience Factors to Childhood Adversity for Clinical Pediatric Practice. *Pediatrics*. 2017;139(5): e20162569

Ungar M. Practitioner Review: Diagnosing childhood resilience--a systemic approach to the diagnosis of adaptation in adverse social and physical ecologies. *J Child Psychol Psychiatry*. 2015 Jan;56(1):4-17. <https://doi.org/10.1111/jcpp.12306>. Epub 2014 Aug 1

### *Websites Re: Resilience*

[www.healthychildren.org](http://www.healthychildren.org)  
[www.aap.org/reachingteens](http://www.aap.org/reachingteens)  
[www.fosteringresilience.com](http://www.fosteringresilience.com)

### *Websites Re: Community-Level Interventions*

[www.search-institute.org](http://www.search-institute.org)  
[www.communitiesthatcare.net](http://www.communitiesthatcare.net)  
[www.kidsathope.org](http://www.kidsathope.org)

### *Free Mindfulness Apps*

Stop, Breath and Think  
 Calm

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# Cultural Considerations

# 2

Ebony S. Vinson and Howard J. Lloyd

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## Definitions and Recommendations

### Introduction

In the broadest sense, culture is defined as a system of attitudes, beliefs, and practices shared by racial, social, or religious groups [1]. Our cultures are the lens through which we receive, interpret, integrate, and make sense of the world around us. Culture is the way we eat, speak, dress, and communicate. Culture is omnipresent and woven into every aspect of daily living. It includes but is not limited to economic status, race, religion, spiritual practice, location, sexual orientation, gender expression, language, appearance, familial patterns, and innumerable other facets. *Everyone* is a cultural being.

As primary care providers, you have the unique opportunity to interface with individuals as they develop their own cultural identities. Your patients walk into your office carrying an entire book bag of perspectives, experiences, and belief systems. However, they are not the only ones lugging baggage. You too have a set of experiences that inform your care and interactions with your patients. Luckily, your job is not to unpack that bag with the limited time you have with patients but instead open the door for them to share the important items that may affect their health and health care.

### Cultural Competency

The intent of culture competence within medical settings is to assist, encourage, and in some cases, require PCPs to gain the knowledge, skills, and abilities (KSAs) necessary to work with a myriad of groups from an array of backgrounds. Cultural

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E. S. Vinson (✉) · H. J. Lloyd  
Lorio Psych Group, Atlanta, GA, USA



competence has been described as “understanding the importance of social and cultural influences on patients’ health beliefs and behaviors; considering how these factors interact at multiple levels of the health care delivery system (e.g., at the level of structural processes of care or clinical decision-making); and, finally, devising interventions that take these issues into account to assure quality health care delivery to diverse patient populations) [2].”

It is widely accepted that in order to engage in best practice and provide quality health care, medical providers should be attuned to cultural differences and their own biases [3, 4]. Cultural competence establishes an expectation that PCPs seek out training, independent education, and resources that equip them with the tools needed to navigate clinical decision-making within the context of overarching commonalities within groups. While cultural competence has led to further exploration of cultural influences in medical care, the term also inaccurately implies that cultural learning has an endpoint. If this flawed implication is not addressed, innumerable PCPs across the country might spend the remainder of their careers imploring the “cookbook model” to address culture in practice.

### **The “Cookbook Model”**

The “cookbook model” is a method of engaging cultural concerns through a myopic lens. It is when a “dash of X, a pinch of Y, and a dollop of Z” gives you all you need to know about an entire cross section of people. For example, in learning about various cultures, you may have come across the idea that young Asian Americans excel in academics and are often among the highest percentage of minority students accepted into Ivy League institutions. The model minority myth and anecdotal evidence make it easier to assume that a child from this population is exceptional in school. The PCP that assumes the child is performing well does not have an ulterior motive or mal intent; however, they are working from a “cookbook model,” and this kind of stereotyping can significantly impact PCP behavior and decision-making [5]. In order to ensure that assumptions and biases do not inhibit professional practice, PCPs must be committed to ask the questions for which they may believe they already have the answers.

Consider scheduling initial appointments with two patients whose demographic data reads like a duplicate record. Both patients identify as 11-year-old girls, living in a stable two-parent household, in a middle-class suburban setting. Each patient is an honor roll student with a solid social support system but endorses moderate depressive symptoms on a screening measure you give to all of your new patients. What are the first things that come to mind about their lived experiences? Many of the assumptions you may be making likely come from the cookbook model of cultural competency.

### **Cultural Humility**

“Real knowledge is to know the extent of one’s ignorance”—Confucius. No matter how much you read or how many people you treat, there will always be variation in

the presentation of culture that is unexpected. The concept of cultural humility is one that arose in part because of the limitations inherent in cultural competence. Cultural humility integrates the knowledge, skills, and abilities that can be gained through the aim of cultural competence and challenges health professionals to commit to a lifelong process of cultural learning [6]. Cultural humility has been defined as "...a lifelong commitment to self-evaluation and self-critique, to redressing the power imbalances in the patient-physician dynamic, and to developing mutually beneficial and nonpaternalistic clinical and advocacy partnerships with communities on behalf of individuals and defined populations."

In the midst of milling through all the ways to capture the cultural context of others, our own perspective can be lost. In any given examination room, there are three factors acting simultaneously: (1) the culture of the patient, (2) the culture of western medicine, and (3) the culture of the PCP [7]. As the culture of the patient has been briefly explored, let us turn to western medicine and the PCP. Take a moment to ask yourself: How would you describe the culture of western medicine? What are the inherent assumptions of western medicine? How might these assumptions be at odds with alternative views of medicine around the world? This line of questioning is important to move through because it challenges you to consider approaches to illness, healing, and medical care that you may not otherwise examine. Challenge yourself to identify important aspects of your culture (family patterns, geography, language, socioeconomic status, etc.), the assumptions you hold about the world, and how those areas may impact your medical practice.

Imagine you are working with a 6-year-old boy from a rural community with an economy based in farming, hunting, and agriculture. The child attends a small school, and his first-grade class is composed of 11 other children. All indications are that developmental milestones are on track, and his academic performance is stellar except on standardized tests. Due to this, a brief screener for cognitive functioning is completed. The screening for 6-year-olds includes prompts for counting, and for recognizing days of the week, primary colors, and the four seasons. During the screening, the PCP says, "Please name the four seasons," and the child replies turkey, deer, bear, and squirrel. When the prompt is repeated, the answer is the same. Do we assume the child does not know the seasons? Do we presume that he struggles on standardized tests because he is not knowledgeable? Perhaps, if we did not consider the cultural variables that may give context to this response, we would make one of the aforementioned conclusions.

However, a cultural humility framework encourages us to explore the rationale behind the response. Growing up in an environment where agriculture and hunting are the primary industries, it is no surprise that identification of a hunting season would assist a 6-year-old in organizing a schema and timeline for activities and changes in the environment just as many of us do when we name the traditional seasons. Was the question answered as intended by the creator of the screening measure? No. Was his answer wrong when considering their cultural context? No. Questions asked often elicit culturally bound responses, especially for children. Cultural context whether it is geographical, social, economic, or otherwise is vital to consider.

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## Summary

Using a predetermined formula for the experiences of any member of a group often leads to inaccurate assumptions. Those inaccuracies lead to the omission of pertinent information that could impact patient outcomes. Lean on practices of cultural humility and responsiveness to seek an understanding of the patient's context. The embrace of culturally responsive care among health professions not only helps to build a foundation of rapport but has contributed to a more nuanced understanding of how critical culture is in health outcomes. Conversing with patients about their cultural views may also help address issues associated with health disparities, stigma, and quality of care concerns across groups [2]. Culturally responsive care has the potential for patients to be more satisfied with their care, better informed about their illness, and ultimately to attain greater health benefits [8].

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## Areas to Assess in Culturally Responsive Care

### Health Beliefs

What is the definition of health? How do you know if you are healthy? What contributes to disease? The answers to these questions may seem obvious to you, with a clear right and wrong distinction. However, these answers could be drastically different based on who you are asking. There are several facets of culture or experience that may influence health beliefs. Development stage, for instance, impacts the way children may conceptualize their own illness. Germs could be seen as little men attacking their nose during a cold instead of a virus. On the other hand, religious parents may conceptualize health or illness in terms of spiritual beliefs. For example, symptoms consistent with mental illness could be seen as an evil spirit attacking a child's mind. If a parent has that conceptualization of the problem, there may be minimal belief that medication or therapy would be effective in treating the problem. There are countless ways that a patient and their family's experiences may impact what they believe about health, illness, and medical treatment. The only way to better understand patients' health beliefs is to engage in intentional assessment to highlight where frameworks for health and medical treatment may overlap or separate for the PCP and patient.

### Health Literacy

As a PCP, an exorbitant amount of your time and energy has been dedicated to becoming well versed in your chosen discipline. For your patients, especially the prepubescent children, this is not the case. The term health literacy has been applied to a "set of skills that are required to function well in the health care or public health setting" [9]. The vast majority of patients you see will not have an in-depth understanding of how to explain their experiences using medical jargon. Using a moment to assess health literacy may save the PCP, the patient, and his/her family frustration and confusion when moving through treatment. The PCP must be purposeful in identifying ways to illuminate

patients' and families' literacy level. Specific questions as well as communication strategies to initiate health literacy assessment will be presented later in this chapter.

## Perceived Parental Role

Depending on the circumstance and cultural realities of a patient, the involvement of the guardian(s) will vary. Irrespective of how engaged the adult is in the office, they undoubtedly have a major role in health outcomes of the child [9]. Therefore, it is important for the PCP to delineate the context through which medical assessment will be most beneficial to the guardian. In some cultures, children are expected to defer to their guardians in professional settings or not to address adults. In other cultures, children may be relied upon to share their symptoms with limited to no guardian involvement. In some instances, the patient serves as an interpreter to bridge the gap between the PCP and a guardian with limited English proficiency. There are innumerable dynamics that complicate the PCP, patient, and guardian(s) relationship. Due to the potential complexity of these interactions, it is helpful to briefly assess cultural norms specific to your patient and their family.

Here's an example of what that may look like in practice:

*PCP: Good morning, I'm glad you all were able to come in today. Before we get started, I'd like to check in about a few things, would that be ok with you all?*

*Patient: Yeah, I guess.*

*Guardian: Yes.*

*PCP: Ok, great. In your family, what is your preference regarding communication during our appointments? Specifically, would you prefer that I ask the patient questions directly or would you prefer that all questions be presented to you?*

*Guardian: I don't know if she will be able to clearly answer the questions about her condition. So, you can try but I'd like to fill in anything she leaves out.*

*PCP: That is ok with me. How does that sound to you? (directed at patient).*

*Patient: Ok, I guess.*

*PCP: (Looking at the patient) In order to get the most accurate picture of what you are experiencing, I will ask you a few questions first, and at the end ask your parent if they have anything to add or would describe the issue differently.*

This brief example shows how PCPs may check in about how to gather and impart information in a more culturally responsive way. In practice, the above example would include variables that may alter the conversation; however, the general concept remains. As the authority figure, the PCP has to take the responsibility of opening the door for patients and their families to share their preferences. In turn, the PCP shares why it may be important to obtain information in a particular way.

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## Communication Style

Communication is the cornerstone of any healthy relationship. When in the role of a PCP, it may feel natural to operate as the person of authority. However, patient-centered communication is crucial in learning how best to treat your patients. PCPs

have limited time with patients, and the amount and quality of information obtained from patients determine the course of treatment. It is imperative to see the patient and the involvement of his/her family as crucial to engaging in the “best practice.” Therefore, we have provided a few specific strategies aimed at quickly and thoughtfully navigating clinical interactions.

## Open-Ended Questions

A crucial component in any medical encounter is gathering information from your patient. There are several ways to gather information, but some approaches facilitate more engagement than others. To put it simply, open-ended questions are questions that cannot be answered with a yes or no. For example, if you are concerned about medication adherence, you could ask “Are you taking this medication as prescribed?” or “What has taking this medication been like for you?” Both questions are clearly aimed at the medication regimen, but one would likely give you more information than the other. Open-ended questions elicit more exploration of a topic and lead to patient-driven responses. Of great importance, there is no right or wrong way to answer open-ended questions. Completing clinical interviews with mostly open-ended questions allows the patient to respond in manners that he or she sees fit and often provides a window to the patient’s values, beliefs, strengths, and potential difficulties. Please see Table 2.1 for examples of open-ended questions for possible

**Table 2.1** Possible open-ended questions for clinical encounters

Open-ended questions			
Social support/ school	Health care	Health beliefs	Symptoms
How would you describe your family?	What brings you in today?	What does health mean to you?	What has changed about your life recently?
What are the best/worst parts about school?	What has it been like taking this new medication?	What can you do to feel better?	In the past, how have you handled difficult things?
Who do you go to when you are upset or in trouble?	What are some difficulties you have been having with this medication?	What has caused your problem?	What are the good changes you have noticed since our last appointment?
Who advises you about your health?	What helps you remember to take your medication?	What kind of treatment do you believe will work?	What difficulties have you faced since our last appointment?
How could your family help you with this problem?	What concerns do you have about your health care?	What treatments have you already tried for this problem?	How can I be most helpful to you?
How are decisions made in your family?	What do you fear most about the proposed treatment?	How would you explain what I just said to a friend?	What is most important for you?

addition to clinical interviews. The applicability of the questions may vary based on age, parental involvement, or type of problem, but the questions are to serve as examples.

## Summarizing

An important component of communication is listening. It is important for people, regardless of age, to feel heard and understood. The amount of information shared by a patient, a patient's family, or the PCP may vary greatly by encounter, but the sharing of information is consistent. Summary statements can be used to capture the essence of the conversation while verifying that the important information was heard accurately. At the end of summary statements, it is helpful to allow the patient to add additional information that may not have been stated through a simple query like "Is there anything that I missed or anything you would like to add?" This process has the ability to decrease miscommunication and allows PCPs to have a more complete understanding of the patient's perspective.

## Elicit-Provide-Elicit

As a PCP, you are in a position of authority. However, it is important that you take that privilege into account when you choose to share information with your patients. Interpersonal style may vary, but generally speaking, it is important for PCPs to foster a collaborative relationship with their patients as they are the experts on their own lives. If the patient and his/her family do not understand or agree with the treatment plan, it is likely that treatment will be ineffective. For example, if it is believed that a patient would benefit from psychopharmacological treatment but her family is against "mind altering medications," a prescription may be written but never filled by the guardians. However, when clinical encounters are approached from a perspective of eliciting information, providing information, and then eliciting a response, the sharing of information may be more impactful and relevant for the patients and their families. Let's use an example of a mother coming in to an appointment with her 14-year-old daughter.

*PCP: Good morning you two. How are you doing (facing the child)?*

*Patient: I am okay (eyes on the floor).*

*Patient's mother: Good morning Doctor. I am concerned about my daughter. She just does not seem like herself.*

*PCP: (Facing the child) How are you feeling?*

*Patient: Fine.*

*Patient's mother: Well, she has been quiet and staying in her room all the time. When I ask her what's wrong, she never gives me a real answer.*

*PCP: Well, has her appetite changed? (facing the mother).*

*Patient's mother: Yes, she barely eats anything.*

*PCP: Do you think it's possible that you are depressed?*

In that scenario, the doctor engaged with the parent and child and asked some appropriate questions. However, it is possible that approaching this clinical encounter with an increased amount of open-ended questions, summary statements, and an elicit-provide-elicite approach may have been more impactful.

*PCP: Good morning you two. How are you doing (facing the child)?*

*Patient: I am okay (eyes on the floor).*

*Patient's mother: Good morning Doctor. I am concerned about my daughter. She just does not seem like herself.*

*PCP: (Facing the child) Tell me about how it has been for you in the past few months since our last appointment.*

*Patient: Fine I guess. (Doctor looks at patient, half smiles, and nods.) I mean, I don't know. I have just been sad. I am not really sure why.*

*PCP: Hmmm, I am really sorry to hear that you have been sad. That is not fun for anyone. What has changed about your life recently?*

*Patient: (Looking quickly at her mother) Well, I am in high school now and it is really hard. I usually get A's and B's, but it is hard to do that now. And, I don't know, I have just been feeling really tired. I have to make myself eat sometimes.*

*PCP: So, school is pretty tough and you have just not had a lot of energy or much of an appetite. (Turning to mother) Mom, what have you noticed?*

*Patient's mother: Well, she has been quiet, staying in her room more, and not eating as much. I keep asking her about school but she just says it's fine.*

*PCP: Okay, thank you both for sharing with me. (Facing the patient) Tell me what you know about depression?*

*Patient: Well, it is something they talk about at school a lot. It's when people are sad and they may cry a lot. Sometimes, people can hurt themselves.*

*PCP: Yes, you are right. Depression can look different in different people but as you said some signs may be sadness and crying. People may also feel tired, eat more or less, lose interest in things they used to like, and sometimes have thoughts about hurting themselves. Hearing those things, what does that mean for you?*

*Patient: I definitely don't want to hurt myself but some of the other things sound familiar. I used to love playing the piano but now it is hard to even sit at the piano.*

In this example, the PCP asked open-ended questions, used a summary statement, and asked the patient to share the knowledge that they already had about a possible diagnosis. Considering the age of the child, the PCP focused on more engagement with the patient while acknowledging the utility of the information from both the patient and the patient's mother.

## Ask-Provide-Ask

Another strategy related to information sharing involves asking permission to share possibly difficult information. Of course, the patient and family understand that the PCP has expertise, but it is possible that the patient may not be ready to hear difficult information or resistant to direct feedback. Asking permission to share a concern or provide information gives the patient a greater sense of autonomy. Here is an example drawn from the previous scenario.

*PCP: I have some concerns about the way you have been feeling. Is it okay if I share them with you?*

*Patient: Yeah, I guess.*

*PCP: Based on what you and your mother are telling me, you have been feeling down, your appetite has decreased, and you are no longer doing something that you love. All of these symptoms could be signs of depression and more assessment may be needed to determine our next steps. What do you make of that?*

In this example, the patient was given the option to hear or not hear the information, thus promoting greater involvement. Consistent with the overarching goal of PCP-patient relationships, giving patients a choice about receiving information facilitates a greater sense of collaboration. Open-ended questions, summaries, elicit-provide-elicited, and ask-provide-ask all have the commonality of increasing patient communication, clarifying the patient's perspective, fostering collaboration, and encouraging active patient involvement in health-care treatment. These strategies in no way guarantee an achieved sense of cultural humility, but they can offer more information about the patient sitting in front of you.

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### Conclusion

Competence is always something to be strived for, but in the context of working with cultural systems, families, and individuals, it may not be an attainable goal. Competence implies that all cultural presentations or circumstances are able to be mastered, but the real work lies in recognizing that your knowledge is incomplete without the involvement of your patient. To become a PCP operating in cultural humility, skill-building in self-awareness, minimizing assumptions, gathering information effectively, and conceptualizing the unique qualities of your patients as well as the context of their lives are imperative. Primary care providers are often the first line of health care. The ability to create a respectful and inclusive environment in the primary care setting will be instrumental in a patient's engagement in other medical settings. Additionally, among the many benefits of cultural humility, recognizing the different cultures of the individual PCP, medical system, patient, and patient's family while learning how to better understand and navigate those cultures for the benefit of the patient allows for better, more impactful health care.

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Michelle P. Durham

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## Scope and Definitions

### Introduction

*We live in a world in which we need to share responsibility. It's easy to say it's not my child, not my community, not my world, not my problem. Then there are those who see the need and respond.*

~Fred Rogers

Children's cognitive, social, and emotional development blossoms when they are in safe, nurturing environments. Learning to respond to stress is a normal part of human development. Our physiological responses to threatening events include increased heart rate, perspiration, increased blood pressure, and elevation in stress hormones. When a stressful event occurs, parents and caregivers may provide the protection needed to enable children to recover from the stressor. A child's cognitive, social, and emotional development is affected when stress occurs repeatedly, when no one offers the child safety or recovery, or when the child's stress response is constantly activated.

This chapter focuses on primary care providers' role in the medical home to assess and intervene on behalf of the child and family. Primary care providers are critical in the lives of children due to mandatory visits in early life and subsequently throughout adolescence. The child and family develop trust in these professionals. Primary care providers provide an environment in which the child and caregiver can feel comfortable discussing both good and bad things that occur in the child's life.

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M. P. Durham

Department of Psychiatry, Boston Medical Center, Boston University School of Medicine, Boston, MA, USA

Department of Psychiatry, Boston Medical Center, Global and Local Center for Mental Health Disparities, Boston, MA, USA

e-mail: [Michelle.durham@bmc.org](mailto:Michelle.durham@bmc.org)

This opportunity is invaluable in recognizing trauma symptoms, assessing its impact on the child and family's functioning, and providing interventions to help them cope and heal from the trauma.

## **Childhood Trauma by the Numbers**

Childhood trauma (all forms of physical/emotional abuse), intimate partner violence, neglect, sexual abuse, or household dysfunction (drug use, criminal behavior) impact youth across all ethnic groups, gender identity, socioeconomic status, and ages. In 2016, the national estimate of children age 17 and younger who received a child protective service investigation response was approximately 2.3 million [1]. 74.8% of victims were neglected, 18.2% were physically abused, 8.5% were sexually abused and 6.9% of victims experienced such "other" types of maltreatment as threatened abuse or neglect, drug/alcohol addiction, and lack of supervision [1]. Children in their first year of life had the highest rate of victimization at 24.2 per 1000 children of the same age in the national population [1]. The majority of victims consisted of three races or ethnicities—White (44.9%), Hispanic (22.0%), and African-American (20.7%) [1]. Other studies have shown that on average children experienced 4.9 traumatic and stressful life events, and nearly 40% of those children had symptoms of posttraumatic stress disorder [2].

## **Consequences of Trauma**

Children who have been exposed to trauma can have learning difficulties, academic decline, and behavioral issues in school. We now know there is an association between early childhood experiences and adult physical and mental health outcomes [3, 4]. Beyond the social-emotional difficulties children have, there are great societal and economic costs including costs to the juvenile justice system, social welfare systems, healthcare, and educational system [5].

## **Defining Trauma**

The American Psychological Association defines trauma as "an emotional response to a terrible event like an accident, rape or natural disaster. Immediately after the event, shock and denial are typical. Longer term reactions include unpredictable emotions, flashbacks, strained relationships and even physical symptoms like headaches or nausea" [6]. The National Child Traumatic Stress Network separates more serious threats into two main categories, acute and chronic [7]. Acute traumatic events include witnessing violence, facing imminent threats of injury, or experiencing violation of personal physical integrity (e.g., school shootings, sudden or violent loss of loved one, sexual assault). Chronic traumatic situations occur repeatedly over long periods of time (e.g., community violence, abusive parents, or living in poverty).

The child who experiences trauma may or may not go on to experience acute stress disorder or posttraumatic stress disorder. There are internal and external factors that may predispose a child to develop posttraumatic stress disorder (PTSD). Risk factors include the child's age, female gender, genetic vulnerabilities, previous exposure to trauma, and how the child functioned prior to the trauma. Environmental risk factors include mental illness in a caregiver, low socioeconomic status, poor attachment, and insufficient community and family supports. The severity and type of the trauma and the number and frequency of traumatic events influence these internal and external risk factors. This in turn promotes traumatic response symptoms in the child. The child's temperament coupled with the caregiver's response can be protective in the child's ability to be less affected (or not at all) by the event. The ability of a caregiver to be attuned and supportive to the child's needs can have lasting positive effects.

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## Signs and Symptoms of Trauma

Acute stress disorder lasts *3 days to 1 month* after a stressful event [8]. The child could have directly experienced the event, witnessed it, or learned that a close family member was hurt. The child then presents with symptoms from the stressor/trauma. Symptoms of acute stress disorder (ASD) can fall into any of the following categories: arousal, intrusion, negative mood, dissociation, and avoidance. PTSD differs from acute stress disorder in that the symptoms are present *for more than 1 month* after the stressful event [8]. Additionally, the symptoms are causing significant distress at home and school while affecting relationships with family, peers, and other caregivers.

Arousal	Irritable (verbal/physical aggression); angry; difficulties with sleep; exaggerated startle response; on high alert to people/places/surrounding areas; difficulty concentrating
Intrusion	Nightmares; distressing thoughts about the event; younger children playing out or talking about the traumatic event repeatedly; intense response to signs that remind of the trauma
Negative mood	Great difficulty in feeling happiness or joy; negative thoughts and feelings about self; feelings of shame/guilt; distortions around the cause of the traumatic event that lead to feelings of blame
Avoidance	Every effort to avoid people, places, or situation that are reminders of the traumatic event
Dissociation	Inability to remember a part of the event; feelings of a dreamlike state; detachment

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## Confounders and Comorbidities

Traumatic events may lead to PTSD but may also coincide with other symptom sequelae. Adjustment disorders, depression, anxiety, disruptive disorders, and attention deficit hyperactivity disorder should be further assessed and are highly

comorbid with PTSD. Screening for substance use is critical, particularly in adolescents. Although comorbidity exists, misdiagnosis may also occur due to the overlap in symptoms across many diagnostic categories. Some youth may be diagnosed with bipolar disorder, disruptive mood dysregulation disorder, or ADHD due to presenting PTSD symptoms of aggression, impulsivity, hyperactivity, and mood dysregulation. Further assessment becomes important in providing diagnostic clarity in these circumstances. All youth who present with symptoms of mental illness should be screened for trauma.

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## PTSD Presentation in Children and Adolescents

Symptoms of trauma in children and adolescents are expressed differently by developmental level and cognitive ability. In young children, reactions are typically in the form of regression. Parents may notice the child requiring extra support for activities he/she had typically completed without difficulty. Primary care providers should be attuned to descriptions of regressive behaviors. School-aged children may reenact the trauma in their play, in their drawings, or by verbally retelling events they remember. Adolescents will present with symptoms that more closely follow the DSM criteria as in the adult population. They may describe responses that include nightmares, flashbacks, hyperarousal, avoidance of trauma reminders, and numbing of emotions.

### Preschool Children

- Nightmares
- Poor appetite
- Scream, cry more than usual
- Changes in behaviors
- Ask about death
- Regression in toilet training
- Fear of separation from caregiver
- Developmental regression

*Juan is a 3-year-old boy who emigrated from El Salvador to the United States. His mother left Juan with his maternal grandmother for work in the United States. Last year, he crossed the border with the help of a family friend. It's been difficult for Juan since that time. You first met Juan and his mother 6 months ago for his first well-child visit. Initially, his mother described issues with sleep. He did not want to sleep alone and could not fall asleep until his mother stayed in bed with him. You wonder if he's adjusting to his new home or if there's more going on. At this visit, you notice further decline over the last 3 months since he started preschool. His mother has been called frequently by preschool staff regarding his severe tantrums. He is clinging to his mother more than usual, wetting the bed almost every night, and having nightmares regularly.*

**School Aged Children**

- Difficulty concentrating
- Change in academic performance
- Clingy with caregiver
- Worried about caregiver, themselves and other family members
- Repeat the story around the traumatic event over and over
- Easily startled
- Difficulty with sleep/nightmares
- Fearful the traumatic event may occur again

*Jacob is an 8-year-old boy who is well known to you. He has a history of seizures diagnosed at the age of 4. His parents are supportive and caring and have been diligently coordinating Jacob's appointments and follow-ups. They come to you after seeing a regression in some of Jacob's behaviors. He has had multiple hospitalizations recently due to uncontrolled seizures. Neurology is working to adjust his medications. Lately he's refused to attend appointments, and his parents have resorted to offering gifts and rewards. Despite these efforts, he continues to avoid. He has been clingy when at the appointments—holding on to his parents—which is atypical for him or kids in his age group.*

**Adolescents**

- Sleep difficulties
- Risk taking behaviors
- Depressed mood
- Impulsive/aggressive behaviors
- Self-injurious behaviors
- Avoidance of places/people that remind them of the traumatic event
- Substance use
- Describe not having any feelings about the traumatic events
- Feel like they are “going crazy”

*Mary is a 14-year-old girl who lives with her biological mother, stepfather, and 10-year-old half brother. You've known her since birth. She has a history of academic difficulties and trouble making friends at school. This past summer she visited her father and family in Puerto Rico. Her mother suspects something occurred over the summer, yet is unclear on the details. Since returning 2 months ago, Mary has been extremely irritable, refused to talk about the summer, and increasingly defiant. She left home twice without letting anyone know who she was with or where she was going. Her mother presents with Mary for help with concerns that she's going down the wrong path.*

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**Role of Pediatric Primary Care Providers**

*You are not alone, it is not your fault, and I will help.*

~American Academy of Pediatrics

Pediatric primary care providers' longitudinal relationship with children and families makes the medical home an ideal location to screen, assess, and intervene on behalf of the child and family. Helping the family recognize trauma and its impact on the child and family is an important first step in intervening. Helping the child and family put into words the symptoms or difficulties they are having and giving meaning to this can be invaluable. Table 3.1 includes some approaches to trauma in the primary care setting.

## Screening and Assessments

An important role is screening and assessing for exposure to trauma during visits with the child and family. Every visit with a child and family is an opportunity to assess for risk, intervene early, and provide effective treatment. There are brief, well-validated screening tools for childhood trauma and adolescent acute stress disorder and PTSD. Two worth highlighting are the Acute Stress Checklist for Children and the Child PTSD Symptom Scale. Both are described in this text's chapter on measurement-based care. Repeated evaluation over time is recommended, as symptoms may present months or years after the traumatic event [9]. In the absence of screening tools, visits with the child/family still offer the opportunity to assess for risk. Families, children, and adolescents can be asked if anything scary or stressful has happened since the last visit [10]. This can lead to further discussion of new symptoms that may be distressing to the child/family.

Once the child and/or family have completed the screening assessment tool and responded yes to questions about trauma, or once a youth or caregiver has spontaneously reported a traumatic event, a conversation about the traumatic experience and response should begin. "I noticed you answered yes to the question(s) about (or Thank you for telling me about what happened)...I would like to hear more about it so that I can see how we can help." The age of the child will influence how the interview is conducted and how questions are asked.

Children 3–5 years of age think concretely and may not give a clear description of what occurred. They need to be oriented to a day or time, i.e., your birthday, the particular holiday, and that time at school lunch. It may be easier for them to draw or demonstrate what may have occurred.

While children 6–9 years of age understand concepts, they may feel guilty about what occurred and fear disclosing details of traumatic events. A supportive, well-known clinician can help the child feel more comfortable. Similarly, children 10–13 years of age understand what happened, yet may have guilt, shame, or denial around the event. They may respond to formal questions surrounding the traumatic event. Teenagers are likely to respond to a direct approach framed in a nonjudgmental tone. In all cases, children and adolescents need reassurance that they are not to blame, that help is available, and that you are there to support them and their family.

When it has been determined that trauma is affecting the child and family's functioning, there are several aspects of care that can be managed in the medical home as outlined below.

**Table 3.1** Trauma interventions in the primary care setting

<i>Education</i>	Many families may not know or understand the impact trauma may have on a child. They may feel the child is “too young” or “does not understand what is going on.” Educating the family on what PTSD is; how trauma can adversely affect development, school, and/or family when untreated; and what treatments are indicated is important in setting the ground work. This can help to provide hope for the family that things can get better and that they are not alone.
<i>Safety</i>	Establishing safety for the family and child is essential for treatment to occur. PCPs should communicate with the family, school, and child protective services when indicated by safety concerns. In some cases, such as community violence, safety cannot completely be accomplished, but providing the child and family with resources and tools to promote healthy, positive, coping skills can be helpful.
<i>Skills</i>	Providing skills and techniques for dealing with difficult behaviors can be critical to a family in distress. Children may react to trauma with aggressive or dysregulated behaviors that can be difficult for the caregiver to manage. Skills such as relaxation techniques, enhancing the caregiver-child relationship, and behavior management are critical to improvement in overall family well-being. Examples include: <ul style="list-style-type: none"> <li>• Maintain a consistent routine for the child</li> <li>• Be consistent and calm when disciplining the child</li> <li>• Praise desired behaviors</li> <li>• Educate the caregivers on how their own emotional responses can affect the situation positively or negatively</li> <li>• For young children and children with impaired attention especially, give directions that are simple and direct</li> <li>• Model calming skills</li> <li>• Set routines to help regulate any sleep disturbance</li> </ul>
<i>Safe space to discuss</i>	Providing time and space to allow the family and child talk about the trauma can be very validating. The provider can also help the family focus on the strengths and protective factors the family has to move forward and get the support they need.
<i>Coordination of care/case management</i>	Helping the family access community resources and communicating with the school are critical in supporting the family. There can be accommodations made in school to help the child and family through the difficult period they are experiencing. Maintaining an open line of communication can help improve overall functioning.

The discussion with the child/family may inevitably result in information that you are required to report as a mandated reporter. This can be difficult as you want to support the child/family and this may seem punitive. As part of the intake process and orientation to the clinic, these guidelines should be discussed and documented clearly so that families are not surprised if/when you must communicate with child protective services in instances such as abuse/neglect. Once you are aware of abuse/neglect, clear documentation in the medical record should be in the words of the child/caregiver. In instances in which the parent is not the abuser, it is also helpful to contact CPS with the parent present so that he/she is aware of what is being communicated. Alternately, the parent can call with your support while in the office.



## Seeking Mental Health Expertise

*Develop empathic therapeutic relationship, convey hope, enhance safety, and coordinate care.*

~Child Parent Psychotherapy

When symptoms persist and are interfering with daily activities and school performance, caregivers are unable to ensure safety or be supportive to the child's needs, or the caregiver is also symptomatic, then referral to specialty mental health services is indicated. A trauma-focused psychotherapy is the first-line intervention for children and adolescents who have experienced trauma. There are several modalities with good evidence bases: trauma-focused cognitive behavioral therapy (TF-CBT) (3–17 years old), child-parent psychotherapy (CPP) (infancy through 6 years of age), or cognitive behavioral therapy (CBT). The interventions have key components: psycho-education, direct exploration of the trauma, symptom management techniques, and exploration and modification of inaccurate cognitive attributions regarding the trauma. In cases where these preferred therapeutic interventions are not available to the child and family, the therapeutic intervention should have the following characteristics at a minimum:

1. Developmentally appropriate and culturally sensitive
2. Strength based rather than deficit based
3. Emphasis on overcoming avoidance and mastering trauma reminders by encouraging children to talk directly about their traumatic experiences in therapy
4. Parent inclusion—recognizing the central role that parents have in children's development and recovery from adversity
5. Skills and safety focused, which supports the youth in managing and reregulating upsetting emotional states, regaining functioning in important areas such as sleep and school, and planning for safety in the present and future

Medication use for PTSD in children and adolescents has not been well studied. At this time, there are no FDA-approved medications for the treatment of PTSD in children and adolescents. Medications are used in the following scenarios: to target disabling symptoms, to improve the quality of life of the child/adolescent allowing for normal growth and development in the long term, and to facilitate the process of psychotherapy by allowing traumatized children to deal with emotionally distressing retelling of events in therapy [11]. Providers should be cautious in using medication as a sole treatment as psychotherapy is the gold standard treatment with the most evidence. Table 3.2 describes medications commonly used for PTSD symptoms.

**Table 3.2** Medications commonly used in youth with PTSD

Medication class	Name	Use	FDA approval for PTSD
Alpha-2 agonists	Clonidine Guanfacine	Evidence in adult PTSD to reduce anxiety and arousal, but limited studies in children/adolescents Can be helpful to decrease hyperarousal, hypervigilance, impulsivity, nightmares, insomnia	No

**Table 3.2** (continued)

Medication class	Name	Use	FDA approval for PTSD
SSRIs	Fluoxetine Citalopram Sertraline	Evidence in adult PTSD, but limited studies in children/adolescents. Can be helpful in comorbid depressed and/or anxious youth	No

*SSRI* selective serotonin reuptake inhibitors

## Summary

Primary care providers are well positioned to identify and provide interventions for trauma in the primary care setting. The trusting, longitudinal relationships providers have with children and their families make them the ideal provider to screen, assess, and intervene. Educating, establishing safety for the child and family, providing techniques to manage difficult behaviors, educating the school, and coordinating further care for the family and child can profoundly help children and their families access appropriate and timely interventions. Families, communities, and society are all enriched if trauma can be prevented or treated before symptoms have lifelong consequences.

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## Resources for Families

The National Child Traumatic Stress Network

<http://www.nctsn.org/resources/audiences/parents-caregivers>

Substance Abuse and Mental Health Services Administration

<https://store.samhsa.gov/product/Tips-for-Talking-With-and-Helping-Children-and-Youth-Cope-After-a-Disaster-or-Traumatic-Event-A-Guide-for-Parents-Caregivers-and-Teachers/SMA12-4732>

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## Resources for Primary Care Providers

The National Child Traumatic Stress Network

<http://www.nctsn.org/resources>

American Academy of Pediatrics

<https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/healthy-foster-care-america/Pages/Trauma-Guide.aspx>

Center on the Developing Child

<https://developingchild.harvard.edu/about/>

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# Suicide and Non-suicidal Self-Injury

# 4

Aditi Vijay, Matthew R. Salmon, and Colin E. Stewart

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## Suicide

### Demographics and Etiology

Suicide is a leading cause of death in adolescents and young adults [2]. Although it is less common in children, it does exist. The Centers for Disease Control and Prevention estimates that approximately two million adolescents attempt suicide each year [2]. This data showed that 17% of high school students seriously considered suicide, 13.6% made a plan to commit suicide, 8% made a suicide attempt, and 2.7% made a suicide attempt that required medical intervention [2].

### Risk/Protective Factors

Common *risk factors* for suicide include but are not limited to:

- Existence of a psychiatric disorder/social isolation
- Prior suicide attempt
- Knowing someone who has died by suicide
- History of abuse or neglect
- Access to lethal means
- Substance abuse
- Sexual and/or gender minority status
- Social stigma around mental health

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A. Vijay (✉) · M. R. Salmon · C. E. Stewart  
Georgetown University School of Medicine, Washington, DC, USA  
e-mail: [aditi.vijay@gunet.georgetown.edu](mailto:aditi.vijay@gunet.georgetown.edu)

- Bullying
- Dysfunctional social media use (e.g., conduit for bullying)
- Trauma

Common *protective factors* include:

- Strong connections to a social network
- Positive social support
- Ability to handle problems effectively
- Restricted access to means to kill oneself
- Accepting, supportive environment

### **Sexual Minorities and Gender Diverse Youth**

Sexual and gender diverse youth are at a disproportionately higher risk for suicide. In samples of transgender adolescents and young adults, 30.3% endorsed making a prior suicide attempt [3]. In representative samples of sexual minority adolescents, 40% endorsed seriously considering suicide in the past year, and 25% reported making a suicide attempt in just the past year alone [4]. The level of acceptance of these issues within the child's environment affects the rate of suicide, with the highest rates existing in non-affirming environments. The implication for clinicians is the need to ask about suicide and to assess the level of support in the home environment in this population. Patients and families should be educated on available options (e.g., online support, therapy groups, psychological services) to help them successfully access resources.

It is incredibly important to take care with this subpopulation of youth as, often times, "coming out" or identifying with a minority sexual orientation or gender identity can be terrifying. Many youth ruminate on coming out and the potential for rejection that comes with such a revelation. In their minds, it is often life or death. Familial rejection or lack of acceptance can involve losing a roof over their head or, quite literally, drive them toward suicide. It is necessary to know if these factors affect youth who may struggle with depression, anxiety, suicidal ideation (SI) and non-suicidal self-injury (NSSI). This information can be obtained through properly formatted intake forms that avoid making heteronormative assumptions. These forms should allow individuals to identify their gender as male, female, transgender, or "other" while still asking about gender assigned at birth. When asking about relationships, these forms should also include language asking about sexual orientation as well as sexual practices as certain people might be sexually active with a sex that is not indicative of the orientation with which they identify. The best way to learn about an individual's gender identity or sexual orientation, however, is to ask about them directly once rapport has been established with the patient. This should be done without the caregiver(s) present and with verbal assurance of confidentiality. When asking, the best method involves the use of open-ended questions while gathering social history, such as:

- “Are you in a romantic relationship?” and, if so, “Tell me about them.”
- “How do you identify in terms of your sexual orientation?” or “Do you consider yourself straight, gay, bisexual, or pansexual?”
- “Some people don’t identify as the gender they were assigned at birth, how do you identify?”
- “I understand the fears that could be associated with identifying this way. Does your family know? Do they support you and accept your identity?”

If youth explain that family does not know or support them, it will be important to fully support them and offer guidance through the process. There may be times when encouraging the youth to talk with their family is not appropriate (e.g., if there is a risk of physical/emotional abuse or becoming homeless). However, if the youth would like to communicate their identity to their family, then the clinician can offer the primary care office as a safe, supportive space in which the youth might share their identity with their parents with the support and guidance of the clinician. Most major cities have support groups for LGBT+ youth, and it is helpful to identify local resources and provide a list to patients. The Human Rights Campaign (HRC) also has multiple resources on its website at <http://www.hrc.org/resources/topic/children-youth> as does the Safe Zone Project at <http://thesafezoneproject.com/resources>.

## Screening and Assessment

Screening and assessment tools can be used to help identify at-risk youth. Per the American Academy of Pediatrics (AAP) Bright Futures Guidelines, screening for depression is recommended for all youth ages 12 and up ([https://www.aap.org/en-us/documents/periodicity\\_schedule.pdf](https://www.aap.org/en-us/documents/periodicity_schedule.pdf)), and the majority of validated depression screening measures will include questions about suicidal ideation. If the depression screening method used in your practice does not include questions regarding Suicidal Thoughts and Behaviors (STB), then STB should be separately screened for in this age group. Any child with a behavioral health chief complaint or history of mental illness should be screened as well.

Evidence-based screening measures can make it easier to engage in this evaluation process. One tool for screening is the *Columbia-Suicide Severity Rating Scale (C-SSRS)*. The C-SSRS (available at <http://cssrs.columbia.edu/>) is an evidence-based measure designed to evaluate and triage suicide risk and intent [5]. The C-SSRS includes questions to assess for both the severity and intensity of suicidal thinking, as well as the presence of suicidal behaviors. The first two questions screen for the presence or absence of suicidal thinking. If a patient screens positive for either of the first two questions, the measure then guides the clinician to ask further about intent, plan, and intensity of ideation. Even if the patient denies suicidal thinking, the measure then guides the clinician to check for a history of suicidal behaviors such as suicide attempts and non-suicidal self-injury. The C-SSRS

website also includes a risk assessment tool that lists risk and protective factors, as well as relevant aspects of the clinical history, which can be useful when documenting the encounter. The C-SSRS is free of cost, and online training videos are easily accessible here at <http://cssrs.columbia.edu/training/training-options>.

### Clinical Interview

One critical component when evaluating suicide risk is to ask youth whether they are thinking about hurting themselves and simply listen to the answer in a nonjudgmental manner. The act of the conversation, without doing anything further, can be incredibly powerful for the patient. Patients with STB are typically experiencing a great deal of pain and suffering, so it is essential to attempt to identify and validate their feelings while also acknowledging that you cannot read their mind. An example statement would be, “My sense is that you are in a great deal of pain. Did I get that right?” A willingness on the part of any provider to engage in this conversation is the first step to connecting youth to the resources they need and increasing the likelihood that they will act on these recommendations.

During the standard screening, start with open-ended questions about the youth’s mood such as: “Everyone feels sad or grumpy sometimes. What gets you feeling that way?” Whether or not the patient endorses depressed mood, clinicians should ease into the discussion of STB with a similar approach. Examples of questions to ask are as follows:

- *Hopelessness*: “When kids or teens are feeling at their worst, they sometimes feel hopeless or like nothing will ever change. Have you ever felt that way?”
- *Suicidal ideation (SI)*: “Sometimes kids or teens also think about death or killing themselves. Have you ever wished you were dead or felt like you wanted to go to sleep and not wake up? Have you ever thought about killing yourself?”
- *Suicidal behavior*: “Have you ever done anything to try and kill yourself or make yourself go to sleep and not wake up?”
- *Non-suicidal self-injury*: “Have you ever hurt yourself on purpose without intending to die or try to kill yourself?”

### Triage

If a patient has had suicidal ideation, the next steps are to evaluate four key factors to inform a treatment plan:

1. The *severity* of suicidal thinking
2. The *intensity* of suicidal thinking
3. The presence or absence of *suicidal behaviors and/or NSSI*
4. *Imminent risk* vs chronic risk

The C-SSRS is an example of one measure that scaffolds the process for clinicians. It is helpful to start with the *C-SSRS screener with triage for primary care* to assess severity of risk and suicidal behavior quickly. If the information obtained

from the primary care screener is insufficient, proceed to the full C-SSRS that includes the intensity scale, which asks questions about the frequency, duration, and controllability of SI, reasons for the SI, and possible deterrents (e.g., why would you not want to die/take action). Assessment of risk and protective factors will provide additional information as well as obtain collateral information (e.g., current behavioral health professional, caregiver, school staff, family members). At this point, the clinician must determine imminent and chronic risk of suicide on a scale from low to high. Once the level of imminent risk has been determined, next steps can be identified.

### Levels of Care

These levels are listed below in order of least to most restrictive and associated interventions:

Level of risk	Treatment recommendations	Time frame for intervention
<i>Low risk or low to moderate risk</i>	Behavioral health referral/appointment	Patient ideally seen within 1–2 weeks
<i>Moderate risk</i>	Behavioral health consult and consider safety precautions	Patient ideally seen within 24 h but up to 1 week, depending on availability
<i>Moderate to high risk</i>	Behavioral health consult and safety precautions	Patient seen same day
<i>High risk</i>	Immediate referral for emergent behavioral health consult, e.g., mobile crisis team and/or emergency room	Immediately

### Behavioral Health Consults

These consults may come from a variety of sources, including the following:

- Clinic-based integrated behavioral health specialists available for “warm handoffs”
- Clinic-based social workers, psychologists, or psychiatrists available for acute referrals
- State-based telephone consultation services (e.g., MCPAP, Massachusetts or the DC MAP, Washington, DC)
- Mobile behavioral health consultation services

### Safety Precautions

Safety precautions include, but are not limited to, the following [6]:

- Collaborative development of a crisis plan with caregivers and youth including
  - List of warning signs of increasing risk
  - Identification of triggers for calling or going to the primary care physician’s office, the crisis line, 911, or the nearest ED
  - Identification of coping strategies and social supports for managing difficult symptoms or circumstances



- Identification and locking up lethal means, e.g., medications, knives, and razors
- Keeping firearms and bullets in separate, locked safes
- Close monitoring of youth by caregivers for 24–72 h or until behavioral health consult

### **Safety Plans**

If you are in a situation where you are concerned about a patient's safety, it is a good idea to create a safety plan (Stanley, & Brown, 2008) to ensure a plan in the event that things change for the patient after the appointment. A safety plan includes the following components: identification of potential warning signs that may indicate a crisis, identification of coping strategies, external coping strategies, environmental changes, and professionals to reach out to. Warning signs refers to anything (i.e. behaviors, thoughts, feelings, sensations) that indicates that a crisis is developing and/or intensifying. Internal coping resources are things the individual can do on their own without external support (e.g. breathing exercises, progressive muscle relaxation) while external coping resources refer to others in the environment or other social activities. It is a good idea to identify professional resources to contact in the event that the patient or family is concerned about safety. This might include reaching out to their therapist, calling a crisis line or suicide hotline or calling 911.

For example, if a patient presents to the office with suicidal thoughts/behaviors that you assess as low-moderate risk, it may be helpful for all to review a safety plan. The function of a plan is to provide concrete suggestions for the family in the event that things worsen. Thus, the way in which you manage this process depends upon the family. It may be helpful to create or obtain a template that lists the components of a standard safety plan. It is ideal for a patient to identify warning signs for themselves (e.g. isolation, not spending time with friends, listening to depressing music) and then list out what coping strategies they may use on their own (e.g. switching activities, distracting themselves) or externally (e.g. reaching out to someone to make a plan to do something together or for suggestions). It is helpful at this point to discuss when the patient may feel it is appropriate to call someone (e.g. crisis line). Throughout this process it is helpful to use a matter-of-fact manner with the patient and communicate that everyone goes through periods where they feel sad or overwhelmed and these types of plans are helpful to get through those phases. At the same time, we want to send the message that the best way to make it through is to seek help from a behavioral health specialist to manage these feelings.

### **Next Steps**

It is critical for both the caregiver and the youth to be invested in the plan; any reluctance or hesitancy on the part of the youth/caregiver to follow through should be factored into the determination of overall level of risk. When the youth is evaluated as moderate risk or above, the clinician must notify the caregiver. It is best practice to develop a plan with the patient to discuss safety with parents in an effort to build

rapport. Caregivers should be provided only the details necessary for safety planning purposes in order to preserve rapport with patients. This is important as good rapport encourages accurate reporting of risky behaviors in future visits. Typically, most patients with SI are not at high risk for suicide and do not require hospitalization.

Psycho-education about the nature of behavioral health care (psychosocial and pharmacologic interventions), the level of imminent and chronic risk, and safety planning is essential. Psychotherapy is the first-line treatment for mildly to moderately severe psychiatric conditions. Referral to a psychotherapist for further evaluation and treatment is strongly recommended in all cases of STB.

STB can indicate more severe pathology. In the case of moderate to severe mood disorders and mild to severe anxiety disorders, medications should be considered as an adjunct to psychotherapy. As detailed in other chapters, selective serotonin reuptake inhibitors (SSRIs), particularly fluoxetine, have the strongest level of evidence for depression and anxiety in youth.

### **Black Box Warning for Antidepressants in Youths**

In 2004, the FDA issued a now controversial black box warning regarding an increase in STB with SSRIs and other antidepressants in youth under 24 years old. The data used to support the implementation of this warning indicated a 2% increase in STB from placebo to drug arms (2% in placebo, 4% in treatment): a drug-placebo difference of 19 additional cases of STB per 1000 patients. Additionally, none of the 2200 youth treated with SSRIs in the review died from a suicide attempt [7]. However, subsequent meta-analyses have indicated that treating depression and anxiety in youth with antidepressants clearly indicates a relative benefit to treatment [8].

A practical interpretation of the available data gives clinicians the following conclusions:

1. Youth with moderate to severe depression and mild to severe anxiety should be treated, and clinicians should consider pharmacologic treatment in combination with psychotherapy.
2. Youth treated with SSRI medications are more likely to have positive outcomes than they are to have increases in suicidality compared to placebo alone.
3. Youth with moderate to severe depression should be closely monitored for STB by both caregivers and clinicians whether or not they are taking an antidepressant medication.
4. Clinicians should frankly discuss the black box warning with caregivers when prescribing antidepressants to youth and encourage open communication about possible STB among patient, clinician, and caregivers.

Both the FDA and national psychiatric organizations such as the APA and AACAP recommend close monitoring of youth after they have been prescribed an antidepressant. The exact frequency of face-to-face visits with an individual family should be collaboratively determined with that family, with the goal of meeting

more frequently and gradually tapering depending upon the specifics of the clinical presentation. If frequent face-to-face contacts are not feasible for either caregiver/youth or clinician, then telephone contacts with informed caregivers and/or sessions with a psychotherapist between primary care provider (PCP) visits can decrease the necessary frequency of face-to-face PCP contacts.

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## **Non-suicidal Self-Injury (NSSI)**

### **Demographics and Etiology**

NSSI refers to the deliberate, self-inflicted destruction of body tissues without suicidal intent that is not explained by social or cultural norms [9]. Common examples include cutting or burning oneself, head banging, or hair pulling. Epidemiological studies suggest rates of NSSI range from 5.9% to 7.3% over the past year, with a lifetime prevalence of 18% [10]. NSSI tends to begin in adolescence, usually between ages 12 and 14 and can continue through the lifespan [11]. Type of NSSI differs by gender with girls more likely to cut themselves and boys more likely to hit themselves [12].

NSSI is typically associated with psychiatric disorders; however, it also occurs in nonclinical populations and is not necessarily indicative of psychopathology. Concurrently, it is also a robust risk factor for future suicide attempts [13]. The broad spectrum of risk and meaning associated with NSSI complicates triage in a primary care setting because it makes determination of the appropriate level of care more difficult.

### **Risk and Protective Factors for NSSI**

NSSI is associated with existing psychiatric conditions, level of emotionality, increases in suicidal thinking, and other environmental issues (e.g., trauma, poor social/family connections, bullying). The two most commonly cited risk factors for NSSI include having an internalizing psychiatric disorder (e.g., depression, anxiety) or an inability to regulate emotions. An example of emotion dysregulation could be when people become so upset that it is difficult to have a conversation with them or they are unable to act effectively to reach their goal/ask for what they need or an inability to soothe themselves. In many cases, NSSI is a dysfunctional coping mechanism that can reduce both somatic and psychological distress. It is critical to determine what functions NSSI serves for each person. Common functions of NSSI include alleviation of overwhelming negative emotions, self-directed anger/punishment, and perhaps influence on or communication of distress to others.

Fewer protective factors have been identified for NSSI as compared to suicidality. Individuals who are skilled in managing their emotions, have strong social connections, are academically capable, and have a healthy self-esteem are less likely to engage in NSSI. When youth are able to act in a manner that allows their needs to be

met (e.g., healthy social connections, stable relationships, academic achievement), they are less likely to use maladaptive coping strategies to meet those needs.

## Screening and Assessment

Primary care visits represent a good opportunity to identify, understand, and treat NSSI at an earlier stage. However, only 25% of medical practitioners routinely assess NSSI despite research debunking the myth that asking patients about NSSI can cause or worsen such behaviors. In one study, only 3.2% of self-injurers reported that they had disclosed their self-injury to a medical doctor [10, 14, 15].

The goal of an assessment is to establish if the patient has ever engaged in/ or is at risk for NSSI. We recommend universal screening for self-harm in pubescent youth and a structured conversation if there is a history of self-harm. It is recommended that structured NSSI assessments are included as part of both standard intake appointments and yearly well-child checks. The simplest way to screen for NSSI is to include a brief self-report measure with other requisite paperwork. Several self-report measures provide information on past NSSI and risk for future NSSI and are detailed below. Additionally, clinical interview of adolescents is imperative, as youth may not feel comfortable documenting their NSSI on a self-report measure.

### Clinical Interview

Though self-inflicting pain in order to relieve pain seems counterintuitive, it is often reported by patients and may be a result of the body releasing endorphins in response to the physical pain. As a clinician, the primary objective in cases of NSSI is to listen to the patient's point of view nonjudgmentally and then use that information to help determine the next steps. As with questions about STB, the standard psychosocial screening section of the clinical interview (e.g., during the HEADSSS assessment) is a great time to ask a basic screening question such as, "Have you ever hurt yourself on purpose without intending to die or try to kill yourself?" Next, it is important to ask about multiple examples of NSSI (e.g., cutting, burning, biting) as rates of detection of NSSI more than double when more than one screening question is asked [16].

The tenor of the conversation is critically important for both the patient and the clinician. Conducting the conversation in a nonjudgmental manner that reduces the level of distress and shame can help both parties to fully engage and yield richer information. Clinicians should maintain a curious perspective with the goal of trying to understand the sequence of events leading up to the self-harm. Once clinicians have as much information as they are able to obtain, they must determine the level of risk and appropriate next steps. The SOARS model offers one way to frame the conversation.

### SOARS Model

The SOARS model (Suicidal ideation; Onset, frequency, and methods; Aftercare; Reasons; and Stage of change) offers a framework to aid in structuring the clinical interview about NSSI [17]. Clinicians can use this as both a guideline for screening

and discussion of NSSI and as a follow-up checklist once NSSI has been identified via screening questions.

*Suicidal ideation* NSSI may be correlated with suicidal thoughts and ideation, but that is not necessarily the case. One way to assess whether STB is present during self-harm would be to ask, “What were you thinking about when you did that?” or “When you harmed yourself did you want to die?” In asking these questions, the clinician sends the message that this might be a possibility, and it is okay to talk about in this office.

*Onset, frequency, and methods* The method and frequency of self-harm are important indicators of severity. Question such as “How often do you do this during the week?” or “What did you use to do that?” offer valuable information. Other considerations include if there is a planning phase or if they have to obtain tools to engage in self-harm.

*Aftercare* Questions about aftercare provide a different lens into the severity of the problem. Assess whether their wounds have needed some type of care before and whether they have ever had an instance where they required medical attention.

*Reasons* It is appropriate and potentially validating to ask patients their reason for engaging in NSSI. It is important to approach this from a curious and nonjudgmental perspective to understand what NSSI provides them (e.g., distraction or relief from intense emotions). It can be helpful to hold in mind the maxim “People do the best they can with what they’ve got,” in order to maintain a firm nonjudgmental stance. Particularly, it is helpful to avoid using the word “why” when questioning, as it typically comes across as inherently judgmental. Alternatives include first assuming the best of the patient verbally, “My guess is that [insert self-harm behavior here] felt like your best or only option at the time” and “What lead you to that decision?” or “What made cutting yourself seem like the best option in that situation?”

*Stage of change* Ask patients whether they would prefer to do something different when upset or if this is their preferred method for self-coping. This provides insight about patients’ perspective on their behavior and whether they would be receptive to referrals for help.

## Screening Measures

### Self-Harm Inventory (SHI)

The SHI measure is a 22-item, one-page self-report measure that takes approximately 3–5 min to complete [18]. This measure assesses 22 different ways in which a patient may self-harm, asks about utilization of mental health services, and identifies psychological symptoms that may indicate an elevated risk for self-harm. Uniquely, this measure includes questions about deliberately self-destructive behaviors that do not necessarily cause direct physical injury, e.g., reckless driving, risky sexual behavior, and self-starvation, and is a good conversation starter. At the time of print, this is a free measure that can be requested from the authors.

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### **Inventory of Statements About Self-Injury (ISAS)**

The ISAS is a self-report measure that asks for information about frequency of self-harm and assesses for consequences of self-harm (e.g., relief, communicating something to someone else) [19]. This measure is effective in distinguishing between self-harm with purpose of dying and self-harm without any suicidal intent. At the time of print, this is a free measure that can be requested from the authors.

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### **Triage**

Once a history of NSSI has been established, the next steps are to assess several key factors in order to determine level of risk for harm:

1. *Possible STB* outside of the context of NSSI (utilization of the C-SSRS is recommended)
2. The *frequency and amount of time spent* engaging in NSSI behaviors (e.g., Is there planning involved? Do they need to obtain supplies?)
3. The *triggers that activate the behavior* and how frequently the triggers occur
4. Possible *major depressive disorder*
5. Possible *substance abuse*

These factors and the risk factors for suicide discussed earlier in the chapter can be combined to determine risk level, and the SOARS interview evaluates the NSSI-related elements. Factors that increase the risk of future suicide attempts in youth who have engaged in NSSI include concurrent depressed mood, substance abuse, and STB. For this reason, depression and substance abuse screening are vital [20]. It is strongly recommended that clinicians use the C-SSRS or another validated instrument to help determine the level of STB. *If STB is present, then follow the triage recommendations in this chapter's section on Suicide.* If STB is not present, then imminent risk for suicide is likely to be low, and clinicians can move on to outpatient treatment planning.

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### **Next Steps**

As with STB, collaboration with the caregiver(s) and youth, careful management of confidentiality, and psycho-education are essential to successful treatment planning after NSSI is discovered. Making the distinction between NSSI and STB is particularly important, as many caregivers may not be familiar with either. This is particularly important because the level of parental distress about NSSI is a risk factor for future self-harm in the youth. Clinicians should help caregivers understand that NSSI does not involve suicidal ideation or intent at the time of self-injury, that there are multiple different reasons why youth harm themselves, and that understanding the youth's reasons for self-harm can help with prevention and problem-solving.

Conveying this information can serve to simultaneously calm and empower an anxious caregiver. Caregivers should be encouraged to maintain a curious, humble stance when talking with their child about triggers for NSSI and possible functions of NSSI, as youth are likely to shut down if they perceive negative judgment from their caregiver. Some clinics may also choose to have a pamphlet that discusses risk and protective factors for self-harm, differentiates NSSI from STB, and provides options for treatment. In the case of NSSI with concurrent STB, *follow the recommendations for next steps in this chapter's section on Suicide.*

If STB is not present, then treatment planning will involve addressing any underlying psychiatric illness, mitigating the impact of risk factors, and determining how the impact of protective factors can be strengthened. First, in addition screen for psychiatric illnesses other than depression and substance abuse likely to be associated with NSSI, such as trauma-related disorders, anxiety disorders, and emerging personality disorders. Second, discuss risk and protective factors with the youth and family to develop a plan to minimize the impact of risk factors and promote strengths, social supports, and healthy coping. Finally, work with the family to delineate their goals, and jointly decide on a treatment plan.

While all patients will not have a diagnosable psychiatric disorder, all should be referred for further evaluation by a mental health professional. The vast majority of these youth would likely benefit from psychotherapy, even those without a diagnosable psychiatric disorder, as supportive psychotherapy can help with both assessment and monitoring. While there is no specific psychopharmacologic treatment for NSSI, if medication is indicated to treat a co-occurring condition such as depression or anxiety, then medications should be considered as an adjunct to psychotherapy. Before leaving the office, the clinician should discuss ways in which youth will try to keep themselves safe. Common ways to do this are to use distraction or seek out social support. Clinicians may want to develop a written “coping plan” with the youth and caregivers which typically includes triggers for intense emotions and/or NSSI, methods for the youth to manage the urge to self-harm independently, and a list of positive social supports.

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## **Key Points to Convey to Caregivers**

As previously mentioned, caregiver collaboration in assessment, treatment planning, and prevention of poor outcomes is essential. Clinicians must keep in mind that the caregivers' discovery that their child has STB and/or is engaging in NSSI typically evokes intense emotions ranging from terror to anger to shame or sadness, depending on what they feel is causing their child's distress. Therefore, it is important to explore the caregiver's thoughts and feelings about the situation, e.g., “I can see this is bringing up some strong emotions. Would you mind helping me understand what you're feeling right now?” and “While you may not know exactly what's causing your child's distress, what guesses do you have?”

It is also essential to ascertain the caregiver's level of comfort with the treatment plan before moving forward. All treatment plans need to be both feasible (i.e., the



plan is realistic and likely to work) and mutually agreeable (i.e., all parties must agree to follow the plan). Clinicians can ask “Now that we have a plan in place, how confident do you feel about it? Is there anything we haven’t taken into account when creating this plan? Or is there anything that you’re worried will get in the way of the plan’s success?” These questions ensure that the caregiver is not just agreeing to a plan to please the clinician or to avoid the anxiety that frequently comes with talking about suicide and self-injury. Finally, clinicians should check in with caregivers about their own level of stress and capacity to manage their feelings when their child is upset, e.g., “Managing a child’s mental health challenges can be taxing for parents. How have you been dealing with the stress lately? What kind of supports do you have that you can rely on?” Caregivers may take this opportunity to discuss their own mental health needs, and it is a great opportunity for clinicians to help connect them with services if indicated.

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### Conclusion

Rates of self-harm and STB are increasing in youth, and PCPs are often the first professional point of contact around these issues. Clinicians face multiple challenges with these patients: treating physical injuries, talking to patients about suicide/NSSI, addressing the concerns of the families, determining risk level, and developing a treatment plan. Throughout their interactions with you, PCPs must maintain a calm and compassionate demeanor while evaluating risk and next steps. All evaluations must consider risk and protective factors, underlying causes, and the risk for future incidents. Once the level of risk has been determined, PCPs may contract with the patient for safety and/or refer the patient to mental health treatment for a more comprehensive assessment.

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# Pediatric Mental Health Assessment in the Primary Care Setting

# 5

Nicole Cotton and Arden Dingle

*Susan, a 14-year-old girl who you have been following since infancy, comes in for a follow-up visit to check the status of a borderline low hematocrit. She continues to complain of fatigue and lethargy. Her stepmother reports that she appears down and has been more sensitive and that it has become a major hassle to get Susan to do her chores. Upon further questioning, it becomes apparent that in addition to doing poorly in school, Susan has not been taking her recommended vitamins and that her stepmother did not take her for her repeat complete blood count (CBC) because it “was just too difficult.” Susan’s stepmother states that she does not know what to do and that it is impossible to get Susan to do anything including taking her vitamins due to lack of motivation.*

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## Assessment

Being able to effectively evaluate, provide some treatment, and triage children, adolescents, and families who suffer from psychiatric conditions is essential for practicing pediatricians, especially in primary care settings. This type of assessment is best done as a multidimensional process, which involves obtaining and synthesizing information from multiple individuals, identifying types and severity of symptoms, and evaluating several aspects of individual and family level of functioning. The usual goals are to acquire enough information to develop a sense of the youth, the circumstances, and the psychiatric symptoms so that an appropriate diagnosis and

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N. Cotton (✉)

Department of Psychiatry and Behavioral Sciences, Morehouse School of Medicine,  
Atlanta, GA, USA

e-mail: [ncotton@msm.edu](mailto:ncotton@msm.edu)

A. Dingle

UT Rio Grande Valley School of Medicine, Harlingen, TX, USA

e-mail: [arden.dingle@utrgv.edu](mailto:arden.dingle@utrgv.edu)

intervention can be identified. PCPs also must determine whether the recognized difficulties are of a type and severity that can be managed in the primary care milieu or whether psychiatric consultation or referral is needed. Usually this procedure is complicated by the need to balance the goal of achieving a reasonable picture of a child and the environment and constraints of time, priorities, and resources. It is essential to have a framework that can structure the evaluation so the information necessary to make the short- and long-term decisions is obtained efficiently and effectively. Given the necessity to obtain a significant amount of information, generally from multiple individuals in different locations, utilizing an approach with data collected by various team members as well as utilizing forms that can be completed between office visits is optimal. This chapter discusses the process of assessing children, adolescents, and families, creating a case formulation and treatment plan, and incorporating mental health services into the primary care setting.

Given the degree of morbidity, associated cost, loss of productive years, and potential mortality associated with untreated mental illness in youth, there has been increasing attention placed on prevention and early intervention, especially in primary care settings [1]. These efforts have built upon the accumulating evidence supporting the importance of gene by environment interaction in the origin of medical and psychiatric disorders. This approach to understanding disease suggests that individuals have a baseline genetic risk and that the expression of disorders depends on exposure to certain environmental factors, including both protective factors and stressors. Universal prevention efforts are aimed at promoting mental wellness in children and families and minimizing environmental insults that may trigger the onset of illness. Prevention efforts aim to reduce modifiable risk factors and promote protective factors.

Universal prevention and early intervention initiatives are targeted at the environments in which children are often involved, such as the school system and the pediatric home. As children are typically assessed annually for a well-child check, this is an opportunity to include open dialogue about social and emotional health. Having a process in which all children and adolescents in the practice are screened for mental health and family difficulties helps identify issues early so that preventative and early interventions can be implemented. Collecting information about the youth's development and behavior as well as the family and school environment as a routine component of data collection, both initial and ongoing, allows practitioners to determine the baseline functioning of individual children, adolescents, and families as well as follow their progression over time.

Questionnaires and self-reports that can be completed by parents/caretakers, teachers, and older youth are an effective approach to collecting a range of information which can then be verified by a pediatric team member before the pediatrician sees the patient. This approach allows the time with the pediatrician to be targeted on confirming and enhancing the obtained information, determining the most likely diagnoses, and identifying how to proceed. Chapter 8 of this text explores measurement-based care and highlights select practical, public domain measures. Additionally, the websites of the American Academy of Pediatrics (<https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Mental-Health/Pages>) and the American

Academy of Child and Adolescent Psychiatry ([http://www.aacap.org/AACAP/Resources\\_for\\_Primary\\_Care](http://www.aacap.org/AACAP/Resources_for_Primary_Care)) have information on pediatric mental health assessment processes, data collection instruments, and rating scales. It is most effective to use general forms that collect a range of information and types of symptoms initially with more focused questionnaires during follow-up. While youth and their families may present with specific complaints, it is essential to remember that symptoms can have different etiologies i.e. just because inattention is a child's main difficulty does not necessarily mean that the child has an attentional disorder. And it is important to consider possible medical etiologies for the youth's symptoms [2–5].

Important considerations related to a psychiatric assessment, especially the initial one, include identifying the reason for the evaluation, who is seeking the assessment, who needs to be involved, what outcomes are being sought, what will the information be used for, potential confidentiality issues, and how much time is available/any potential deadlines. For example, evaluating a young child for developmental concerns involves significant differences compared to assessing an adolescent who is suspected of using substances. The evaluation is complicated by unique characteristics of children and adolescents as well as the need to include multiple individuals as informants. Consideration of the youth's developmental status is essential since it is constantly changing and impacts the presentation of psychiatric symptoms as well as the level of functioning. Important variables include age, cognitive functioning, emotional maturity, and social relationships.

Also, social and life experiences significantly can affect developmental and cognitive skills. Key environmental considerations include level of support, type and number of stresses, as well as the influence of cultural, ethnic, racial, and socioeconomic characteristics. Exposure to risk factors and extent of personal and family resilience are essential aspects of development. Assessment challenges include children and adolescents having less developed cognitive and language skills, being brought in by others rather than their own initiative, and having their behavior identified as the issue even when others' actions may be problematic as well as the youths. Additionally families may be ill prepared for the evaluation and treatment process and may have misconceptions and negative attributions about mental health. Many psychiatric disorders involve difficulties with communication, motivation, and initiative and tend to be more common in families who are struggling with health, mental health, and environmental adversities. The information collected during a psychiatric assessment should cover biological, psychological, and social aspects of the individual and problem and should identify potential barriers to treatment interventions.

The content of a psychiatric assessment is listed in Table 5.1; depending on the identified problem and the circumstances, various sections may be emphasized more than others, based on difficulties and developmental status. For example, a detailed school history is necessary in a youth with academic difficulties and may be less crucial in a child with a good school record but significant behavior problems at home. Information necessary for adolescents may not be relevant for younger children. Of note, much of the information overlaps with a standard

**Table 5.1** Psychiatric assessment content*Patient identification*

- Name, age, gender, school/employment status, living situation

*Chief complaint*

- Reason for visit, patient own words

*History of presenting illness*

- Story of illness, often helpful to obtain chronologically
- Includes relevant history, pertinent positives and negatives, related circumstances
- Symptoms: location/radiation, quality, quantity/severity, timing (onset/duration/frequency/progression), setting/context, factors relieve/aggravate, associated symptoms

*Review of systems*

- Systematic review of presence or absence of symptoms in all organ systems, head to toe

*Allergies*

- Any allergies to drugs and other substances

*Past history* (medical, surgical, obstetric/gynecologic, psychiatric)

- All previous disorders and treatment, including medications; adherence to treatment recommendations
- All preventative and well-person care
- All integrative and complementary medical care
- Puberty, menarche
- Pregnancies (for both boys and girls)

*Medications*

- Current medications and indications, dose, frequency, length of treatment; any adverse/side effects
- Includes over-the-counter (OTC), herbal, and homeopathic medications

*School/employment history*

- Level of educational attainment, any issues
- Current employment, relevant past employment
- Factors possibly related to health status (e.g., exposure to toxins, stress)

*Developmental history*

- Acquisition of milestones
- Current developmental abilities
- Temperament/personality/coping style
- Gender identification

*Family history* (medical/psychiatric)

- Immediate biological relatives, parents, siblings, children, grandparents, aunts/uncles, cousins, etc.
- Age of onset of any problems, individual affected, severity, type/response to treatment, alive or deceased
- Focus on inheritable disorders, problems with shared environmental factors

*Personal social* (peers, friends, family background, current circumstances, recreational activities, romantic relationships)

- Living situation/family constellation and functioning/parenting
- Recreational activities
- Relationships
- Sexual behavior and activity (e.g., birth control, type of sexual activity, who having sex with, etc.)
- Tobacco, alcohol, drug use, past and present

pediatric assessment. Additionally, other team members can assist in gathering much of the background information, which the primary care provider (PCP) can simply verify or clarify as needed, saving valuable time. An essential component of the evaluation is the mental status exam described in Table 5.2. Much of the data

**Table 5.2** Mental status examination

<i>Orientation</i>
• Knows identity, location, time, purpose of session
<i>Appearance/dress</i>
• If age and activity appropriate
<i>Level of consciousness</i>
• Alertness, awareness, responsiveness
<i>Attitude</i>
• Level of cooperation, interest in process
<i>Behavior</i>
• If age and activity appropriate
<i>Relatedness</i>
• Ability to engage with interviewer and others
<i>Motor activity/level of activity</i>
• If age and activity appropriate; level of impulsivity
<i>Speech and language</i>
• Fluency, tone, pattern, descriptive detail; ability to communicate effectively
<i>Mood</i>
• Patients' description of how they feel
<i>Affect</i>
• Examiner observation of how the patient appears to feel
<i>Thought content</i>
• What patient discusses during the interview; includes content related to suicide, homicide, aggression
<i>Thought process</i>
• Level of logical thinking, organization, coherence
<i>Cognitive abilities</i>
• Attention: ability to attend to stimuli during interview/impacts memory performance
• Memory:
– Immediate: recall of events/items during interview
– Recent: recall of events during last week or so
– Remote: recall of events over years
• Problem-solving: calculations, reading, writing
<i>Fund of knowledge</i>
• Vocabulary/facts: general and/or related to patient's life
• Cognitive functioning: acquisition of concrete or abstract thinking
<i>Insight</i>
• Patient understanding of difficulties/situations
<i>Judgment</i>
• Patient ability to make reasonable decisions about factors and situations that impact functioning/life

related to this examination is obtained by observation and descriptions by the practitioner with the aim of identifying if there are areas in which the youth is not at the expected age-appropriate developmental level [6–9].

A significant amount of information can be obtained from questionnaires, rating scales, and other types of reports. However, interviewing the youth and caretakers is essential to the assessment process. Unless young or severely impaired, children and adolescents should be seen alone for at least part of the assessment to help with engagement and to discuss potentially sensitive information. It also can be very helpful to meet with parents without the youth in some situations. Of note, in situations where there is collaborative or integrated care and the team includes a mental health clinician who is eligible to bill for diagnostic psychiatric evaluation codes (90791 or 90792), these codes can be completed more than once for the same patient when separate diagnostic evaluations are conducted with the patient and other informants, such as guardians; however the interviews would have to be conducted on two separate days (CPT Coding Manual). Addressing confidentiality early in the process to clarify what information can and will be shared is recommended to promote transparency and avoid future complications.

Interviewer behaviors that can facilitate the interview process include: balancing attention between the youth and family, being flexible and allowing the youth and family to help determine the agenda and structure, adjusting the agenda and plan as necessary, positively responding to feedback, taking the necessary time to engage the participants and make them comfortable, being aware of and carefully managing sensitive topics, and emphasizing open-ended questioning. It is essential that interviewers be aware of and effectively manage their own beliefs, biases, and reactions. Prioritizing such details as having a physically comfortable and private interview space; preparing adequately; having clear, but adaptable assessment structure and goals; and effectively managing potential interfering factors such as other demands on the physician or unrealistic expectations of the evaluation can greatly improve the evaluation process. It is crucial to schedule enough time to conduct an adequate assessment which includes thoroughly evaluating all of the information obtained, conveying the physician's impressions and recommendations, and discussing possible concerns and questions. Possible challenges that can complicate an assessment include patient/caretaker refusal or inability to participate, difficulties obtaining information from patient or relevant others, contradictory information/perspectives from youth and caretakers, total focus on youth as the problem, or unwillingness to consider proposed diagnoses/treatments.

Once adequate information has been collected and analyzed, making a diagnosis is one of the initial steps. In the United States, the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5, <https://www.psychiatry.org/psychiatrists/practice/dsm>) developed by the American Psychiatric Association (APA) is the system used to diagnose psychiatric conditions. It is harmonized with the International Classification of Diseases (ICD) used by most of the rest of the world. It is a categorical approach with an emphasis on considering the dimensional, developmental, and lifespan aspects of illness; disorders are grouped based on similarities across a set of indicators which include biological, environmental, symptom, and other

factors. Conditions are in the general categories of neurodevelopment (e.g., autism spectrum disorder), internalizing (e.g., depression or anxiety disorders), externalizing (e.g., oppositional defiant disorder), neurocognitive (e.g., delirium), and others. Individuals of any age can be diagnosed with any illness as long as they meet the symptom and duration criteria.

Psychiatric disorder severity can be identified in addition to subtypes, specifiers, and remission status. All disorders require distress and/or impairment. Most illnesses have versions caused by medical conditions or substances. The DSM is a non-axial system with the relevant disorders, both psychiatric and medical, listed in order of importance; psychosocial and contextual factors as well as level of disability can be indicated with separate notations. No specific assessment tool is required to determine disability. Recent DSM revisions have improved the applicability of diagnostic criteria across the lifespan; however, it can be challenging to fit the symptoms of specific youth neatly into a diagnostic category, especially those disorders that were initially described in adults.

Developing a formulation to integrate and summarize the data to guide and inform treatment planning is crucial. While making a psychiatric diagnosis based on DSM criteria is necessary, a DSM diagnosis generally is not sufficient. A case formulation is a synthesis of the information obtained and clinician's observations, with goals of understanding the patient and situation (internal and external factors) and explaining patient's symptoms. The DSM diagnosis system is insufficient because it does not take the context of patient, family, or environment into account. In other words, it is not a "story" of the child or adolescent. The diagnosis alone does not describe the intricacies and uniqueness of each patient's situation. A more nuanced approach considering such factors is necessary to develop an understanding about where the youth's symptoms began and what can help the youth get better.

The DSM criteria tend to have an overemphasis on individual psychopathology, minimizing the influential role of psychological or social factors. The purpose of case formulation is to provide an integrated picture and a focus for treatment planning. Rather than simply state a diagnosis of mental illness, it includes information that is distinctive and descriptive, permitting the development of hypotheses about underlying causes, precipitants, and maintaining factors as well as potential strengths and ameliorating factors. Additionally, case formulation describes an integrated understanding of a particular issue at a specific point in time. A formulation is not a "complete explanation" of a person and may change depending on the acquisition of new information or changes in events or circumstances.

There are a variety of approaches to formulating clinical cases. One commonly used in medicine is the biopsychosocial model, which describes the patient's difficulties, level of functioning, abilities, and circumstances in biological, psychological, and social terms. Biological factors are those related to the characteristics of living organisms. Psychological factors refer to processes that are internal to the individual's mind, while social attributes are those related to the environment. Take the example of a young child who has been abused. The abuse is the social component. The biological component is the changes to the child's brain and



**Table 5.3** Biopsychosocial model

Biological
• Family/genetic history
• Temperament
• Development (height, weight, physical abilities, age, stage of maturity)
• Intelligence
• Medical conditions
Psychological (child and family)
• Emotional development
• Personality styles
• Coping strategies
• Child's sense of self-esteem
Social
• Peers
• Family relationships
• School
• Extracurricular activities
• Community
• Race, ethnicity, culture
• Economic status
• Spirituality

neuroendocrine system, and the psychological component is the child's thoughts and feelings about why the abuse occurred. It is important to include areas of resilience in addition to information on risk factors. The main components of the biopsychosocial model for case formulation are listed in Table 5.3.

Formulations include protective or ameliorating factors (strengths) that contribute to resilience, qualities that are different and distinctive about this child and family, underlying causes or precipitants of the problem, and factors responsible for condition maintenance. It is a synthesis of information with an indication of its relative importance and connections, a coherent, comprehensive, and succinct summary, which includes an explanation of the presenting problem or symptom. A common structure consists of introductory and concluding statements with the body consisting of the three general categories of biological, psychological, and social factors. Employing a brief model in which the formulation is a short paragraph promotes usability. An example of a biopsychosocial formulation for the case described at the beginning of the chapter is given in Table 5.4.

The case formulation then can be used to inform and guide treatment planning. It helps prioritize the problems and issues and provides information on individual, family and environmental strengths, protective factors, and any other characteristics that would promote resilience. Determining and implementing the desired interventions is based upon a number of factors. These include the problems needing to be addressed and the desired changes. An additional very practical factor is what therapies are available and most appropriate for the targeted difficulties, youth and family. Treatment plans are based on a comprehensive understanding of the child's and family's problems and strengths. Collaborating with youth and families in the

**Table 5.4** Biopsychosocial formulation example

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Susan is a 14-year-old female with significant symptoms for several months of sadness, fatigue, poor concentration, low self-esteem, declining academic performance, increased appetite, and decreased social interaction consistent with major depressive disorder.

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*Biological*

Relevant biological factors include a family history with several immediate family members having identified depressive and anxiety disorders. Susan recently started her menses and possibly has iron deficiency.

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*Psychological*

Contributing psychological issues include the recent appearance of her stepmother and subsequent disappearance of her biological mother. Feelings of abandonment and loss were significant for Susan, and she appears to be struggling with perceived rejection despite having a good relationship with her father and stepmother. Susan has several strengths including a positive sense of self and feelings of self-worth. She has adopted some positive coping strategies including using dance and writing to help cope with her symptoms.

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*Social*

Her father and stepmother have a history of loud verbal arguments with one another, primarily around financial and childrearing issues, but they have recently been in less conflict due to their concern for Susan. Susan has two close friends who have maintained frequent contact despite Susan's current refusal to see them.

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process of plan development is a necessary step in patient-centered care. Additionally, all possible relevant resources and coordination and communication among providers should be used.

Treatment targets should include short- and long-term goals or interventions for the child, caretakers, and environment. Treatment should have a staged series of interventions that target specific difficulties with specific goals and objectives in a manner that allows periodic reassessments and adjustments. Treatment aims should focus on outcomes that are realistic and attainable by translating disorders or problems into specific thoughts, feelings, or actions, which can be targeted by particular interventions. Overall, interventions generally are designed to support an individual and family achieve a typical developmental trajectory (“normal functioning”) or to help youth obtain the highest level of functioning possible given the youth's condition. Treatment plans should be designed so that they can be periodically reviewed and modified, allowing the monitoring of progress and possible adaptations as the child develops [10].

Currently, there is a spectrum of interventions, biological, psychological, and environmental, that can be employed to help children and adolescents with psychiatric illnesses. While medications are important and effective treatment agents, many children and adolescents who have psychiatric difficulties can be effectively treated with psychotherapeutic and psychosocial interventions. A key decision for pediatricians during the assessment process is the determination of whether the youth and family should be referred for therapy elsewhere or if the issues are treatable within the pediatric practice.

Factors to consider include risk of harm to self or others, the child's functional status, level of family functioning, the presence of psychiatric and/or medical

comorbidities, protective factors, and the capacity of the office to manage the presenting symptoms. Milder and earlier stages of illness tend to be more manageable in an outpatient primary care practice. While there are exceptions, in general, cases in which the families need significant interventions are probably best referred, as are cases in which the child is severely ill, treatment requires multiple interventions involving a variety of individuals and institutions and/or the psychotherapeutic treatments require significant time and expertise. Imminent risk of harm to self or others warrants immediate psychiatric evaluation. The chapters in Part II of this text provide additional diagnosis-specific guidance on when to refer.

In Susan's case, the level of depression is in the moderate range. She is having a decline in both academic and social functioning. There are significant family factors perpetuating her depressive symptoms. There is no presence of self-harm or suicidal ideation. Though there is family discord, she had a good relationship with her guardians, and they are involved in her treatment. It is reasonable to consider psychotherapy without medication. However, family therapy may play an important role in her treatment. For this reason, the provider may consider collaborative care with or direct referral to a mental health provider.

There are some basic psychotherapeutic interventions that can be implemented in the primary care setting. Elements of supportive therapy can readily be incorporated into the pediatric home. One of the principal elements is the relationship with the clinician. The clinician's approach should be encouraging and nonjudgmental, and the clinician can use reflective listening skills to build rapport and allow patients to hear their own thoughts and identify their feelings. Reflective listening involves identifying the basic message being conveyed and paying attention to verbal and nonverbal expression of the child's feelings. The listener may repeat or paraphrase key elements of the underlying emotion back to the speaker without introducing additional meaning to those emotions [11]. The clinician should identify strengths in the child and family and foster these strengths. It is helpful to be familiar with the basic concepts of behavioral management including the concepts of positive reinforcement of desired behaviors and establishing age-appropriate consequences for negative behaviors.

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## **Considerations for Integrating Mental Health into the Pediatric Setting**

Training to enhance the mental health skills of the clinician is helpful when considering integrating mental health treatment in the primary care setting. This may take several forms. Ongoing peer consultation has been used successfully in several programs across the country. This has led to increased use of rating scales, more systematic monitoring of response, and improved patient outcomes [12, 13]. The pediatric provider can attend presentations and workshops, review online material, and utilize the medical and psychological literature review both to sharpen current skills and to learn new ones.

**Table 5.5** Types of mental health providers

Licensed clinical social worker (LSCW)	Completed a masters or higher degree in social work. Has completed a minimum number of supervised postgraduate clinical supervision (varies by state). Trained to diagnose mental health disorders and to provide individual, group, and family counseling. Trained in case management and helping people obtain tangible services
Licensed professional counselor (LPC)	Completed a master's or higher degree in psychology or related field. Completed a minimum number of supervised postgraduate clinical supervision (varies by state). Trained to diagnose mental health disorders and to provide individual, group, and family counseling
Licensed family and marital therapist (LMFT)	Completed a master's degree or higher degree in psychology or related field. Completed additional training in marital and family therapy
Advanced practice registered nurse (APRN) in mental health	Certified nurse specialist (CNS) or nurse practitioner (NP). Completed a degree in nursing and a master's or doctorate degree in psychiatric mental health nursing. Able to assess diagnosis and treat mental health disorders. In some states can prescribe medication either independently or under supervision of a physician
Child and adolescent psychologist	A doctorate-level psychologist who completed a PhD, PsyD, or ED in psychology. Trained to diagnose and treat a variety of mental health disorders. Trained to administer and interpret a variety of tests to aid in diagnosis and treatment planning. Trained in counseling and psychotherapy
Child and adolescent psychiatrist (CAP)	Completed a medical doctorate (MD). Completed a 5–6-year residency program in general, child, and adolescent psychiatry. Trained to diagnose and treat a variety of mental health disorders. Trained in psychotherapy and in the use of medication in the treatment of mental disorders

There are several types of mental health providers with whom the PCP may interface. These providers have a variety of levels of education and formal training. The differences between various providers are outlined in Table 5.5. It is helpful for the pediatric provider to become familiar with local mental health providers who can serve as consultants and collaborators that may assist with referral sources. The pediatric clinician may consider having a care coordinator, particularly one with additional training in behavioral health, to assist the provider in performing mental health assessments, gathering supporting history, and helping the provider and family execute the treatment plan. The care coordinator can help to administer rating scales, obtain collateral history, and coordinate follow-up care. The coordinator may be a pediatric technician, a pediatric nurse, or a master's level pediatric mental health provider.

### Primary Care Only

In this model, the primary care provider (PCP) directly provides mental health services. The PCP prescribes medications and administers brief psychological and/or behavioral interventions. The PCP assumes the role of monitoring progress of treatments using patient/parent interviews and validated rating scales. The PCP may

utilize the care coordinator to assist in obtaining history, completing rating scales, providing brief interventions, and helping the family to navigate the treatment plan. This model is applicable to children with uncomplicated mental health problems, minimal or no comorbid psychiatric illnesses, and mild to moderate impairment in functioning, such as a child with uncomplicated attention deficit hyperactivity disorder (ADHD) who may need medication and behavioral interventions.

### **Consultation with a Mental Health Provider**

In the consultation model, the mental health specialist provides brief, focused clinical recommendations to the PCP. This can include information about diagnosis, treatment needs, treatment approach, and availability of resources. These consultations may vary in terms of their frequency (as needed, regularly scheduled) and format (phone, video conferencing, in person). The consultation is most fruitful when the primary care clinician has completed an initial assessment and has outlined a specific question for the consultant. Several regional and statewide consultation models have emerged across the country in recent years. These programs offer a variety of services including a “warm line,” where the pediatric clinician can call a child mental health specialist for consultation on a specific case, webinar trainings, webinar case presentations, and assistance with locating mental health resources [12, 13]. In this model, the pediatrician may also use a staff member to serve as a care coordinator. This approach may be best suited for children and families with more complicated behavioral health needs, higher levels of functional impairment, and physical and mental health comorbidities.

### **Collaboration with a Mental Health Provider**

In the collaborative model, the primary care provider works together with a mental health specialist or multidisciplinary team. This may be accomplished between sites (primary care and mental health) or with an on-site mental health specialist. This specialist may be a child and adolescent psychiatrist, a child psychologist, or a master’s level mental health professional trained to work with children. Ownership of the treatment is shared to varying degrees between pediatrics and mental health. For example, the PCP may provide initial assessment and treatment planning and decide that medication and therapy would be appropriate interventions. The PCP may initiate medications and have the specialist provide psychotherapy. Or, for example, in the case of a child with diabetes mellitus with associated depression, the PCP may treat the medical illness while the mental health provider manages the comorbid depression. Both providers would work together to track progress in the management of depressive symptoms and would communicate regularly about the patient’s care.

Having a behavioral health consultant in the primary care home allows for the patient to be treated in an environment where he/she already feels comfortable

receiving care. This helps to reduce the stigma associated with mental health treatment, allows for more rapid access to mental health services, and helps to facilitate future referrals outside of the clinic if needed. When the PCP and behavioral health specialist collaborate and track outcomes, there has been demonstrated improvement in both physical and mental health outcomes [14, 15].

## Direct Referral

In this model, the PCP refers the child to specialty care, and the mental health provider assumes responsibility for behavioral health care. This model is appropriate for children with the most severe needs, whether due to severity of symptoms, degree of functional impairment, family issues, degree of comorbidity, or other factors.

## Summary

Various combinations of these practices may be appropriate for different PCPs. It may be helpful for the pediatric office to develop an algorithm to determine which patients may be treated more effectively in the medical home and which may need consultation as opposed to referral directly to mental health services. Barriers to integrated care include time constraints and lack of adequate reimbursement systems. While ICD-10 has added new codes for reimbursement for mental health in the primary care setting, further advocacy in this area is warranted.

Though challenging, performing quality psychiatric assessments in outpatient pediatric settings is possible and, given the number of children and adolescents affected and the shortage of child mental health providers, necessary. The likelihood of having success increases with having a team approach, a range of information gathering techniques, a clear evaluation structure, and a sense of what problems are manageable in the office setting. There are several ways to integrate mental health treatment into the primary care setting. The strategies implemented will vary by practice setting.

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# Interfacing with the Mental Health-Care System

# 6

Phillip Murray

## Introduction

Current estimates show that as many as one in five children has a mental or behavioral health disorders, but only an estimated half are fortunate enough to obtain treatment [1]. Half of all mental illnesses start exhibiting symptoms by age 14, making it imperative they are identified and treated as early as possible [2]. Left untreated these conditions can lead to several morbidities such as social impairments, poor academic achievements, and limited employment prospects. In more severe cases they can lead to suicide, which is currently the third leading cause of death for children ages 5–14 [3] and second leading cause for teenagers ages 15–18 [4]. Identifying, diagnosing, and treating mental illnesses are something that are easier said than done. There can be years between when symptoms first start and people are diagnosed and connected with treatment. For some people with symptoms beginning in childhood, it is possible they will not see a provider until adulthood [2]. Youth express symptoms in complex ways that are in contrast to their regular development. Child and adolescent behaviors adapt to the many environments they live in. This inconsistency can make it difficult to distinguish between normal and abnormal behaviors and establish a coherent narrative. This lack of recognition can make it difficult for the responsible adults to seek care and delay connecting with treatment.

The current mental health system is a fragmented collection of entities dedicated to child and adolescent wellness. It has come to being from incremental changes as a result of an increase in clinical knowledge, social awareness, and political will. It is rare that all three of these align perfectly, so the current system reflects progress being made when it is possible. Federal policies and legal precedents help to protect families and guide the delicate balancing act between autonomy and paternalism.

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P. Murray  
Behavioral Health, Atrium Health, Charlotte, NC, USA  
e-mail: [phillip.murray@atriumhealth.org](mailto:phillip.murray@atriumhealth.org)



Legislation and legal decisions have established standards for multiple precedents such as rights of people undergoing involuntary commitment [5], notifying people in cases of dangerousness [6], and treatment in the least restrictive environment [7] which are now included in clinical decision-making. In the current system, voices of children and families ring louder than before.

Today's system is promising compared to past standards, but it is constantly evolving to meet the complex challenges children and families can face in the context of fragmentation and limited resources. The nation is facing a severe shortage of child and adolescent mental health specialists with need continuing to outpace the available workforce [8]. Most states are considered Health Professional Shortage Areas due to not having enough providers to service their current level of need. Estimates show we have approximately one fourth of the providers necessary to handle the system's current needs. This information is further skewed because it does not reflect the distribution of providers who are mostly located in urban areas, or near academic centers, making for a much worse shortage in rural communities.

Funds for behavioral health interventions have consistently been cut or remained stagnant despite growing need in many states, and children have remained a minor political priority. The medical system continues to have issues funding mental health services as there is difficulty implementing parity laws. There are further potential limitations from challenges to the Affordable Care Act such as not expanding Medicaid or attempts at weakening the law. Many times families are left to navigate a challenging system. This can result in families, even well-intended ones, having difficulty following through on referrals or obtaining recommended mental health services for their symptomatic children. This reality highlights the necessity of primary care providers' (PCPs) active involvement in the referral and care collaboration process.

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## **The PCP's Role in Children's Mental Health**

Primary care clinicians are asked to do more with their limited time. Estimates are outpatient pediatricians have just over 16 min to provide care for the total child [9]. During that time pediatricians have to attend to developmental tasks, parent inquiry, and any acute changes. Both pediatricians and child and adolescent psychiatrists agree primary care clinicians should identify and refer most mental health conditions [10, 11]. Pediatricians admitted more comfort with treating ADHD, which has detailed guidelines from the American Academy of Pediatrics [12], but do not exhibit the same confidence when treating other conditions such as anxiety and depression [13, 14]. They identified barriers of lack of training in identifying child mental health problems, long waiting periods for referrals, and difficulties with reimbursement [10, 11]. Still, primary care clinicians see the highest number of children for mental health conditions, proving they are on the front lines for treatment or referral. Rates of office-based visits for mental health conditions in children and adolescents have nearly doubled compared to a modest increase in adults, mostly in the primary care setting. Primary care visits for these conditions were

more likely to result in medications being prescribed, which could be a reflection of limited access or awareness of non-medication interventions [14].

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## Integrated Care Approaches

There has been a movement for over a decade to break down the separation of mental and physical health through care collaboration and integration, leading to innovation and transformation for providers [15]. Broad principles for change are keeping care family centered, minimizing barriers to appropriate services, and doing so in a financially responsible way. This will vary for each provider and individual system, but integration can take on a variety of forms such as care coordination, co-location, collaborative care, or fully integrated care. Traditionally primary care providers and mental health providers, like most other disciplines, operate in silos. Youth and families are not immune to the stigma associated with mental health care and can feel more comfortable being seen in primary care. Primary care clinicians' efforts toward inclusion, which can be reflected at varying levels of care integration, help to normalize mental health care and make it more accessible. One way that this can be accomplished is mental health screenings with wellness exams, so it is clear mental health is acknowledged as a part of holistic health. Each system and provider will need to assess what works best for them in these situations.

Of note, there are CPT codes that will have varying degrees of applicability at each level of integrated care. Please refer to this text's [Appendix A](#). Also, the American Academy of Pediatrics (AAP) projects that the 2019 version of its Coding for Pediatrics manual will have a dedicated section on billing for integrated care.

## Coordinated Care

In coordinated care, though mental health care and primary care are delivered through different systems and in different physical locations, a concerted effort is made to facilitate communication between the two. It is imperative to have knowledge of available local mental health resources for youth and families readily available when a mental health issue is identified. In this model, not only gaining familiarity with the mental health system but also developing relationships with local mental health providers is of benefit.

By providing vetted, specific resources and completing referrals, your office can assist families in navigating the disjointed system. In doing so, one potential barrier, the family's lack of familiarity with the system, is being actively addressed. This approach will take an initial investment. This could include preparing and periodically updating a list of local mental health resources such as mental health specialists, school resources, and parent/consumer organizations dedicated to mental health issues. Ultimately, "You should get your child therapy for their anxiety" is less likely to result in mental health treatment engagement than "We've made a referral to Dr. Smith's office and they will be calling you about an intake appointment."

### Tips for Coordinated Care

1. Create a culture where this is seen as part of the child's whole health, and identify who on staff will take the lead in coordinating care.
2. Prepare a list of local mental health resources by treatment type and insurances accepted, periodically confirming that the information remains up-to-date.
3. Communicate with local mental health providers regarding their referral process.
4. Make sure that your office has a readily accessible mental health referral form that includes, at a minimum, the referral question, the best way for the provider to communicate with your office, and the youth's identifying information, medical conditions, and current medications.
5. Have a central location for your mental health referral forms as well as the referral forms for the most frequently used local mental health service providers when applicable.
6. Give families specific information re: mental health resources.
7. Send completed referral forms to mental health-care providers. Also, when possible and the family consents, include a release of information with the referral form to facilitate communication between providers.
8. Consider also providing a copy of the child's most recent history and physical if the family consents.
9. Schedule follow-up with the family and inquire about their engagement and treatment progression with the recommended mental health service.
10. Receive updates of treatment plans from mental health-care providers. It is common for children to change service back to primary care for their psychiatric medication treatment as they stabilize.

### Collaborative Care

Collaborative care models are characterized by a joint effort of primary care providers, a care manager, and a mental health specialist in providing mental health care and follow-up. In this model as compared to coordinated care, the primary care clinician takes a more active role in providing mental health care but does so with "backup" from a mental health specialist. Working with the mental health specialist can take the form of multiple innovations including educating primary care clinicians directly and/or some combination of electronic, phone, and/or face-to-face consultations [16–18]. The majority of primary care clinicians and families that have participated in such models are satisfied with the experience, and report increased confidence in managing some mental health conditions [16–19]. Dissatisfaction came from wait times for appointments outside of primary care or limitations in incorporating mental health recommendations [16–19]. This model will allow some patients to be managed in the primary care setting; however, some will still require services in a specialty mental health-care location. In these cases, a coordinated care approach is helpful. Once the patient's mental health symptoms are stable, care may be transferred back to the primary care provider.

## Co-location

Co-location involves mental health-care professionals, be they counselors, social workers, psychologists, nurse practitioners, or psychiatrists, being physically in the same location as primary care providers. This approach facilitates increased collaboration between providers and increases the success rate of specialty services engagement following a referral. It is often more convenient for families and can also circumvent the stigma of going to a mental health clinic. Additionally, the explicit and implied endorsement by the trusted primary care provider of a mental health provider can hold a great deal of meaning for families apprehensive about engaging in mental health care. In this model, though physically in the same location, the mental health-care provider is not fully integrated into the primary care treatment system. Depending on the arrangement, he/she may have a different scheduling process and/or medical record. Often during clinic hours, all providers are busy providing patient care. Co-location in and of itself is not a guarantee that informational exchanges will occur. In order to maximize the benefit of co-location, having some predetermined way of communicating regularly across specialties is helpful as are negotiated times for the mental health professional to accept walk-ins or warm handoffs.

## Fully Integrated Care

In fully integrated care, the mental health and medical health silos are eliminated and there is one cohesive system. The medical home model is consistent with fully integrated care, which revolves around the idea of a fully integrated mental and physical health-care experience [15, 20]. Providers share not only the same physical location but also a medical record. The intake and treatment processes, staffing, and clinic workflow are optimized to simultaneously address the patient's behavioral and medical care needs.

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## Family Education Re: Engagement with the Mental Health-Care System

For families, mental health referrals can feel like a daunting process. Most families have not had exposure to the mental health system, and misinformation abounds. “Mental health treatment” has many negative connotations, which can lead to families having concerns about losing custody, exposing their child to extreme side effects from psychiatric medications, involuntary hospitalization, or having their child subjected to extreme interventions such as electroconvulsive therapy. It is important to provide clear reasons for the referral. One way to help parents feel less anxious is to educate them on what to expect when entering the mental health system. It is also of benefit to set appropriate expectations about the treatment process. Problematic behaviors would have been developed over time, and there are rarely quick fixes.

When referring to outpatient mental health services, you can prepare families for the appointment by letting them know what to expect. Psychiatry intake appointments can take much longer than intake visits for primary care and may be split into multiple sessions. Behavioral issues are rarely straightforward and can manifest different ways in each environment. To get the best picture of what is going on, assessments look at each aspect of the child's life. Some of this can be streamlined if families come with information that may have been compiled from primary care clinicians including information on school performance, educational plans, prior testing or interventions, and a thorough medical history with any prior laboratory studies. This serves the dual purpose of informing the clinician about any medical issues contributing to the problematic behavior and/or any ongoing issues that could influence the selection of psychiatric medications for treatment.

During mental health evaluations, permission to communicate with outside sources including teachers, additional family members, or other participants in the patient's care is commonly requested. As always, parents have the final decision in what information is shared. While this can seem intrusive, it is essential information to help understand the presenting problem and determine the appropriate diagnosis and treatment plan.

Interviews usually start with families together, and then separate at some point to gather more information. Younger children are often engaged in more demonstrative activities in addition to interviews as they are usually not as sophisticated in verbally articulating distress. With older children and teenagers, mental health-care providers don't spend as much time engaging with the patient through play but talk with them to learn more about their lives. They are often more comfortable talking about personal topics away from their parents.

Appointments may conclude with a wide range of treatment recommendations. Many families are surprised that an evaluation doesn't automatically result in weekly treatment or psychiatric medications. The truth is that is not appropriate for all cases. The goal is to address the youth's symptoms and support the family in the best way possible, which is likely to involve interventions outside of the mental health-care system, whether specialty care on an ongoing basis is warranted or not. These interventions can include behavioral, social, or educational interventions at school, coordination with the PCP, shoring up community supports or providing treatment for parents, or simple guidance and psycho-education.

Clinical decisions are guided by a family-centered approach that provides treatment in the least restrictive environment. It is important to emphasize there are clinical and legal protections that retain a family's rights to refuse treatment. Families may also be relieved to know that information in mental health treatment sessions is still protected through Health Insurance Portability and Accountability Act (HIPAA) just like any other medical encounter [21]. In the cases of teenagers, information that can be kept from parents is decided by each state's legal statutes. Assure families that treatment is confidential with a few exceptions regarding harm or if records are requested from a legal entity.

Many people are dismayed to see how long it can take to get an appointment. Times to first appointment can vary based on many factors including insurance status, location, and provider availability. Wait times for first appointments with child

and adolescent psychiatrists are usually 1 month longer than wait times to see a pediatrician within a 300-mile radius [22]. This issue is likely compounded in more focused populations such as youth with autism spectrum and substance use disorders. During this waiting period, symptoms can continue to worsen, and it is important that families are monitored in the interim and have information regarding emergency evaluations.

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## Involuntary Commitment

Every primary care office should have an identified procedure for initiating involuntary commitment when necessary. Though it is likely that it will be rarely needed, having a procedure in place ahead of time can lessen the stress associated with an inherently challenging situation. A commitment is a legal document, which is usually carried out by partnerships through law enforcement and medicine. The rules for involuntary commitment vary by state and are covered by legal statute, which usually dictates reasons for commitment, and who can initiate it. The use of involuntary commitments is guided by concerns about immediate harm to the patient or others, or cases where someone is having significant impairment from a mental condition. Since youth often will not have medical decision-making authority, parents and/or social service workers functioning as the guardians of the youth play an important role. Typically, when guardians consent for the youth to receive an emergency mental health evaluation, involuntary commitment paperwork is not necessary even in the absence of assent from the youth.

Most commitment paper work gets families to an emergency mental health evaluation. To be clear, this does not invariably result in a required inpatient psychiatric stay. The point is to conduct an assessment for potential intervention and the appropriate level of care. If it is determined that inpatient care is necessary, there is usually information at the facility outlining legal rights within that context. If families have further questions, facilities may also have designated patient advocates or legal counsel to provide that assistance.

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## Emergency Mental Health-Care Evaluations

If psychiatric symptoms become so severe that there is a concern about imminent risk to the youth or others and/or an inability to function, emergency evaluation may be warranted. Options can include emergency rooms, mobile crisis teams, or specialized mental health emergency services. Sometimes private hospitals will have their own assessment units that allow youth and families to bypass the general emergency room, cutting down on wait time. These options will vary based on local resources. Primary care clinicians can send families to these services, or if there is sufficient concern, they can pursue involuntary commitment.

Emergency evaluations are the most direct way into services but primarily focus on safety and stabilization. Many emergency assessments can result in the child

being discharged home. Families can wait for hours only to be sent home without an intervention they are satisfied in receiving. Medications are rarely started during these visits because people do not have follow-up. Psychiatric medications can have many side effects that require ongoing monitoring, especially when someone is just starting them. Emergency providers attempt to refer to resources that can provide long-term care; however, many times, with the exception of acute inpatient units, there can still be long waits for follow-up appointments.

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## **Inpatient Mental Health Treatment**

The goal of the inpatient stay is to stabilize an acute issue and develop a long-term plan for improvement as quickly as possible. Inpatient psychiatric treatment is provided in a locked facility with around-the-clock monitoring. While inpatient, patients will meet with members of a multidisciplinary treatment team and have varying levels of group and individual therapy. In some cases there can be recommendations for medications. The number of inpatient treatment beds has significantly decreased, and they are reserved for youth who absolutely need it. Providers understand that such intensive interventions can be disruptive to a child's routine and expensive for families depending on their insurance or financial means. Parents are not allowed to stay overnight but are allowed to visit the facility during designated visiting hours and will need to be available to participate in treatment meetings. Parents have to provide consent for every aspect of the child's care, including medication. A child's commitment or inpatient hospitalization does not take away parents' rights to decide the medications that their child is given on an ongoing basis; however, in cases of extreme agitation or aggression, emergency medication may be given.

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## **Intermediate Levels of Care**

There are care models that are more intensive than outpatient mental health treatment and less intensive than inpatient care. Examples include wrap-around services, intensive outpatient programs (IOPs), and partial hospitalization programs (PHPs). In all of these interventions, children are seen more frequently than is common for traditional outpatient care. In wrap-around models, providers meet the children and families where they are in the community, and therapeutic contacts are made multiple times per week. When available, these are good options for highly symptomatic children in stressed family systems.

Intensive outpatient and partial hospitalization programs are a step up from wrap-around services and provide assessment and individual and group therapy with continuous monitoring for a portion of the day. The differentiation between IOP and PHP typically hinges on how many days per week and/or hours per day the child attends. These programs usually occur during school hours and take place at psychiatric or mental health treatment facilities. Family members have to be



available for pickup, drop-off, and family sessions. In some states, Medicaid will not pay for these interventions, thus they are only available to privately insured youth.

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### Conclusion

In conclusion, mental health issues are ever present in the primary care environment. There are still workforce shortages showing most states are not adequately staffed to handle their current and increasing burdens of caring for mental and behavioral health disorders. Primary care clinicians are shouldering an increasing burden of treatment for behavioral health conditions, encouraging change at multiple levels. The characteristics of the primary care and mental health-care interface are changing. There are increased efforts to provide quality mental health interventions in primary care, coordinate care, help families navigate the mental health system, and increase service capacity through the use of various levels of care integration with multidisciplinary treatment teams [15, 17, 19]. Evidence-based practices are being developed to optimize the treatment process and improve outcomes. Professional organizations continue to develop resources to aid in decision-making at the point of care and to support practice changes for collaboration [23]. Primary care providers can facilitate families' engagement with mental health-care agencies through education about referrals and assistance with navigating. This requires up-to-date knowledge of the variety of local resources and entities designed to help families.

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# Interfacing with the School System

# 7

Deborah Kulick and Nancy Rappaport

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## Introduction

Schools are a vital system in the life of a child, since children spend the majority of their day learning and interacting with teachers and peers. Primary care providers (PCPs) increasingly recognize how critical school systems are in helping struggling children access necessary services in order to thrive. Building relationships with your patients' schools can enhance the rewards of caring for children with mental health challenges and provide lifesaving interventions that can have a lasting impact on a child's development.

While the PCP-school relationship would ideally be provided for all students, it is imperative for students with mental health difficulties. These students are at risk for adverse school outcomes. Following attendance, tardiness, and grades can help to pinpoint patterns of improving or deteriorating mental health symptoms and overall functioning. Regular monitoring of symptoms specific to the child's presenting mental health problem can guide treatment and interventions both at school and at home.

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D. Kulick (✉)

School Based Programs, Cambridge Health Alliance, Cambridge, MA, USA

Harvard Medical School, Cambridge, MA, USA

e-mail: [dkulick@challiance.org](mailto:dkulick@challiance.org)

N. Rappaport

Harvard Medical School, Cambridge, MA, USA

Cambridge Health Alliance, Cambridge, MA, USA

e-mail: [nancy@nancyrappaport.com](mailto:nancy@nancyrappaport.com)

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## Student Support Teams

Concerns about a child's mental health should prompt the PCP to inquire specifically about the current types of support the student has in place, types of school-based evaluations that have been conducted (special education testing, functional behavioral assessment (FBA), psychiatric consultation to the school), and the names/roles of each school professional involved. For elementary school children, it is best to begin by contacting the child's teacher. For middle and high school students, the guidance counselor is the best person to provide assistance in gathering pertinent information from the team of teachers. Each school should have a student support team (sometimes called a teacher assistance team) that meets regularly to review students whose learning, emotional, or behavioral functioning has become a concern. These multidisciplinary teams usually consist of a school guidance counselor, school psychologist, school social worker, principal, vice principal, and special educator(s). The teams engage in problem-solving to address concerns about learning, attendance, behavior, or social-emotional difficulties. They gather information through a variety of methods and then develop and monitor interventions.

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## What to Do When Communicating with Schools

When working with schools, it is helpful to have a framework for communication. Please keep in mind that there is often a role in school communication for clinicians or staff under the PCP's supervision, as often times the communication need not be done by the PCP directly. We encourage you to think about building the relationship by collaborating, followed by inquiring about the needs of the student, and then careful planning.

### Collaborate

1. Always inform parents and obtain permission to communicate with the school. Keep them informed about progress. Start communicating with the school early in the year to identify difficulties. Share results of the medical evaluation of the child with the school. Request copies of the educational records, including the results of formal testing and other evaluations.
2. Approach all school personnel as co-professionals with skills and interests that complement your expertise and can provide information that you don't have.
3. Reach out on a regular basis for updates and find out the best way to communicate with the school (i.e., phone call, emails, written forms). Set up mechanisms for follow-up on behavioral and educational progress of the child.

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## **Inquire**

1. Have clear objectives in mind when speaking with the teacher and team.
2. Request the teacher's perception of the child's learning and behavior.
3. Frame concerns around you rather than the child or teacher: such as "I am concerned that Alex is falling behind in math."
4. Ask the teacher/team for suggestions: "Do you have any suggestions about how we can address this?" Focus on some positives and ask "What do you see as this child's strengths?"
5. For questions about Individualized Education Program (IEP) implementation—"His IEP provides for x. How is this being implemented?"

## **Plan**

1. Make specific requests for assistance in writing, referencing the child's disability and your rationale.
2. Ensure appropriate mental health consultation services for more complicated psychiatric presentations.
3. Suggest in-service training programs to enhance awareness about childhood psychiatric disorders.
4. Assist parents/families in becoming good advocates with the schools. Know when a family may need to consult an educational advocate.
5. If you know a child very well or are the primary advocate during a critical time, ask to be informed throughout the planning stages.

## **Special Concerns**

1. For high-risk youth, set up follow-up for monitoring school attendance, performance, and suspensions.
2. For students who take medication at school, be in contact with the school nurse about adherence and side effects.

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## **Functional Behavioral Assessments**

Conducting a functional assessment of a student's behavior is often the first step in identifying why a problem behavior or symptom is occurring and what can be done to intervene. Some schools routinely conduct functional behavioral assessments (FBAs) for students with acting out or avoidant behavior. As a PCP, knowledge of this assessment and its role in schools is critical because it can provide valuable

information about problematic behavior. Sometimes the classroom teacher is tasked with conducting this assessment, and other times a school counselor or behavioral specialist is asked to observe the student and document the data. Usually the behavior that is most unsafe or of greatest concern is prioritized. The first step is to be as detailed as possible about what the behavior looks like. An ABC data sheet can be used to analyze a behavior more completely [1]. The “A” stands for antecedent or what happens immediately before the behavior. The “B” is a complete description of the behavior. The “C” is the consequence, or what happens immediately after the behavior, which can include teacher or peer responses. This data is then reviewed in order to look for patterns, such as acting out occurring at a certain time of day (i.e., recess), with a specific activity (i.e., after a request to write independently), or with the same people. This helps us understand the function of a behavior (to get attention, escape/avoidance, child is stuck and doesn’t have the skills to solve the situation any other way). With this information, the teacher and team can begin to explore why the behavior is occurring in that setting (time, place, people, circumstances). The school’s responses are informed by this (i.e., avoiding sending student to the principal or the nurse, as this reinforces escape behavior, but rather giving extra support with this task). Either appropriate accommodations or further evaluation can follow from the functional behavioral assessment.

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## Strategies for Identifying/Intervening

PCPs can be helpful by educating teachers about the way that common mental health problems present at school. Your recommendations to schools about specific accommodations for mental health conditions will be critical to the success of your patient.

### (1a) Clues for Identifying Student Anxiety at School

- Children are not likely to identify anxious feelings, which can make it difficult for educators to understand why a student is performing poorly. A student may come to the PCP with difficulty getting out of bed in the morning or somatic symptoms at school such as stomachaches and headaches. This can lead to refusal to go to school.
- Student can be inflexible, irrational, emotionally intense, over reactive, easily frustrated, or tearful.
- Student displays inconsistent behavior and school work; may have difficulty starting or completing work.
- Pattern of difficulty at certain times: unstructured times (recess, lunch), transitions, writing demands, social demands, and unexpected changes in routine
- Perfectionistic tendencies and is easily upset by mistakes

### (1b) Managing Student Anxiety

- The child should be encouraged to attend school daily. If school avoidant, he/she may need gradual transition back to school.

- Provide a preferred, designated spot in the classroom. The student may benefit from a nonverbal sign or pass to seek out an identified, preferred school adult.
- Schedule student check-ins with preferred school adult before the start of the day to assess daily concerns.
- Give the student anxiety-reducing breaks throughout the day.
- Consider alternative lunch and recess.
- Help the student with organization, do only a few problems at a time, consider modified homework amount or deadlines, untimed or added time to tests.
- Provide self-esteem and relationship-building activities, helper duties.
- Teach ways to identify emotions and intensity of feelings and teach self-calming skills.

### **(2a) Clues for Identifying Attention Deficit Hyperactivity Disorder at School**

- Distracted with difficulty staying on task or finishing assignments
- Disorganized and easily loses books, supplies, homework
- Impulsive and may blurt out answers or have difficulty keeping hands to self
- May be irritable, impatient, emotionally dysregulated
- Chronic failure can lead to low self-esteem, depression, school failure.

### **(2b) Managing Attention Deficit Hyperactivity Disorder**

- Ensure assignments are written down correctly. Have teacher check this daily.
- Define clear expectations.
- Break down instructions and tasks into one or two steps at a time.
- Allow student to move about within reason. Give tasks that require them to move.
- Catch your student being good. Look for positive behavior to reward.
- Create a secret code to help the child recognize he/she is off task and must refocus.
- Reduce stress/pressure and teach mindfulness practices.

### **(3a) Clues for Identifying Oppositional Behavior**

- Frequent tantrums and angry outbursts.
- Excessively argues, challenges rules, or blames others for his/her mistakes.
- Annoys others and may appear resentful.

### **(3b) Managing Oppositional Student Behavior**

- Set enforceable, reasonable, clear limits, rules, and expectations.
- Avoid power struggles by giving choices and preferences throughout the daily routine to improve behavior, such as choice of assignments or place to work (i.e., You can either read this text or work on this essay. Which do you prefer to start with?).
- Keep student busy. Give hands-on lessons.
- Help them develop daily self-calming practices and conflict resolution skills.
- Alternative recess with a small group of students involved in a highly structured activity.

- Use strength-based terms to describe students (i.e., they are standing up for themselves) and praise when they respond positively.
- Give a demand kindly, but without asking if it’s okay. Then avoid lingering or making eye contact.

#### **(4a) Clues for Identifying Depression in Students**

- Significant change in their interest in schoolwork/activities
- Grades may drop significantly due to lack of interest, loss of motivation, difficulty concentrating.
- Withdrawal from peers socially
- Sleeping in class, absences, tardiness
- Talking, writing, or drawing about suicide

#### **(4b) Managing Depression**

- Reduce classroom pressures by modifying assignments to assess student’s understanding.
- Reassure students that they can catch up and show them the steps to take.
- Help students use realistic and positive statements about their performance and outlook for the future.
- Keep a record of their accomplishments, since depressed students often fail to notice their progress.
- Encourage gradual social interaction.

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## **Evaluation of a Child with Learning Difficulties**

Many students with mental health problems are identified by their school as needing an evaluation to determine which accommodations or services are indicated to support them. We review the legislation and procedures involved. While a parent may request the evaluation, sometimes the school or the PCP prompts the parent to initiate the request. If you are a PCP, concerned about a student who needs specialized support but doesn’t currently receive services, this chapter explains how to request these services and advise the families in your practice.

### **What educational services are available for a child with learning difficulties?**

- The federal laws (**Public Law 94–142, Individuals with Disabilities Education Act (IDEA) 2004, and Section 504 of the Rehabilitation Act of 1973**) mandate that schools must provide free and appropriate education to students with disabilities.
- This can take the form of an **Individualized Education Program (IEP) developed by the Committee on Special Education (CSE) or a 504 plan. The timeline for the CSE process varies by state.**

## What is an IEP vs. a 504 plan?

- **IEP:** Offers individualized educational interventions and related services to address a student's disability. It will detail specific supports, such as instruction with an additional teacher in the classroom (push in) or outside of the classroom (pull out) for specific amounts of time per week, requiring a system for ongoing evaluation.
  - When would you consider an IEP?
 

A child has a disability outlined by IDEA that interferes with his/her ability to learn and make effective progress, which requires specific educational interventions. Two terms often used are free and appropriate public education (FAPE) that is tailored to the student's needs and least restrictive environment (LRE).
- **504 Plan:** Broader, more general educational supports and changes to the learning environment to meet the needs of the child (i.e., increased time to complete tasks, homework, tests, and ability to leave the classroom as needed when overwhelmed). The critical question is whether a student's impairment substantially impacts the ability to learn.
  - A parent, teacher, or doctor can request a 504 plan in writing by documenting the child's disability and needed accommodations, **without a special education evaluation.**
  - When would you consider a 504 plan?
 

If a patient has a disability (i.e., includes mental health difficulties) that does not meet the criteria for an IEP.

To bridge academic supports until an IEP is in place. Getting an IEP can take at least 45 school days until implemented.

## How do you get an IEP?

1. Parents, teachers, and doctors can file a written request that the school district complete a **special education evaluation.**
2. Once a referral for a special education evaluation has been received, schools have a set number of days (varies by state) to obtain consent from parents to complete an assessment.
3. Schools must complete a special education evaluation, related to areas of disability, within a set number of days, determined by each state.
  - (a) What is a special education evaluation?
    - Schools must complete individualized psychological and educational testing. They often request an assessment by the student's teacher.
    - Additional assessments include a health and home assessment, medical assessment by primary care physician, psychiatric assessment, speech and language evaluation, and occupational therapy evaluation.



- A good assessment by the school includes not just testing, but also classroom observation, teacher and parent checklists and reports, interviews, evaluation of curricula, and examination of school records.
4. After completion of the assessments, a special education team reviews the results within a set number of days from receipt of parental consent to evaluate (varies by state).
- (a) Who is on the IEP TEAM?
- Parent(s) must get a copy of the reports prior to meeting.
  - At least one regular education teacher.
  - At least one special education teacher or service provider.
  - A school official with authority to commit special education resources.
  - A professional who is qualified to interpret and explain test results (school psychologist).
  - A representative of agencies that may be involved with transition of services (for older youth).
  - Student if age 14 or older.
  - Any other person designated by the parent (PCP, child psychiatrist, educational advocate).
- (b) What happens in a **Committee on Special Education (CSE) team meeting**?  
The team determines if the child requires an IEP by answering the following:
- Does the child's disability meet **at least 1** of the 13 criteria for disability under IDEA (autism, deaf-blindness, deafness, emotional disturbance, hearing impairment, intellectual disability, multiple disabilities, orthopedic disabilities, health impairment (mental health), specific learning disability, speech/language impairment, TBI, and/or visual impairment/blindness)? Establishing the presence of a disability requires documentation from the PCP or other specialist physician.
  - Does the child's disability interfere with the child's ability to make effective progress in the general education curriculum?
  - Does the child need special services/education to make such progress?
- (c) Does the child meet the above criteria?
- **Yes**, the child is eligible for an **IEP** and the team creates an educational plan.
  - **No**, the child does not meet criteria for an IEP, but he/she may be eligible to receive a **504 plan**, designed with input from those who are familiar with the student. If found ineligible for an IEP, the school must notify the parent in writing along with what the parent can do to challenge this finding. Parents have a right to request an individual educational evaluation (IEE), which is completed by someone who doesn't work for the school district and may be paid for by the school district.
5. Development of the IEP:  
The IEP sets goals for a child and describes the services the school will provide to reach those goals.

The IEP must include the following:

- (a) The child's present levels of academic and functional performance.
  - (b) Annual, measurable, educational goals for the child and how the school will track his/her progress.
  - (c) The specific services that the child will get—special education services (classroom placement, consultant teachers or aides, resource room), supplementary aids (keyboard), related services (speech therapy, counseling, occupational therapy), and extended school year services.
  - (d) The timing of the services—when they start, how long they last, and how often they occur.
  - (e) Any accommodations—changes to the child's learning environment.
  - (f) Any modifications—changes to what the child is expected to learn or know.
  - (g) How the child will participate in standardized tests (smaller setting or additional time).
  - (h) How the child will be included in general education classes and school activities (the emphasis is on inclusion).
  - (i) For teens 14 and up, a plan must be made for transitional services to adulthood that will begin at age 16 or younger (vocational course, job coaching, and training).
  - (j) The emphasis is on **inclusion** in the **least restrictive environment**.
  - (k) The final plan is reviewed at an in-person meeting.
  - (l) The final plan must be signed by the parent/guardian.
6. Monitoring of the IEP Plan:
- (a) The CSE team must review the IEP at least once per year to make sure the plan is meeting the needs of the student and whether the student is making progress toward the goals.
  - (b) A parent can reconvene the CSE team at any time to review progress, discuss concerns, or make needed changes.
  - (c) The student must be reevaluated every 3 years to determine that services are still needed and to determine if the goals or services need to be changed.
  - (d) Changes in placement usually occur along the following continuum: general education classroom (inclusion), resource room (working with a special education teacher outside the regular classroom, for up to 50% of the school day), self-contained class (a full-time special education placement in a regular school building, with a modified curriculum), special school (differs significantly and offers specialized mental health treatment such as a therapeutic day school or residential school).
  - (e) For IEP students suspended in excess of 10 days, a manifestation determination hearing must occur that looks at whether their disability has led to the suspensions and what corrections to their IEP need to be implemented to better address their disability.

7. Resolving disputes:

- (a) IDEA provides several ways to resolve disputes in this preferred order—mediation, due process complaint, resolution session, state complaint, civil lawsuit.
- 8. Funding:
  - (a) Students receive these services at no charge.
  - (b) States receive additional funding for eligible students.

### **How do you get a 504 plan?**

1. A child has any disability.
2. The disability must interfere with the child’s ability to learn in a general education classroom.
3. The rules about participants on the 504 team are less specific than the IEP meeting. A 504 plan is created by a team of people who are familiar with the child and understand which accommodations will be helpful. This can include the child’s parent, teacher, principal, and guidance counselor or 504 plan administrator for the school.
4. A 504 plan includes specific accommodations, supports, or services for the child as well as the names of the people who will provide the services and the name of the person responsible for ensuring the plan is implemented.
5. The 504 plan is reviewed annually, although this can vary by state.
6. Options for resolving a dispute include mediation, alternative dispute resolution, impartial hearing, complaint to the office of civil rights, or a civil lawsuit.
7. Students receive these services at no charge. States do not receive extra federal funding for eligible students; however, the federal government can take funding away from states that don’t comply.
8. IDEA funds can’t be used to serve students with 504 plans.

Adapted from the following sources:

- US Department of Education. A Guide to the Individualized Education Program. 2000. <https://www2.ed.gov/parents/needs/spced/iepguide/index.html> [2]  
 Wrightslaw. <http://www.wrightslaw.com/idea/art/iep.roadmap.htm>  
 Accessed October 2017 [3]

### **How Can PCPs Best Advocate for Children Throughout the CSE Process?**

1. Assist parents in learning the special education evaluation process by providing helpful resources.
2. Directly contact school special education personnel to bring the needs of the child to their full attention.
3. Send written documentation regarding the student’s disabilities.
4. Refer to clinics and clinicians specializing in educational assessment, planning, and advocacy.

5. Help the family access community agencies and support groups. Each school district must have a special education parent advisory council, which provides family to family support and information sharing.

## Sample Request for Special Education Eligibility Evaluation

Re: (Child's name, DOB, grade, teacher), Request for Evaluation.

Date:

Dear Principal,

My name is () and I am writing to you because my child () is having difficulties in school (detail teacher communication and test scores and explain what has been tried, including response to intervention (RTI) and informal accommodations). Special education programs could help with his/her difficulties. I am formally requesting that the school immediately begin the process for instituting a special education program. I understand that this process begins with the initial evaluation to determine eligibility and that you will send me an evaluation plan that explains the tests you will administer to my child. If possible, I would like to receive the plan within 1 week so that I have time to prepare for the process. Once I have given my consent for the plan, please let me know the date you set for the evaluation. I would appreciate any other information you have regarding the evaluation process, including your criteria for determining eligibility and your general IEP framework and timeline.

I look forward to working with the school to make sure my child gets the education he/she needs.

Sincerely,

Guardian Full Name.

Address.

Daytime phone number.

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## Specific Situations

There are several specific situations that require more immediate, sustained collaboration between the PCP, school, and mental health providers. In each of these situations, an evaluation of the student's safety and potential need for additional mental health services is required.

## The Student with Self-Injuring Behavior

About 15–20% of teenagers have engaged in self-injurious behavior such as cutting [4]. When either the PCP or school staff discovers that a teen is self-injuring, they need to fully assess the stressors and safety of the teen. The type of self-injury, frequency, and severity should be noted. Higher-risk forms of self-injury include

severe injury requiring medical attention or self-injury that occurs on the face, breasts, or genitals. Although self-injury is not usually a suicide attempt, it puts a student in a higher-risk category for suicide [5]. The PCP or school staff should ask about suicidal ideation, history of suicide attempts, symptoms of psychiatric conditions, access to weapons, substance abuse, and risk-taking behaviors. This is a time for immediate communication and collaboration involving the parents, PCP, school counselor, and other mental health treaters involved in the child's life. The team of providers must determine whether an emergency evaluation or more intensive mental health treatment is needed. A student with high-risk self-injury or imminent risk of suicide should be urgently evaluated in the emergency room. If a student who is self-injuring is already participating in outpatient therapy, school staff need to coordinate with the student to ensure access to distress tolerance skills at school. Schools should have a protocol for what steps to take when a student is self-injuring.

## **The Student with Suicidal Ideation**

About 17% of high school students have seriously considered suicide, and 8% have attempted suicide at least once during the previous year [6]. Students who talk, write, draw, text, or act out thoughts of suicide must be taken seriously no matter how old they are. An immediate, careful evaluation and intervention is needed. Schools have protocols for managing suicidal students. School counselors will refer the student to either a local mobile mental health crisis team (who may be able to see the child at school if a parent is present) or send the child, with a parent, to a local emergency room by ambulance (and possibly with legal paperwork indicating an evaluation must occur due to significant safety concerns). Sometimes a student's family may request to see their PCP for an urgent appointment to evaluate the severity of suicidal ideation after the school raises a concern. If this occurs, the PCP must determine whether the child needs an urgent psychiatric evaluation. (More about evaluating for suicide risk can be found in Chap. 4 of this text.) One of the main goals in the evaluation of a suicidal student is to decide whether a child needs immediate hospital level of care for safety reasons due to imminent risk or more intensive outpatient mental health treatment. At times, the student's school or parents may request a letter indicating that the child has been seen by the PCP and is "safe to return to school." It is helpful for the PCP to clearly document in the letter that "this is a time-limited evaluation."

Suicidal students who have been hospitalized require a carefully planned return to school. There should be a reentry meeting for the student that reviews the stressors and events leading up to hospitalization, how to support and monitor the student at school, accommodations/modifications needed, and types and frequency of mental health treatment in place. PCPs can help ensure that this critical reentry process is followed.

## **The Student with School Avoidance**

School avoidance or school refusal is a significant problem that requires close collaboration between the school and the PCP. This is different from truancy (which is an absence from school that parents are unaware of). Students with school avoidance are reluctant to go to school due to physical or mental health symptoms that they observe persisting or worsening in school. Several common fears that avoidant youth have are not being able to leave the classroom or school if they become uncomfortable, not being released from school by parents if their discomfort increases, being negatively evaluated, looked at, or laughed at by peers, and feeling they cannot perform well enough. There are two types of school avoidance: anxiety related and secondary gain. Examples of anxiety type include students who are worrying too much about grades, catching up, and being liked by others. While the child may be a good student, their parent may wish to protect them from the stress of school or struggle with how to get them to school when their child refuses to go. Children with secondary gain often experience an acute illness and then struggle with returning to school. The secondary gain for these students often comes in the form of time spent alone with parents (at home or in the community), increased attention, or permissive use of electronics and reinforces remaining in the sick role and avoiding school.

Times of transition between schools (elementary to middle and then to high school) are particularly stressful times when school avoidance may begin or return. Many families often only accept this diagnosis after a thorough medical evaluation. School attendance should always be inquired about whenever a child is being evaluated for persistent or recurrent physical symptoms. Intervention should take the form of reassurance about the medical condition, consideration of referral for mental health treatment, planning for immediate return to school with needed support, and monitoring of the student's progress. It is highly recommended that students with depression, severe anxiety/panic, OCD, traumatic stress, and an enmeshed parent-child relationship get mental health counseling. In general, requests for physician letters to support a medical leave or home tutoring should be denied. Such letters tend to interfere with the school's ability to support a child through accommodations and modifications that can lead to student success. This can also create a lasting pattern of school avoidance that will recur at future times of stress. There are many therapeutic services to support the full functioning of the child in the school setting.

## **The Bullied Student**

Bullying is a form of aggression in which one or more children repeatedly and intentionally intimidate, harass, or physically harm a victim. Bullying includes making threats, spreading rumors, attacking someone verbally or physically or excluding someone from a group on purpose. With the increasing use of social

media, more bullying is occurring in this setting, and schools are increasingly taking to monitoring social media forums. Victims of bullying report more sleep disturbances, headaches, and feeling sadder than other children [7]. Recent studies indicate that youth who have been bullied and youth who have bullied others are at increased risk of suicidal ideation and attempts [8]. PCPs can serve as helpful advocates in situations where a child is being bullied. They can assist parents in recognizing and reporting bullying. They can advocate that the school intervene and monitor the students involved. PCPs will also need to follow-up with kids who've suffered from bullying to see if the situation has improved and the student is recovering and feels supported.

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### Conclusion

Students with mental health difficulties benefit greatly when the family, PCP, and school collaborate to advocate and provide for the specific needs of the child. PCPs have a pivotal role in helping to ensure that a child with mental health difficulties can thrive in school.

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Kevin M. Simon and Glenda L. Wrenn

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## Introduction

Children with mental health and substance use disorders treated in routine care experience worse outcomes than patients enrolled in clinical trials that have demonstrated the effectiveness of evidence-based treatments. This wide gap between routine outcomes and optimal outcomes spans across a wide range of patient populations and clinical treatment settings. One of the contributors to poor outcomes in routine care is that providers do not regularly use symptom rating scales in behavioral health to determine quantitatively whether their patients are improving. Almost all randomized controlled trials with frequent and timely feedback of diagnostic-specific, patient-reported symptom severity to the provider during the clinical encounter found that outcomes were significantly improved compared to usual care across a wide variety of mental health and behavioral disorders. All pediatric and behavioral healthcare providers treating children with mental health and substance use disorders should implement a system whereby patients and/or observers routinely complete measurement-based care (MBC) validated symptom rating scales that are

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K. M. Simon (✉)

Department of Psychiatry and Behavioral Sciences, Morehouse School of Medicine,  
Atlanta, GA, USA

e-mail: [ksimon@msm.edu](mailto:ksimon@msm.edu)

G. L. Wrenn

Department of Psychiatry and Behavioral Sciences, Morehouse School of Medicine,  
Atlanta, GA, USA

Kennedy Satcher Center for Mental Health Equity, Satcher Health Leadership Institute,  
Atlanta, GA, USA

e-mail: [gwrenn@msm.edu](mailto:gwrenn@msm.edu)



reviewed by clinicians during encounters. MBC will help pediatric providers determine whether treatment is working or if there is a need to facilitate treatment augmentation, consultations, or referrals for higher-intensity services when patients are not improving.

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## **What Is Measurement-Based Care in Mental Health?**

Measurement-based care (MBC) has been defined as “enhanced precision and consistency in disease assessment, tracking, and treatment to achieve optimal outcomes” [1]. MBC includes symptom scales (also known as patient-reported outcome measures) and screening tools. These scales and tools are brief structured instruments that patients and/or observers (parents, guardians, or teachers) use to report their perceptions about the frequency and/or severity of the psychiatric symptoms experienced by the patient.

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## **How Well Do Providers Detect Behavioral and Emotional Problems?**

Across a wide range of treatment settings for mental health patients, there is quite a gap between the outcomes achieved in randomized controlled trials (RCT) and routine care [2–7]. One of the main reasons RCT tend to have better outcomes is RCT often include patient-reported outcome measurement of symptom severity, followed by algorithm-based treatment adjustments when patients are not responding to care. There are numerous brief, validated symptom rating scales that reliably measure change in severity of symptoms over time, but less than 20% of mental health providers in the United States routinely administer symptom rating scales to their patients [8, 9], and the same can be said of pediatric providers [10]. Clinicians’ ability to identify developmental and behavioral problems in primary care, on the basis of clinical judgment alone in the absence of a standardized measure, has been shown to have low sensitivity, ranging from 14% to 54% and a specificity ranging from 69% to 100% [10].

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## **What Are Barriers to MBC in Screening?**

Pediatricians overwhelmingly report a lack of confidence in their training and ability to successfully manage children behavioral and emotional problems, with only 13% of pediatricians reporting confidence [11]. This is within the context of limited access to mental healthcare providers. Understandably, there can be reluctance to systematically identify problems that one does not feel prepared to address. Additionally, adopting new screening practices and the use of the screens once the practice is implemented take time.

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## How Many Scales and Tools Exist?

The sheer number of available instruments can make the choice of a rating scale quite daunting. A review series in the *Journal of the American Academy of Child and Adolescent Psychiatry* lists nearly 100 instruments [12], while the *American Academy of Pediatrics* provides a link that lists more than 50 available instruments ([https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Mental-Health/Documents/MH\\_ScreeningChart.pdf](https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Mental-Health/Documents/MH_ScreeningChart.pdf)) [13].

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## How Were the Scales for This Chapter Selected?

The list of available scales was narrowed to those that address some of the pediatric mental health issues most frequently seen and appropriately diagnosed in a primary care setting [14], or in the case of the suicidality measure, the one most likely to necessitate hospitalization. Thus, Table 8.1 displays commonly used psychometrically validated instruments that measure the severity and/or frequency of symptoms associated with attention deficit hyperactivity disorder (ADHD), anxiety, depression, autism spectrum disorder (ASD), trauma, and substance use disorders. Scales used to assess suicidality and psychosocial dysfunctions are included as well.

Additionally, the scales selected are easy for patients and observers to use in clinical practice or home settings, with none taking more than 10 min to complete. These symptom rating scales are practical to administer, interpretable, reliable, and sensitive to changes in the frequency/severity of psychiatric symptoms and functional impairment over time. Another consideration for the scales chosen included the measures' reliability (ability of a measure to produce consistent results), validity (ability to discriminate between a child with a problem and one without such a problem), sensitivity (the accuracy of the test in identifying a problem), and specificity (the accuracy of the test in identifying individuals who do not have a problem) when available [13, 15]. Sensitivity and specificity levels of 70–80% have been deemed acceptable for developmental screening tests [13]. Lastly, an emphasis was placed on the use of public domain scales.

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## Who Fills Out These Scales?

The person that completes the scale varies from measure to measure and sometimes within a given measure. Some scales (e.g., CRAFFT 2.0) are meant to be filled out by clinicians only, giving a clinician's view of a patient. Other scales are completed by patients only (e.g., PHQ-A). Then there are the scales completed by parents and/or youth (e.g., SCARED and SMFQ). Lastly, there are scales completed by parents and teachers (e.g., Vanderbilts). Having different individuals who are part of a child's life completing scales provides multiple views of each patient's functioning. This is important because children rarely seek treatment for behavioral concerns on their

**Table 8.1** Child and adolescent rating scales suitable for use as core outcome measures

Measure	Domain	Age validated and no. of items	Completed by	Administration and scoring times training (none, unless otherwise indicated)	Languages available
Pediatric Symptom Checklist (PSC)	Psychosocial dysfunction	4–16 years 35 items	Clinician	<5 min Scoring 2 min	English, Spanish, Japanese, German, Dutch, Chilean
Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT-R/F)	Autism spectrum disorders	16–30 months 20 items	Clinical		Translated in >20 languages
CRAFT	Substance abuse	Adolescents Three screener questions, then 6 items	Clinician	1–2 min	English, Mandarin, French, Haitian Creole, Hebrew, Japanese, Russian, Portuguese, Turkish, and Vietnamese
Short Mood and Feelings Questionnaire (SMFQ)	Depression, dysthymia	7–17 years and short form (13 items)	Parent and youth	<5 min	English, Spanish
Patient Health Questionnaire for Adolescent (PHQ-A)	Anxiety, eating problems, mood problems, and substance abuse	13–19 years (83 items)	Adolescent	Scoring: <5 min	Original PHQ-9 is available in more than 50 languages
PHQ-A depression	Depression	12–18 years Abbreviated 9-item specifically for depression	Adolescent	<5 min	Original PHQ-9 available in more than 60 languages

Generalized anxiety disorder—7	Anxiety	12+ years (7 items)	Self-report	Scoring: <5 min	Numerous languages
Vanderbilt ADHD Rating Scale-Parent	ADHD, scored for ADHD subscales, ODD, and conduct disorder, performance As above	6–17 years (55 items)	Parent	10 min	English, Spanish
Vanderbilt ADHD Rating Scale-Teacher	As above	6–17 years (43 items)	Teacher	10 min	English, Spanish
Screen for Child Anxiety-Related Disorder (SCARED)	Anxiety (general anxiety disorder, separation anxiety disorder, panic disorder, and social phobia)	8–18 years (41 items)	Parent and youth	10 min Scoring: 1–2 min	Arabic, Chinese, English, French, German, Italian, Portuguese, Spanish, Thai
Acute Stress Checklist for Children (ASC-Kids)	Acute traumatic stress reactions (including ASD diagnostic criteria)	8–17 years (29 items)	Self-report	5 min	English, Spanish
Columbia-Suicide Severity Rating Scale (C-SSRS)	Suicide	12+ years	Self-report (free training available for communities and healthcare)	10 min	Available in more than 100 country-specific languages. Many of these translations have been linguistically validated

*Modified reference:* Addressing Mental Health Concerns in Primary Care A Clinician Toolkit—mental health screening and assessment tools for primary care [https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Mental-Health/Documents/MH\\_ScreeningChart.pdf](https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Mental-Health/Documents/MH_ScreeningChart.pdf)

own, and observer vs. patient awareness can vary by type of disorder. Compared to the patient, parents and teachers are often more aware of problematic behaviors that affect the youth's external world, aptly named, externalizing behaviors (aggression, delinquency, and hyperactivity). On the other hand, patients are more likely to be aware of their own thoughts and feelings. For this reason, the use of scales that reflect both the patient's report of his/her internal state and the use of scales that reflect caregiver observations is ideal. A combination of patient, parent, and other collateral, with an emphasis on the patient's report, will best inform clinical decision-making.

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## Paper vs. Computer Scoring

All of the scales highlighted are traditionally completed via paper and pencil; however, some do have versions online, modifiable PDFs or Excel sheets that facilitate scoring. Additionally, given the rise of electronic medical records (EMR), for practices that exist within a system that has information technology support, it is possible that scales could be integrated into the EMR. Each method of data entry, scoring, and output has advantages and disadvantages.

Hand-scored scales can often be completed in minutes, providing instant feedback. For clinicians or patients who are not computer savvy, paper and pencil may create fewer barriers and/or less anxiety for patients or staff. Computer-score EMR output often looks more authoritative and is easier to track. Computerized data entry through kiosks or tablets can automate some of the clerical work generated by rating scales and/or shift this burden to patients, parents, or teachers, thus saving clinician time.

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## Language and Cultural Considerations

For English-speaking patients, any of the scales in Table 8.1 can be used. PSC, PHQ-A, M-CHAT, CRAFFT, and SCARED have all been translated in more than five languages, while MFQ-SF and Vanderbilts only have English and Spanish translations. If you do not have access to a translated version and you have a non-English-speaking patient, the scale could be administered with the assistance of a translator; however, the psychometric properties may be compromised. Regarding cultural validation, many of the scales selected for Table 8.1 have been studied in various economic and demographic communities; however, overall, many scales have not.

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## Brief Description of Each Scale and Score Cutoffs

1. The *Pediatric Symptom Checklist* (PSC) is a psychosocial screen designed to facilitate the recognition of cognitive, emotional, and behavioral problems so that appropriate interventions can be initiated as early as possible. For children ages 4 and 5, the PSC score of 24 or higher suggests the presence of significant behavioral or emotional problems. For children ages 6 through 16, the cutoff

- score is 28 or higher (available at: [http://www.massgeneral.org/psychiatry/services/psc\\_forms.aspx](http://www.massgeneral.org/psychiatry/services/psc_forms.aspx)).
2. The *Modified Checklist for Autism in Toddlers, Revised with Follow-Up* (M-CHAT-R/F) is validated for screening toddlers between 16 and 30 months of age to assess risk for ASD. The M-CHAT-R/F can be administered and scored as part of a well-child checkup and also can be used by specialists or other professionals to assess risk for ASD. The primary goal of the M-CHAT-R/F was to maximize sensitivity, meaning to detect as many cases of ASD as possible. Because of this, some children who score as at risk for ASD do not actually have ASD. The following algorithm informs the use of the M-CHAT-R/F: 0–2 (low risk), 3–7 (medium risk), and 8–20 (high risk) (available at: [http://mchatscreen.com/wp-content/uploads/2015/09/M-CHAT-R\\_F.pdf](http://mchatscreen.com/wp-content/uploads/2015/09/M-CHAT-R_F.pdf)).
  3. The *CRAFFT 2.0*, a screening instrument that asks about problems related to the use of alcohol or drugs (other than tobacco), is a widely used screen for alcohol and other substance misuse in adolescents, has the ability to inform providers whether a longer conversation about drug and alcohol use is warranted, and has been endorsed by the American Academy of Pediatrics (AAP) for use with adolescents. CRAFFT is a mnemonic acronym of first letters of key words in the six screening questions. It demonstrates good sensitivity and specificity levels with its established cut point of 2 (refer for further assessment), 1 (brief intervention), and 0 (brief advice) [10] (available at: <https://ceasar.childrenshospital.org/crafft/crafft-2-0-self-administered-questionnaire/>).
  4. The *Mood and Feelings Questionnaire—Short Form* (MFQ-SF), child version, is a 13-item subscale from a longer 33-item questionnaire (the original MFQ). The questions asked on the survey are based on the DSM criteria for depression; however, the screening tool and rating scale should not be used as a measure to diagnose. Each item is rated on a 3-point Likert scale with values of 0–2 assigned to response statements of “True” (0), “Sometimes” (1), and “Not True” (2) given a time frame of the previous 2 weeks. A total score of 12 or higher may signify that a child is suffering from depression (available at: <http://devepi.duhs.duke.edu/mfq.html>).
  5. The *Patient Health Questionnaire-Adolescent* (PHQ-A) is a modified version of the most widely used tool in MBC, the PHQ-9. It is validated for use in both primary care and school-based healthcare. It is a multipurpose tool used for screening, diagnosing, monitoring, and measuring the severity of depression and suicide risk. Scores include no or minimal depression (0–4), mild depression (5–9), moderate depression (10–14), moderately severe depression (15–19), and severe depression (20–27) (available at: [https://www.aacap.org/App\\_Themes/AACAP/docs/member\\_resources/toolbox\\_for\\_clinical\\_practice\\_and\\_outcomes/symptoms/GLAD-PC\\_PHQ-9.pdf](https://www.aacap.org/App_Themes/AACAP/docs/member_resources/toolbox_for_clinical_practice_and_outcomes/symptoms/GLAD-PC_PHQ-9.pdf)).
  6. The *Vanderbilt ADHD Diagnostic Rating Scale* is an assessment tool for ADHD symptoms and their effects on behavior and academic performance in children ages 6–12. There are two versions available: a parent form that contains 55 questions and a teacher form that contains 43 questions. Shorter follow-up versions of the Vanderbilts are also available for parents and teachers and consist of 26 questions with an additional 12 side effect measures. To meet DSM-5

criteria for the diagnosis, one must have at least six positive responses to the queries about inattention and hyperactivity/impulsivity symptoms of ADHD. A 2 or 3 (often, very often) counts as a positive response to a specific question. To aid in scoring, one can draw a line down the page between scores 1 and 2. There is a place to record the number of positives in each subsegment. The initial scale also includes limited screening questions for oppositional defiant disorder, conduct disorder, anxiety, depression, and learning problems (available at: [https://www.nichq.org/sites/default/files/resource-file/NICHQ\\_Vanderbilt\\_Assessment\\_Scales\\_0.pdf](https://www.nichq.org/sites/default/files/resource-file/NICHQ_Vanderbilt_Assessment_Scales_0.pdf)).

7. *The Screen for Child Anxiety-Related Disorders (SCARED)* is a child and parent self-report instrument used to screen for childhood anxiety disorders including general anxiety disorder, separation anxiety disorder, panic disorder, and social phobia. In addition, it assesses symptoms related to school phobias. The SCARED consists of 41 items and 5 factors that parallel the DSM classification of anxiety disorders. The child and parent versions of the SCARED have moderate parent-child agreement and good internal consistency, test-retest reliability, and discriminant validity. Additionally, the scale is sensitive to treatment response. It is available in nine languages (Arabic, Chinese, English, French, German, Italian, Portuguese, Spanish, and Thai). A total score of greater than or equal to 25 may indicate the presence of an anxiety-related disorder (available at: <https://sspediatricassociates.com/Forms-and-Policies/Forms/Behavioral,-Mental-Health-Assessment-Forms/SCARED-form-Parent-and-Child-version.aspx>).
8. The *Generalized Anxiety Disorder-7 (GAD-7)* scale is a self-report questionnaire that is widely used to screen for anxiety. This seven-question screener will help assess a patient's anxiety symptoms during the prior 2 weeks. The GAD-7 asks about the degree to which the patient has been bothered by feeling nervous, anxious or on edge, not being able to stop or control worrying, worrying too much about different things, having trouble relaxing, being so restless that it is hard to sit still, becoming easily annoyed or irritable, and feeling afraid as if something might happen. The GAD-7 score is calculated by assigning scores of 0, 1, 2, and 3, to the response categories of "not at all," "several days," "more than half the days," and "nearly every day," respectively, and adding together the scores for the seven questions. When screening for an anxiety disorder, a recommended cutoff point for referral for further evaluation is 10 or greater. Total score interpretation is as follows: mild anxiety (5), moderate anxiety (10), and severe anxiety (15) (available at: <http://www.phqsreeners.com/>).
9. The *Acute Stress Checklist for Children (ASC-Kids)* is a 29-item questionnaire designed to assess child acute stress reactions within the first month after exposure to a potentially traumatic event. Most items are rated on a 3-point Likert scale (never/not at all, sometimes/somewhat, often/very much). The ASC-Kids is a stand-alone self-report measure suitable for use by children age 8 and older; however, for children 10 and younger, it may be helpful to read the items aloud while the child completes the answer on his/her own form. All items are scored as 0-1-2 (with two items reverse scored). An item rated as "2" (very or often true) is considered to be a positive item when assessing presence of diagnostic criteria. The ASC-Kids Symptom Scale is a continuous severity score

- (sum of 19 symptom items) (available at: <http://www.istss.org/assessing-trauma/acute-stress-checklist-for-children.aspx>). Of note, access to this scale requires membership in the International Society for Traumatic Stress Studies.
10. The *Child PTSD Symptom Scale* (CPSS) is a 24-item measure that includes a 17-item PTSD Symptom Scale and a 7-item scale assessing functional impairment. PTSD symptoms are rated on a 4-point Likert scale, with 0 = “not at all or only at one time” and 4 = “five or more times a week/almost always.” The cutoff for a positive screen is 11. This measure’s Likert scale format allows for more sensitivity to changes in symptoms than would a measure using a dichotomous assessment of specific symptoms. Additionally, randomized trials with ethnically diverse children suggest that the measure can detect change in PTSD symptoms that are due to treatment. Of note, though 8 years old is given at the low end of the age range, some of the questions may be difficult for a child that young to comprehend without assistance (available at: [https://www.aacap.org/App\\_Themes/AACAP/docs/resource\\_centers/resources/misc/child\\_ptsd\\_symptom\\_scale.pdf](https://www.aacap.org/App_Themes/AACAP/docs/resource_centers/resources/misc/child_ptsd_symptom_scale.pdf)).
  11. The *Columbia-Suicide Severity Rating Scale* (C-SSRS) is a 6-item questionnaire designed to assess suicide risk through a series of simple, plain-language questions that anyone can ask. The answers help users identify whether someone is at risk for suicide, assess the severity and immediacy of that risk, and gauge the level of support that the person needs. C-SSRS contains six “yes” or “no” questions in which respondents are asked to indicate whether they have experienced several thoughts or feelings relating to suicide over the past month. Each question addresses a different component of the respondent’s suicidal ideation severity. Comprehensive scoring information is only available to trained and certified administrators, but an answer of “yes” to any of the six questions may indicate a need for further assessment for suicidal thoughts and behaviors (available at: <http://cssrs.columbia.edu>).

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## The Screen Is Positive. What Next?

A positive screen, in and of itself, is not diagnostic. It is, however, an indication that a full mental health assessment is needed, either by the primary care provider or a mental health specialist. (Please refer to Chap. 5 of this text for guidance on mental health assessment in the primary care setting.) Because of overlap in the manifestations of different mental illnesses in children and adolescents, overreliance on screens can lead to misdiagnoses and improper treatment. For instance, consider a 9-year-old boy with an anxiety disorder who is restless and preoccupied with his worries. If Vanderbilts are done in the absence of information from the child about his internal experiences, the observations of a teacher and parent could point to a diagnosis of ADHD. If there is an overreliance on the scale, the boy may be misdiagnosed with ADHD and started on a stimulant medication, which could actually exacerbate his anxiety.

## When Do I Refer Out?

That depends. Given that these screens and assessment tools exist on a spectrum, there will be times when it is appropriate to manage the care of the patient in your practice



and others when immediate referral is needed. In general, referral is indicated when symptoms pose an acute risk or are significantly disabling. It is also useful when interventions in the primary setting do not produce adequate symptom improvement. Evaluation by a mental health specialist can serve to clarify diagnostic questions or better match the level of intervention to the child's distress or impairment. The use of MBC can be helpful in tracking treatment response. Of note, the diagnoses chapters of this text provide information regarding when to refer for specific diagnoses.

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## Could MBC Improve Health Equity in Your Practice?

It has the potential to do so. As it currently stands, without regular use of MBC, pediatric providers are less likely to identify behavioral and emotional problems in minority or non-English-speaking children and adolescents [16]. And for those patients who are appropriately identified, the use of scales can help prompt clinicians to overcome treatment inertia (defined as not changing the treatment plan despite a lack of substantial improvement in symptom severity [17]) and change the treatment plan when patients are not responding to treatment [18]. MBC facilitates the detection of residual symptoms and prompts clinicians to consider intensifying the treatment plan until the patient's symptoms have remitted (i.e., treatment to target). Regular use of MBC can help patients and parents recognize improvement earlier in the course of treatment than they might without symptom rating scales. Patients' recognition of even small decreases in symptom severity may help them feel more optimistic and hopeful, possibly inspiring them to maintain better adherence to the treatment plan [18]. Parents and patients alike are in the best position to assess patients' well-being. Moreover, patient-reported symptom rating scales have been shown to be equivalent to clinician-administered rating scales in their ability to identify treatment responders and remitters [19]. The use of symptom rating scales also empowers patients and families by helping them communicate more effectively with their providers. MBC focuses on collaboration and coordination not only across providers but also with patients and families.

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## How Feasible Is MBC Implementation?

Symptom rating scales are feasible to administer in a range of clinical settings and are highly acceptable to patients and parents. MBC can be incorporated into routine care regardless of the characteristics of the patient population or the treatment philosophy and training background of providers. Patients perceive symptom rating scales to be efficient, complementary of their provider's clinical judgment, and as evidence that their providers are taking their behavioral health problems seriously. Again, most providers find symptom rating scales helpful in monitoring response to treatment and prompting treatment changes such as adjustment in antidepressant dose, adding or switching medications, starting psychotherapy, or asking more questions about suicide. Table 8.2 highlights and describes key steps to implementing MBC in practice adapted from the American Academy of Pediatrics (AAP).

**Table 8.2** Key steps to implementing MBC

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1. *Readying the practice:* Front-end work is needed to train and prepare an office to adopt screening practices. It may be helpful to enlist the assistance of local mental health professionals or developmental-behavioral pediatricians in selecting and implementing screening procedures.

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  2. *Identifying resources:* Before initiating a behavioral and emotional screening program, primary care practices need to determine what they will do when a child or parent has a positive screening result. Primary care practices should familiarize themselves with local resources and identify referral sources. In the absence of this, PCPs are likely to feel frustrated and overwhelmed when they identify children and adolescents in need of services but are unable to find appropriate, high-quality treatment of them. PCPs will need to work with the community to advocate for more treatment and intervention services.

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  3. *Establishing office routines for screening:* As with developmental screening, children should be screened at regular intervals for behavioral and emotional problems with standardized, well-validated measures beginning in infancy and continuing through adolescence. Screening beginning in the first year of life can identify disturbances in attachment, regulation, and the parent-child relationship, although the optimal approaches to screening infants and very young children are less clear-cut than screening children at older ages. Ongoing care involves maintaining a good history regarding factors that can influence the early parent-child relationships, such as discipline practice, parenting stress, psychosocial risks, and positive parenting.

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  4. *Tracking referrals:* If the child was referred for services after screening, it is important for pediatricians to inquire as to whether referrals were completed and services were obtained or understand what barriers parents have experienced and how these can be overcome. Furthermore, it is important for PCPs, with parental permission, to obtain information from the referral and to learn whether services obtained were effective and whether symptoms in the child have been reduced or eliminated. This follow-up may require a separate office system than screening procedures.

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  5. *Seeking payment:* One of the biggest “systems” hurdles facing PCPs is the difficulty obtaining payment for screening patients for behavioral and emotional problems and for screening families for psychosocial risk and functioning. The adoption of the proposed screening and surveillance practices may lengthen visit time to discuss results without additional payment to support that time and create significant non-face-to-face work. This includes referring patients and families to appropriate resources, tracking referrals, communicating with other professionals (which may require reviewing lengthy reports and school plans), and following up with children and families. Overcoming this critical barrier is fundamental to transforming pediatric practice to a medical home model.

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  6. *Foster collaboration:* Innovative collaborations have been well described and include colocation and integrated and consultative models, such as the Massachusetts Child Psychiatry Access Project, the North Carolina Chapter AAP/NC Pediatric Society (ICARE), and the Washington Partnership Access Line. These relationships help build the capacity of pediatricians to manage various behavioral and emotional problems in the office. This is particularly true for the management of subthreshold problems not meeting the severity level warranted to refer for treatment.

*Modified reference:* Promoting optimal development: screening for behavioral and emotional problems

Carol Weitzman, Lynn Wegner. The section on developmental and behavioral pediatrics, committee on psychosocial aspects of child and family health, council on early childhood, and society for developmental and behavioral pediatrics. *Pediatrics* Feb 2015, 135(2)384–395; <https://doi.org/10.1542/peds.2014-3716>

One of the biggest barriers, yet mentioned, is the difficulty obtaining adequate payment for these interventions. The adoption of the proposed screening and surveillance practices may protract appointments to discuss results. It could also create significant non-face-to-face work. This work may include referring patients and families to appropriate resources, tracking referrals, communicating with other providers (which may require reviewing lengthy reports and school plans), and following up with children and families. However, there are ways to optimize workflow and avenues available to receive some reimbursement for use of MBC. Workflow can be streamlined so that the use of the primary care providers' time is optimally used. For example, scales can be distributed by nurses or even trained front desk staff. In collaborative care models, the care manager can serve as the point person for administering, scoring, and following scale results and then subsequently communicating them to the care team.

Of note, currently there are often reimbursed billing codes for the use of screens. Also, when scales prompt additional time spent in patient counseling and education by the primary care clinician, this can be counted toward time-based billing for E & M codes provided greater than 50% of the session time is spent on counseling or care coordination. Additionally, as of January 2018, there are new codes for psychiatric collaborative care management services. Though the frequency and rate for reimbursement have yet to be defined at the time of print, their inclusion is encouraging. These codes reflect the work of care managers, including non-face-to-face work, operating within collaborative care models. More information on this topic can be found in [Appendix A](#).

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## Conclusion

In order to evaluate and promote optimal child development and well-being, assessing developmental and behavioral domains in the context of the family and/or school is vital. Mental (emotional and behavioral problems) health conditions are quite common and persistent and cause significant functional impairment for many children, adolescents, and families. As the number of children and adolescents diagnosed with mental health conditions increases, there is a great need to more effectively disseminate knowledge of MBC in order to facilitate identification and optimize treatment for children and adolescents suffering from depression, anxiety, and substance use disorders to name a few. The scales and recommendations highlighted in this chapter can serve as a starting point for the implementation of MBC in pediatric primary care practices.

## Resources for Primary Care Providers

American Academy of Pediatrics

<https://www.aap.org/en-us/advocacy-and-policy/aap-health-initiatives/Mental-Health/Pages/Primary-Care-Tools.aspx>

Pediatric Symptom Checklist (PSC)

[http://www.massgeneral.org/psychiatry/services/psc\\_forms.aspx](http://www.massgeneral.org/psychiatry/services/psc_forms.aspx)

Modified Checklist for Autism in Toddlers, Revised, with Follow-Up (M-CHAT-R/F)

[http://mchatscreen.com/wp-content/uploads/2015/09/M-CHAT-R\\_F.pdf](http://mchatscreen.com/wp-content/uploads/2015/09/M-CHAT-R_F.pdf)  
 CRAFFT  
[http://www.ceasar-boston.org/CRAFFT/pdf/CRAFFT\\_English.pdf](http://www.ceasar-boston.org/CRAFFT/pdf/CRAFFT_English.pdf)  
 Childhood PTSD Symptom Scale (CPSS)  
<http://nctsn.org/content/child-ptsd-symptom-scale-cpss-0>  
 Short Mood and Feeling Questionnaire (MFQ-SF)  
<http://devepi.duhs.duke.edu/mfq.html>  
 Patient Health Questionnaire—Adolescent (PHQ-A)  
[https://www.aacap.org/App\\_Themes/AACAP/docs/member\\_resources/tool-box\\_for\\_clinical\\_practice\\_and\\_outcomes/symptoms/GLAD-PC\\_PHQ-9.pdf](https://www.aacap.org/App_Themes/AACAP/docs/member_resources/tool-box_for_clinical_practice_and_outcomes/symptoms/GLAD-PC_PHQ-9.pdf)  
 Vanderbilt Assessment Scale—Parent and Teacher version  
[https://www.nichq.org/sites/default/files/resource-file/NICHQ\\_Vanderbilt\\_Assessment\\_Scales\\_0.pdf](https://www.nichq.org/sites/default/files/resource-file/NICHQ_Vanderbilt_Assessment_Scales_0.pdf)  
 Screen for Child Anxiety Related Disorder (SCARED)—Child and Parent Version  
<http://sspediatricassociates.com/Forms-and-Policies/Forms/Behavioral,-Mental-Health-Assessment-Forms/SCARED-form-Parent-and-Child-version.aspx>

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# Medicolegal Considerations in Prescribing Psychiatric Medications to Youth

# 9

Peter Ash

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## Introduction

The general principles of legal regulation that apply to pediatric primary care provider (PCP) prescribing apply as well to the prescribing of psychotropic medications. However, psychotropic medications can raise special issues, and the bulk of this chapter will focus on those issues. PCPs do much of the prescribing of psychotropic medications for children, reflecting, first, that many mental conditions are quite common and so part of general primary care practice and, second, that there is a national shortage of child and adolescent psychiatrists such that in many locations such specialists are not readily available. PCPs vary widely in their level of comfort and experience in prescribing psychotropic medications. This chapter has as its goal to assist practitioners in prescribing medications in a manner that comports with legal regulations and will minimize liability in the event of an adverse result. Liability issues can arise in a variety of contexts. These include being sued for malpractice, undergoing administrative investigations such as investigations by state medical boards, Health Insurance Portability and Accountability Act (HIPAA) violations, and hospital credentialing investigations.

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## Informed Consent

After a clinician has made the clinical decision about what medication to recommend for the patient, the next step is to obtain appropriate consent. Informed consent is ethically required of PCPs [1] and legally required in all states except Georgia [2]. In the event of an adverse reaction to a medication, failure to have obtained appropriate informed consent generally constitutes malpractice.

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P. Ash  
Forensic Psychiatry, Atlanta, GA, USA

Department of Psychiatry and Behavioral Sciences, Emory University, Atlanta, GA, USA  
e-mail: [pash01@emory.edu](mailto:pash01@emory.edu)

While there are exceptions, in most cases minors cannot provide legal consent for themselves, and so, except in emergencies, formal consent needs to be obtained from a parent, guardian, or, if the child is in state custody, from the person designated by the custodial agency. Some exceptions to the general rule of requiring consent from a parent are in such areas as treatment for sexually transmitted diseases, pregnancy, substance abuse, and birth control and can vary by state. Additionally, state law determines the age of majority and who is an emancipated minor. Some states have mature minor rules that allow adolescents who are deemed by the physician to be capable of reasonable decision-making to consent for themselves. Pediatric primary care providers should be familiar with the laws in their own state. Even for youth who are not legally capable of making decisions, however, the Committee on Bioethics of the American Academy of Pediatrics states that the minor should be involved in the decision process and the assent of the minor be obtained whenever reasonable [1].

The “informed” aspect of informed consent involves a number of factors, which include discussing the risks, benefits, and alternatives of treatment, in addition to risks involved in refusing the treatment. Just how much discussion does this entail when prescribing psychotropic medications to children and adolescents? General legal rules, such as “what a reasonable person would want to know when deciding whether to undergo a particular treatment,” provide only limited guidance.

Consider the example of a depressed adolescent for whom the pediatrician recommends treatment with the antidepressant fluoxetine. There are two types of decision involved for the patient and parent. The first is which antidepressant to use: this might be considered a technical decision, analogous to the decision as to which antibiotic to use if the patient had an infection. While the pediatrician might well go over the side effects of various antibiotics to be considered, it would be somewhat unusual for a patient or parent to say, “Oh, no. Rather than amoxicillin I’d prefer to take ampicillin.”

Decisions about psychotropic medications frequently involve value judgments that rarely arise with antibiotics. Typically with an antibiotic, the patient’s decision as to whether to take a medication *at all* seldom arises. With psychotropic medications, such issues are common: “I just don’t like the idea of my daughter taking a medication that might affect her mind.” Such concerns require the pediatrician to explore the patient’s parent’s concerns beyond the more straightforward issues of risks, benefits, and possible side effects.

## **Yellow Flag Issues: When the Informed Consent Discussion Is More Complicated**

### **Off-Label Prescribing**

Prescribing medications off label occurs in over half of all pediatric visits [3]. In large part this reflects the fact that drug companies are often reluctant to conduct the additional, expensive research studies that are required to obtain approval from the Food and Drug Administration (FDA) for the special populations of children and

adolescents. While some psychotropic medications have been approved for use in children and adolescents for particular indications (see list in Ref. [4]), clinicians need not restrict their practice to this relatively short list. However, when a drug use is not FDA approved for minors, the informed consent process is somewhat more extended. Some recommend discussing that a use is not FDA approved during the informed consent process.

Some psychotropic medications are used off label for conditions that are not FDA approved even for adults (e.g., the use of atypical antipsychotic agents for aggression). Since new advances in treatment are, by definition, not (yet) mainstream, a key principle is that the further a practice is from the mainstream, the more documented justification it requires.

### **Black-Box Warnings**

A black-box warning is the FDA's strictest warning in prescribing information. The use of selective serotonin reuptake inhibitors (SSRIs), the mainstay pharmacological treatment for depression, has become more problematic since 2004 when the FDA began requiring a black-box warning in product labeling of SSRIs. The FDA based its decision on a pooled analysis which found that reports of suicidal thinking in children and adolescents increased from 2% on placebo to 4% on active drug [5] although no actual suicides took place in the studied sample. In 2007, the FDA updated its required labeling of antidepressant medications to include a black-box warning for antidepressants being prescribed to youth under age 25 [6]. The warning identifies an increased risk of suicidality in the young and that SSRIs should be "monitored appropriately" for adverse side effects but does not define what could constitute appropriate monitoring (unlike the previous required warning that specified this as including face-to-face monitoring weekly for the first 4 weeks of treatment [7]). The warning was controversial, reflecting a concern that the warning would discourage the use of antidepressants and the risk of not treating depression in youth outweighed the risk of suicide. Follow-up 10 years later provided some hard evidence for these concerns [8].

SSRIs are not the only medications that carry black-box warnings for use in children and adolescents. Other psychoactive medications with black-box warnings regarding use in children and adolescents include most first-generation antidepressants (imipramine and derivatives), aripiprazole (concern for suicidal thoughts in youth), and valproic acid (birth defects). In 2016, the FDA required a black-box warning for benzodiazepines when prescribed concomitantly with opioids.

Because black-box warnings carry the official imprimatur of the FDA, it is important that those risks be explicitly addressed with the person consenting to the treatment, and it is good practice to document in the record that those possible side effects were discussed.

### **Documentation**

In deciding how much to document about the informed consent process, a useful perspective is to assume that an adverse reaction to the medication occurred and the patient's attorney is scrutinizing the record. What information would one



want in there? The note need not be a verbatim transcript of the discussion but should address that the risks and benefits were discussed and particularly note that black-box issues were talked about. Some clinicians utilize preprinted drug information sheets or otherwise develop written policies regarding what is discussed, and such policies can be referenced without then having to include all the text of the policy or handout in the note. In most jurisdictions, a signed consent form is not required but may be utilized to document the consent process.

### **Ongoing Monitoring**

While most of the focus on the informed consent process is on what takes place when a medication is first prescribed, informed consent is actually an ongoing process that takes into account how the patient is progressing and is responsive to the patient's progress and the development of any side effects. Furthermore, some side effects, such as weight gain, increase in importance when medications are used long term.

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### **Treatment Monitoring**

Once a medication has been prescribed, the prescribing physician is responsible for monitoring the patient's progress. At the beginning of treatment, more frequent monitoring by the primary care team and caregivers is especially important to ascertain the effectiveness of the medication and the development of side effects. While antidepressants typically take several weeks to have effect, the black-box warning discussed above mandates increased monitoring for side effects in the first month of treatment.

### **Who Controls the Pills?**

The pediatrician wants to maximize compliance with the prescribed medication regimen and also to support the developing autonomy of the patient. There are several competing factors that go into the decision as to who has actual control of administering the prescribed medication and who is monitoring compliance: the preferences of the patient and parent, the level of maturity of the youth, and the level of harm that might occur if the medication is misused. While these concerns arise when prescribing any medication to a youth, some special considerations are relevant for psychotropic medications. First, the nature of the mental disorder being treated may involve increased impulsivity that would lead a clinician to be more cautious in recommending that an adolescent be in charge of his or her own medications. Second, with depressed patients and especially patients with a history of self-harm, the risk of an adolescent self-administering an overdose needs

to be carefully considered. Third, especially with adolescents receiving stimulants for attention deficit hyperactivity disorder (ADHD), the possibility of medications being diverted and sold to other students needs to be considered. Since parents may not on their own consider these possibilities, it is useful to raise them explicitly in a discussion with the parent when discussing who will be in charge of the medication.

## Split Treatment

Many children and adolescents for whom psychotropic medications are appropriate will also benefit from psychotherapy, which is generally provided by someone other than the pediatrician. The pediatrician may be the clinician who initiates the referral for a psychotherapy, or a patient may be referred by a therapist for consideration of medication. In some cases, treatment may have been started by a child and adolescent psychiatrist, the patient has been stabilized, and the patient has been referred to the pediatrician for maintenance treatment. In each of these situations, multiple clinicians are involved in the patient's care, and the issue is how to coordinate their work for the benefit of the patient. While coordination of care with multiple clinicians is becoming more common and has many advantages, in the event of an adverse outcome, such as a patient suicide, how the clinicians interacted in providing care will be closely scrutinized.

The basic principle in split treatment arrangements is to keep the lines of communication open between clinicians so that critical information is shared. In practices in which both clinicians are members of the same practice group, this is relatively straightforward. If the clinicians practice separately, it is important that the patient and parent know that the clinicians will be communicating. This does not mean that the psychotherapist will be communicating all of the patient's fantasies and private information to the pediatrician but that information relevant to the pediatrician's management can flow back and forth. HIPAA allows for communications between care providers that are relevant for continuity of care [9], but some states afford greater confidentiality to mental health information, and in those states, a signed release is required.

The important point is to make sure that relevant information is passed back and forth. If the psychotherapist sees side effects, such as oversedation, that information should be communicated to the prescribing physician. If the pediatrician notes suicidal thinking, that should be communicated to the psychotherapist. While previously some recommended that practices develop written policies about how much information should be communicated and when, it is very difficult to formulate precise rules. As a result, such policies tend to be overly inclusive. The downside of a written policy on sharing information is that once a clinician adopts such a policy, the clinician will be held to adhering to it, even if the policy requires more than the standard of practice would ordinarily require.

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## Confidentiality of Electronic Communications

Increasingly, communications from parents and patients to their providers are being done with electronic means such as texting, email, and smartphone apps. The standards for the appropriateness of such communication are rapidly evolving, and professional associations have difficulty keeping guidelines current. For example, the guidance provided by the American Academy of Pediatrics in 2004 [10] was retired without being replaced in 2014 [11]. Some of the issues that policies about electronic communications need to address are a relative lack of confidentiality and a lack of certainty that the communication was received and received in a timely manner. Before engaging in electronic communications with patients that include confidential personal health information, physicians are well advised to develop policies tailored to their own practice that spell out possible problems and obtain appropriate consent for such use.

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## State Monitoring Programs

### Youth in Foster Care

Several large-scale studies of Medicaid recipients found that children in foster care are up to seven times more likely to receive psychotropic medications, especially second-generation antipsychotic medications, and multiple medications, than children who live with their parents [12, 13]. Much of the prescribing was by primary care physicians, and the findings raised considerable concern that foster care children were being overmedicated, in large part for behavioral control. In response, the American Academy of Child and Adolescent Psychiatry developed standards for treating children in state custody [14] which include recommendations for state programs to monitor psychotropic medications of this population. State programs vary in the standards they use, and it is important for PCPs who treat children in foster care with psychotropic medications to be aware of the standards and type of monitoring in their state.

### Scheduled Drugs

The opioid crisis has led to grave concern about the misuse of prescribed scheduled drugs. The most recent *Monitoring the Future* study, a national survey of adolescent drug use, reveals that while adolescent use of non-prescribed drugs has come down somewhat from its height in 2005, about 12% of 12th graders reported using non-prescribed controlled psychotherapeutic drugs (stimulants, sedatives, tranquilizers, and narcotics other than heroin) [15]. One governmental response to the opioid crisis has been an increasing number of states establishing physician drug monitoring programs (PDMP). These programs typically establish databases for prescriptions of scheduled drugs and vary in which drugs are included in the database, the duration for which prescriptions can be written, and the conditions under which physicians need to check the database. PCPs need to be aware of the regulations governing the PDMP in their own state.

## High-Risk Situations

The most common high-risk situation involving psychotropic medications that primary care providers face is the depressed adolescent who is at some risk for suicide and is being treated with an SSRI antidepressant. Any adolescent diagnosed as depressed needs to be assessed for suicide risk, a process discussed in more detail in Chap. 4 of this text. That said, a good assessment does not protect against an adverse result: suicide is simply not that predictable. Accurate prediction of suicide in an individual case is not possible with adults, and adolescent suicide is even more difficult to predict than suicide in adults for two main reasons. First, the baseline for suicidal thinking is much higher than it is in adults—over 17% of 12th graders have considered suicide, and over 14% had made a plan in the previous 12 months [16]. Second, adolescents as a class are more impulsive, and while most adolescent suicides have an identifiable precipitant, in about half the cases, the precipitant occurred within 24 hours of the suicide [17], leaving very little time for assessment and intervention. Therefore, even a well-done suicide assessment is not completely protective, so the PCP needs to take steps to limit liability in the event of an unexpected adverse result.

In addition to discussing with parents the black-box warning regarding SSRIs, the PCP should also enlist the parents in helping monitor their child with regard to the level of depression and, if the adolescent appears to be at some risk but nevertheless manageable as an outpatient, to inform the parents of this risk. Obviously if a youth is thought to be at high risk, he or she should be assessed for need of hospitalization, but the high frequency of some suicidal thinking compared to completed suicide (over 2000:1) means that many such youth will be managed as outpatients. High-risk situations call for more detailed documentation both of the assessment and the clinician's reasoning process.

A key principle in protecting against liability is, "When in doubt, shout!" [18]. Get a second opinion and have it documented. In the event of an adverse outcome, the question will be "What would a reasonable clinician have done?" In obtaining a second opinion, protection against the hindsight bias might affect a plaintiff expert coming in after the fact and testifying, "If I were there, I would have..."

The need for consultation for complex mental health situations arising in primary care settings has been well recognized [19]. Many states have implemented programs that allow for telephone consultation with a child psychiatrist to help in dealing with mental health problems (for list and contact information, see Ref. [20]). The legal risk for the consultant in providing advice, even in high-risk situations, appears to be quite low [21].

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### Conclusion

Primary care physicians prescribe many of the medications used to treat mental health problems in child and adolescent patients. By choosing appropriate medications, obtaining appropriate informed consent, monitoring care well, being aware of pertinent state regulations, obtaining consultation when needed in complex situations, and documenting well, they can provide excellent care to their patients and minimize liability risks to themselves.

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## Part II

# Diagnosis Chapters



Courtney L. McMickens and Amber J. Landers

## Introduction

Depression is the leading cause of disability worldwide, contributing to underperformance in school, decline in productivity, and disruption of family functioning [1]. Adolescence is the period of highest risk for onset of depression with peak incidence in the United States in the early 20s [1, 2]. Depression is generally a chronic episodic condition, which at its worst can lead to suicide, the leading cause of death in individuals ages 15–29 worldwide [1, 2]. Individuals with depression can experience low mood, decline in interests, low energy, disturbances in sleep and appetite, and feelings of hopelessness. In children and adolescents, depression may be associated with changes in behavior, such as irritability, social withdrawal, and somatic complaints [3].

The spectrum of depressive disorders include major depressive disorder, persistent depressive disorder (formerly known as dysthymia), and depressive disorder related to substance use or a medical condition, among other categorizations [3, 4]. Over the last 30 years, safe effective treatments for depression have become increasingly available; therefore, screening, identification, and early treatment are important public health efforts. Signs and symptoms of depression can often go unnoticed or mischaracterized. This, among other factors such as social stigma and limited access to mental health services, can delay or deter adequate treatment.

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C. L. McMickens (✉)

Boston Medical Center, Boston University School of Medicine, Boston, MA, USA

A. J. Landers

California School of Professional Psychology, Alliant International University,  
San Francisco, CA, USA

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## Brief Review of Epidemiology and Pathophysiology

The overall prevalence of depression in the United States by the age of 18 is about 20% [3]. In children, the prevalence of major depressive disorder (MDD) is about 2%, and in adolescents it is about 4–8% [5]. It is estimated that another 5–10% of children and adolescents have symptoms of MDD that fall below the threshold for full diagnostic criteria; however, they are at elevated risk for suicide [5]. Depression occurs equally across genders in children, but in adolescence, the risk for developing depression increases for females, with a female to male ratio of 2:1 [5].

Risk factors for depression can be characterized by a biopsychosocial framework. Biologically, it has been shown that first-degree family members of individuals with MDD have a two- to fourfold risk of developing depression compared to the general population [6]. Additionally, the presence of other parental psychiatric disorders, including anxiety, substance abuse, ADHD, and eating disorders, has been associated with the development of depression in children and adolescents. Experiences of stressful life events, such as abuse, neglect, exposure to violence, and family disruption, in childhood have also been associated with the onset of MDD [7, 8]. The effects of these experiences are often mediated by the child's sources of support, socioeconomic status, IQ, and coping style [9].

The course of depression can range from 3 to 8 months [10]. About one in five adolescents has persistent depression that can last 2 years or more [10]. Recurrence after remission of symptoms is common with an estimated 20–60% of children and adolescents experiencing a recurring episode of depression in 1–2 years and 70% over 5 years [11, 12]. Additionally, it is estimated that 40–90% of children and adolescents with depression also have another psychiatric disorder. The most common comorbid conditions include anxiety disorders, attention deficit hyperactivity disorder, and disruptive behavior disorders. In adolescents, substance abuse disorders commonly occur with depression [4].

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## Diagnosis and Key Components of History

The DSM5 lists major depressive disorder within the category of depressive disorders and describes “The common feature of all of these depressive disorders is the presence of sad, empty, or irritable mood, accompanied by somatic and cognitive changes that significantly affect the individual's capacity to function. What differs among them are issues of duration, timing, or presumed etiology” [2]. Individuals meet criteria for major depressive disorder if they have depressed mood or loss of interest along with five or more of the following symptoms for 2 weeks [2]:

1. Depressed mood
2. Lack of interest or pleasure in all or most activities
3. Unexpected changes in weight (for children, failure to gain weight as expected)
4. Sleep disturbance (insomnia or hypersomnia)
5. Feeling of slowing or agitation



6. Fatigue or loss of energy
7. Feelings of worthlessness or excessive or inappropriate guilt
8. Diminished ability to think or concentrate or indecisiveness
9. Recurrent thoughts of death or suicidal ideation

Major depressive disorder can be a pervasive and debilitating disorder that impacts an individual's view of the world, themselves, and others [13, 14]. Depression in children and adolescents is also associated with negative attributions that impact feelings about self-worth and abilities (e.g., self-esteem), interactions with others (e.g., isolation or anger), and views of the world and the future (e.g., helplessness, foreshortened future) [15–17]. For depressed children, negative attributions and depressed mood can increase over time, particularly during adolescence; therefore it is important for healthcare professionals to be able to identify and treat early when possible [16, 18].

Assessment of severity is necessary for determining relevant psychoeducation, appropriate monitoring, and next steps. Screeners such as the Patient Health Questionnaire for Adolescents (PHQ-A) that assess presence and level of symptoms are useful for assessing severity [19]. Symptoms may fall in the mild, moderate, or severe range. The child with mild severity (PHQ-A score 5–9) may exhibit few symptoms or low levels of symptoms that may or may not noticeably impair daily functioning. Mild symptoms may or may not require treatment beyond primary care. The child with moderate severity (PHQ-A score 10–14) may exhibit several symptoms that impact functioning and may likely require further evaluation and treatment. The child with severe symptoms (PHQ-A score 20–27) may exhibit many symptoms at high levels that clearly negatively impact daily functioning and likely require specialty treatment, monitoring, and follow-up. PHQ-9 scores  $\geq 10$  have a sensitivity of 88% and a specificity of 88% for major depression [19].

It is important to remember that depression may be exhibited differently in children than in adolescents or young adults. While adolescent depression is more common, it is important to be aware that young children (e.g., under age 10) can show signs of depression, especially when risk factors such as parental depression are present [16, 18]. While adolescents and young adults may exhibit sad mood associated with depressive symptoms, younger children may express negative mood by displaying other types of behaviors. This may include irritable behaviors (misbehavior, anger, tantrums) instead of/or in addition to sad behaviors (tearfulness and low mood). Directly asking about suicide attempts and thoughts of wanting to die is particularly important for depressed adolescents and teens (e.g., “Have you ever had thoughts of wanting to hurt or kill yourself?” “Have you ever tried to hurt or kill yourself?”) [19]. Whereas teenage girls make more suicide attempts, teenage boys are more likely to complete suicide [19, 20]. Rates are higher among Native American, White, and Hispanic teens than among Black, Asian, or teens from Pacific Islands [20].

There are variations in reporting of depressive symptoms by gender and ethnicity [21]. While prepubescent males and females tend to have equal prevalence rates of depression, girls begin to report more depressive symptoms than boys after puberty.

**Table 10.1** Key questions during assessment

Behavior topics: sleep, appetite, social withdrawal/isolation, tearfulness, concentration, tantrums/misbehavior	<p>Is the child spending less time with friends than before?</p> <p>Is the child spending less time doing activities they used to enjoy?</p> <p>Have you noticed changes in their appetite?</p> <p>Have you noticed changes in their sleep?</p> <p>Does the child appear more tired than usual? (For older children, ask if they seem to take more naps)</p>
Mood topics: irritable, sad, angry, flat, sluggish/lethargic	<p>Does the child seem angry or easily frustrated?</p> <p>Does the child seem easily tearful?</p> <p>Does the child seem to have less energy than before?</p>
Thought topics: suicide, low self-esteem, failure	<p>Is the child hard on themselves or expressing statements about failure or worthlessness?</p> <p>Does the child express statements about wanting to die?</p>
Social environment topics: changes/transitions, stressors, major losses, school, peers	<p>Have there been any recent changes or transitions you can think of, such as moving, changing schools, etc.?</p> <p>Have there been any recent losses, deaths, or anniversaries?</p> <p>How are the child's grades/have there been changes in grades or completion of school work? Are there concerns about bullying or being bullied?</p>

Healthcare providers should be aware of biological and social/contextual reasons for these variations and continue to listen carefully to how more “acceptable” symptoms may be described by patients and families (e.g., angry or bored versus sad). Research on mental health disparities shows that ethno-cultural minority children are frequently underserved and misdiagnosed relative to their white counterparts [21–23]. Research suggests cultural differences in reporting of symptoms, where families from ethno-cultural minority groups may underreport depressive symptoms. Nevertheless, it is crucial for healthcare providers to listen carefully, clarify concerns, minimize blame, and seek accurate diagnosis. For example, parental concerns about “laziness, missed chores, and failing grades” may also be an expression of concerns about anhedonia and low mood.

Key areas to ask about for assessment including behavior, mood, thoughts, and social environment are included in Table 10.1.

This list is not an exhaustive account of which questions to ask but is intended to provide some direction in the assessment of pediatric depression. Consequently, taken individually the above symptoms could also be indicative of other disorders, but taken together it is likely that the child is exhibiting symptoms of depression.

It is also important to note how long symptoms have been present, when they were first noticed, and how much trouble they are causing the child and family. If possible meeting separately with the child after obtaining some information from the parents can be informative, as often the child's experience of symptoms may be different and may have preceded becoming outwardly noticeable to family

members and others. Holidays, birthdays, and other meaningful markers of time for children and families can be helpful in understanding onset and chronicity of symptoms. Possible questions include “Do you remember feeling this way last school year?” “What grade did you first notice...?”, and “Was it the same, better, or worse last summer?”. These anchors/markers can be useful in obtaining a timeline.

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## Confounders and Comorbidities

Depression can co-occur with other disorders, and healthcare professionals should seek accurate diagnosis and rule out diagnoses for other common childhood disorders characterized by troublesome behavior such as attention deficit hyperactivity disorder, oppositional defiant disorder, and anxiety and trauma-related disorders.

Medical conditions can mimic signs and symptoms of depression. Medical illness is also a risk factor for comorbid depression with medically ill children and adolescents having depression rates twice as high as the general population [24]. In the pediatric setting, it is important to distinguish between primary mood disorder, mood symptoms as a reaction to medical illness, and mood symptoms secondary to a primary medical condition [25]. This is sometimes difficult to determine. Specifically, in children, as mentioned earlier in the chapter, depression can be marked by symptoms of irritability and misbehavior or be associated with somatic complaints, causing the diagnosis to be misidentified. Common physical manifestations of depression in children include headaches, abdominal pain, joint pain, fatigue, and insomnia [24].

On the other end of the spectrum, there are several medical conditions that have been etiologically linked to depression. Common conditions include seizure disorders, post-concussive syndrome, cancer, sleep apnea, mononucleosis, anemia, failure to thrive, endocrine disorders, and other metabolic imbalances [24, 26]. These conditions often have overlapping symptomatology with depression, such as weight changes, sleep disturbance, and fatigue. When medically indicated, it is important to diagnose an underlying medical condition based on history and physical exam. Laboratory assessment of thyroid, hepatic, and renal function may be indicated, along with metabolic and hematologic status [24]. Some cases may warrant imaging and further diagnostic tests.

Recognition of comorbid depression is important for improvement in function and quality of life. Though most studies have been done in adult populations, it has been shown that depression is associated with engagement in health-risk behaviors, such as overeating, smoking, and sedentary lifestyle [27].

Research suggests that there is a mutually influential relationship between substance use and psychiatric comorbidities [28]. Alcohol, drug, and tobacco use can be a precipitant for depression or occur as a result of depression [3]. Moreover, substance use disorder and depression can share common risk factors such as family conflict and exposure to violence and other adversities in childhood [10, 29]. Some overlapping symptoms of depression and substance abuse include lack of interest,

fatigue, functional decline, sleep disturbance, and problems with concentration. These symptoms may be associated with intoxication or withdrawal. Withdrawal from nicotine can be associated with irritability, difficulty concentrating, and depressed mood [10]. The use of marijuana, particularly at high quantities, can be associated with low motivation. Opiate dependence is increasingly becoming a major health problem among teenagers, with opioid dependence leading to school failure, criminal activity, and even death due to overdose [29]. Cocaine initially causes euphoric effects but is associated with a post-intoxication blues, marked by irritability, fatigue, drowsiness, and depressed mood. One study showed effectiveness of fluoxetine in adolescents with comorbid substance use disorder and depression [30].

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## Screening and Measures

The American Academy of Pediatrics Bright Futures recommends psychosocial/behavioral assessment and screening at well-child visits. The US Preventive Services Task Force recommends depression screening for all teens ages 12–18. Recommended measures can be found in Table 10.2. While questionnaires and screeners can be used in the pediatric setting to obtain information about mood and depressive symptoms [44], a screener alone is not sufficient for diagnosis, and best practice includes proper attention to total scores, individual items, and information gathered directly from the child and family. Identifying a shared vocabulary during initial conversations about the child's depressive symptoms using the terminology that the child or family uses (e.g., sad, depressed, gloomy, stuck) is a patient-centered approach to mood assessment that attempts to match developmental and cultural considerations of the child and adolescent. Additionally, all children or adolescents discovered to have a depressive disorder should also be screened for trauma, anxiety, and substance use disorders.

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## Initial Management

Depression treatment starts with diagnosis and engagement of patients and families in understanding the diagnosis and treatment options. Treatment recommendations are made on the basis of symptom severity and impairment in function. If there is concern for acute safety and/or report of suicidal ideation, the patient should be referred for acute emergency psychiatric evaluation. For non-emergent cases, treatment can include behavioral interventions, psychotherapy, medication, or, more often, a combination of the three.

Depression is categorized by severity and course. Severity can be mild, moderate, or severe depending on the number and intensity of symptoms and degree of functional impairment [2]. For mild to moderate depression, behavioral interventions and psychotherapy alone can be an adequate treatment. Moderate to severe depression generally requires a combination of pharmacological and behavioral

**Table 10.2** Clinical assessment tools for depression and mood symptoms

Measure	Domain	Age validated No. of items	Completed by	Administration and scoring times Training (none, unless otherwise indicated)	Languages available	Reference
Pediatric symptom checklist—35 (PSC)	Interpersonal domains, psychosocial dysfunction	4–16 years 35 items	Parent	<5 min Scoring 2 min	Translated in >20 languages <sup>a</sup>	Jellinek et al (1998) [31]
Patient Health Questionnaire-9-Modified for Teens (Modified-PHQ9)	Depressive symptoms based on DSM criteria	12+ years 9 items	Youth	5 min Scoring: 1–2 min	English and Spanish	Spitzer et al (1999) [32]
Patient Health Questionnaire-Adolescent (PHQ-A)	Includes question about self-harm/suicide					
Pediatric Symptom Checklist-17 (PSC-17)	Screeners for general emotional and behavioral problems Includes items relevant to mood	4–18 years 17 items	Parent	<5 min Scoring: 2 min	English, Spanish, Chinese, Vietnamese	Jellinek et al (1986) [33]
Revised Children's Anxiety and Depression Scale (RCADS)-Youth and Parent Versions	Anxiety, depression	8–18 years 47 items	Youth and/or parent	5–10 min Excel scoring sheets online available for English versions in children grade 3 and up at <a href="http://www.childfirst.ucla.edu/resources.html">http://www.childfirst.ucla.edu/resources.html</a> Hand scoring: 5 min	English, Spanish, Danish, Dutch, Korean	Chorpita et al (2005) [34]
Center for Epidemiological Studies Depression Scale for Children (CES-DC)	Depressive symptoms	14+ years 20 items	Youth	5 min Scoring: 2–3 min	English <sup>b</sup>	Radloff (1977) [35]

(continued)

**Table 10.2** (continued)

Measure	Domain	Age validated No. of items	Completed by	Administration and scoring times Training (none, unless otherwise indicated)	Languages available	Reference
Mood and Feelings Questionnaire (MFQ)	Depressive symptoms	6–17 years 33 items	Youth and/or parent	5–10 min Scoring: 5 min	English	Angold et al. (1987) [36]
Short Mood and Feelings Questionnaire (MFQ-SF)	Depressive symptoms	6–17 years 13 items	Youth and/or parent	<5 min Scoring: 2–3 min	English	Angold et al. (1995) [37]

Psychometric references for the CESD: [34, 38–40]

Psychometric references for the PHQ9: [41–43]

<sup>a</sup>[http://www.massgeneral.org/psychiatry/services/psc\\_forms.aspx](http://www.massgeneral.org/psychiatry/services/psc_forms.aspx) for complete list of languages

<sup>b</sup>Has been translated into Arabic, Spanish, and Norwegian but less psychometric testing is available for those forms

interventions. In the primary care setting, this often warrants initiation of medication while awaiting engagement in additional services, including psychotherapy or child and adolescent psychiatry. In collaborative care models, depending on licensure, training, and state regulations, the behavioral care manager may be able to initiate psychotherapy.

## Psychosocial and Behavioral Interventions

Psychoeducation involves sharing information about depressive symptoms, diagnostic procedures, and prognosis with children and caregivers. Psychoeducation can also be utilized as a collaborative method for establishing shared expectations with children and families. Psychoeducation as a stand-alone intervention shows mixed effectiveness in prevention and treatment of youth depressive disorders, but is an intervention that can be executed by many members of the primary care team.

Therapeutic interventions require specialized skills and training, and primary care providers (PCPs) are not expected to conduct psychotherapy with their patients. However, some awareness about the evidence base regarding a given disorder for the types of therapy offered by mental health clinicians in the community or co-located in primary care clinics can be useful for collaboration and informed decision-making about referrals. In addition, basic skills in evidence-based goal setting and behavioral techniques such as motivational interviewing, behavioral activation, pleasant activity scheduling, problem-solving, and generating alternative perspectives have been found to be effective interventions for depression [45–49]. PCPs can utilize elements of these interventions for initial management [50, 51]. In addition, skills in collaborating with children and families around treatment planning are crucial [52].

Cognitive behavioral therapy is effective for treating mild to moderate child and adolescent depressive symptoms [45, 53, 54]; however, there is variability in the long-term staying power of treatment [46, 53]. Interpersonal therapy has been found to be effective for mild to moderate depression in adolescents [46]. Targeted interventions for youth with depression or risk factors for depression have been shown to be more effective than universal prevention programs for youth depression [47, 48], suggesting the utility of appropriate depression screening and history gathering.

Mood tracking is a simple behavioral monitoring strategy and intervention that can be offered by pediatricians during initial management. This involves asking the child or adolescent to identify and track their mood for a specified time frame (usually 1–2 weeks). A mood diary, journal, pictures, or list can be used. Reviewing the diary while listening for patterns can provide information about duration, intensity, and malleability of mood (e.g., when, where, and in which situations mood is high or low), as well as identify opportunities for introducing more specific interventions (e.g., behavior activation, pleasant activities, problem-solving).

Behavior activation addresses symptoms of low mood, fatigue, and anhedonia that contribute to isolation and less participation in daily activities and routines. Behavior activation can include enjoyable activities such as going for a walk,

drawing a picture, calling a friend, or regular day-to-day activities such as folding laundry. Active participation (e.g., drawing a picture) is better than passive participation (e.g., watching TV); however, buy-in and motivation are also important; therefore soliciting a variety of activities to choose from (3–4) is often a useful start. The aim of behavior activation is to break the cycle of low mood and low activity. PCPs can help children and families develop daily routines and structure as an initial management strategy.

Pleasant activity scheduling helps youth with depression identify activities that are pleasant and enjoyable. The aim of pleasant activity scheduling is to reduce the cycle of inactivity, anhedonia, and negativity and consequently boost mood with active participation in activities.

Problem-solving encourages youth with depression to identify a target problem and brainstorm solutions. This active coping strategy is intended to help youth identify multiple possible solutions to a pressing concern or problem. By doing so, the goal is to reduce negative thinking and hopelessness and increase mastery and coping skills.

Relaxation and mindfulness skills can assist in coping with negative affect and somatic distress and distract from negative thoughts. Guided imagery, progressive muscle relaxation, and diaphragmatic breathing are examples of techniques that can be taught during initial management of emotional distress. Several online resources and YouTube videos are available that can aid the caregivers in initiating practice.

Encouraging parent/caregiver involvement is especially important for young children with depressive symptoms. Goals include increasing positive reinforcement and communication in the child's environment. Key points for parental and family education are listed in Table 10.3.

### **Mobile Applications and Technologies**

There are free and low-cost child- and family-friendly apps for mood tracking (e.g., Mood Meter), relaxation (e.g., Breathe2Relax), and activities. Additionally, there are websites that help compare app cost and functionality ([www.wellocracy.com](http://www.wellocracy.com)). As new apps and technologies continue to emerge, it can be difficult to keep up; however, PCPs can offer guidance in selecting apps based on evidence-based strategies (e.g., mood tracking, behavior activation, relaxation) and encourage families to look for apps that augment these strategies while conveniently fitting with their routines [61, 62]; and to empower families to compare, try out, and report back their experience. A review of apps developed after 2007 found that the most common behavioral components in mobile apps included self-monitoring, feedback and action alerts, and social support [63].

### **Psychopharmacologic Interventions**

For cases of depression with higher severity that require medication management, treatment can be divided into three phases: acute, continuation, and maintenance [4]. During the acute phase, treatment with an antidepressant is initiated and titrated



**Table 10.3** Key points for parental/family education [19, 47, 52, 55–60]

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*Provide a description of depressive symptoms:* It is important for families to know that a child with depression may not look sad and that depression may look like irritability and anger. It is also important for families to know that depression is not their fault.

*Encourage families to remain active:* Explain the cycle of doing less leading to feeling worse and the role of activities and routines (e.g., behavior activation). It is helpful for families to know how they can help by including pleasant routines and family time in their schedule as much as feasible.

*Encourage families to plan ahead:* Develop a coping plan for parent and child to include stress relief/self-soothing/relaxation activities, social supports, and who to talk to, what to do now, and what to do if symptoms worsen.

*Identify family strengths and psychosocial supports:* Explain the role of social support and capitalize on existing prosocial and supportive relationships among family members and peers.

*Address emergency and safety planning:* It is important for families to know that asking about suicide does not lead to suicide. Not asking is far more dangerous. Modeling ways to ask about how their child is feeling and providing safety planning supports (emergency/crisis numbers and procedures) can help caregivers feel more comfortable observing and asking their child about risk.

*Address concerns about treatment:* Although individual psychotherapy, family therapy, pharmacotherapy, or some combination may be warranted, families may experience worries and hesitation about beginning treatment. Worries may derive from stress and uncertainty, concerns about side effects, stigma, and/or cultural experience. Listen carefully to families' concerns, welcome questions, and provide information in a way that is open, accurate, and clear.

*Identify potential risks in the home:* Access to lethal means, especially guns, should be restricted or eliminated. Also, any old or surplus prescription or over-the-counter medications with abuse potential should be promptly and properly removed from the home.

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to a response dose. In the continuation phase, treatment is continued for 6–12 months to achieve remission [4]. Lastly, the goal of the maintenance phase is to prevent recurrence by continuation of medication and/or booster therapy session. Maintenance phase is particularly important for children and adolescents who already experienced a prior depressive episode or suffer from more severe symptoms [4, 64].

Selective serotonin reuptake inhibitors (SSRIs) are the mainstay of antidepressant treatment for children and adolescents. The response rate for SSRIs is 40–70%. However, placebo response rate is quite high; therefore, the calculated number needed to treat is 10 [4]. Fluoxetine, which was the first medication approved by the FDA for the treatment of depression in children and adolescents, has shown the largest difference between medication and placebo response. The second, and only other antidepressant approved by the FDA for the treatment of depression in children and adolescents, specifically ages 12 and up, was escitalopram [3]. Other SSRIs, including citalopram, sertraline, and paroxetine, have been shown to be effective in children and adolescents for other mental health conditions [3, 10]. Other antidepressants such as venlafaxine and bupropion have also demonstrated efficacy in the treatment of depression in adolescents [3–5, 10]. Tables 10.4 and 10.5 include medication charts for quick reference. Table 10.6 contains talking points for parents about the initiation of antidepressants.

**Table 10.4** Antidepressant medications [3, 4, 10, 64]

Selective serotonin reuptake inhibitors (SSRI)				
Medication	Initial dose, mg	Target dose	Maximum dose, mg	Clinical considerations
Escitalopram (Lexapro)	5–10	Children 10–20 mg Adolescents 10–20 mg	30	FDA indication for treatment of depression in ages 12 and up; lower risk of drug-drug interactions, intermediate half-life Available in liquid formulation
Fluoxetine (Prozac)	10	Children 20 mg Adolescents 20–40 mg	60	FDA indication for treatment of depression in children and adolescents. Also approved for treatment of OCD in children 7 and up Long half-life; potential for drug-drug interactions Available in liquid formulation
Fluvoxamine (Luvox)	25	Children 50–200 mg Adolescents 50–200 mg	200 300	FDA indication for treatment of OCD in children 8 and up Drug-drug interactions due to inhibition of CYP1A2, CYP2C9, and CYP3A4
Sertraline (Zoloft)	12.5–25	Children 50–200 mg Adolescents 50–200 mg	200	FDA indication for treatment of OCD in children 6 and up Intermediate half-life Available in liquid formulation
Citalopram (Celexa)	10	Children 20–40 mg Adolescents 20–40 mg	60	Fewer drug interactions and fewer side effects Potential for QTc in combination with pimozide Available in liquid formulation
Paroxetine (Paxil)	10	Children 10–30 mg Adolescents 20–40 mg	50	No FDA indication for use in children or adolescents with depression; particular concern re: SI Short half-life; higher risk of discontinuation syndrome; requires a slower taper on discontinuation; slightly greater potential for wt gain Available in liquid formulation

With the initiation of any antidepressant medication, start low and increase slowly. Clinical response usually occurs in 4–6 weeks after medication is titrated to a treating dose [64]. In cases of moderate depression in which a trial of an antidepressant is warranted, treatment can be initiated and managed in the primary care setting. For children and adolescents, close monitoring for suicidal ideation, suicidal behaviors, and other side effects upon initiation of treatment is required. Monitoring is particularly important for children or adolescents with a history of

**Table 10.5** Non-SSRI antidepressant medications for depression [3, 4, 10, 64]

Medication	Medication class	Initial dose	Target dose	Maximum dose, mg	Clinical considerations
Bupropion (Wellbutrin) Bupropion SR	NDRI	100 mg	Children 150–300 mg Adolescents 300 mg	300	Contraindicated with arrhythmias, atrioventricular block, bulimia, and seizure history; lower rate of sedation; weight neutral
Bupropion XL	NDRI	150 mg	Children 150–300 mg Adolescents 450 mg	450	Slightly lower risk of seizure; otherwise, same as above
Desvenlafaxine (Pristiq)	SNRI	50 mg	Children 50 mg Adolescents 50–100 mg	100	Requires gradual taper for discontinuation, risk of excessive sweating, palpitations, and tachycardia
Duloxetine (Cymbalta)	SSNRI	20 mg twice a day	Children 40–60 mg Adolescents 40–60 mg	60	Also indicated for chronic pain and urinary continence; risk of elevated blood pressure; potential for drug-drug interaction via inhibition of CYP2D6; avoid use in hepatic disease
Mirtazapine (Remeron)	NaSSA	7.5– 15 mg	Children 15–45 mg Adolescents 15–45 mg	45	Useful for insomnia due to sedative effects; associated with weight gain and increase in appetite; rare risk of neutropenia Available in dissolvable formulation
Trazodone (Desyrel)	SARI	25– 50 mg	Children 100–150 mg Adolescents 100–150 mg	150	Sedative effects; can cause postural hypotension; rare risk of priapism; not commonly used as a monotherapy
Venlafaxine XR (Effexor)	SSNRI	37.5 mg	Children 150–225 mg Adolescents 150–225 mg	300	Acts as an SSRI at low dose; also indicated for chronic pain; use with caution with hepatic impairment Can cause excessive sweating and tachycardia

*NaSSA* noradrenergic and specific serotonergic antidepressant, *NDRI* norepinephrine-dopamine reuptake inhibitor, *SARI* serotonin agonist and serotonin reuptake inhibitor, *SSNRI* selective serotonin-norepinephrine reuptake inhibitor

self-injurious behavior, impulsivity, or family history of bipolar disorder [3]. While this text will include the most common and/or concerning potential side effects, the FDA package insert for each medication will include a comprehensive list of adverse effects.

Common side effects of SSRIs, reported by 10–20% of those prescribed, in the initiation of treatment include drowsiness, weight gain, insomnia, dizziness, anxiety, headache, and sexual dysfunction [10, 64]. Particularly in younger children, SSRIs may be associated with disinhibition, agitation, and anxiety. Other side effects to consider when prescribing an SSRI are nausea, rash, daytime malaise, and cognitive dulling [10]. These side effects are typically short-lived or tolerable, but reducing the dose, if recently increased, or dividing the dose may be helpful. If intolerable side effects persist, management with adjunct medication or switching to another antidepressant may be required. There is a risk of mania in children and adolescents with genetic vulnerability; therefore, assessment of family history for other mood or psychotic disorders is essential [4]. Other possible serious adverse reactions, which are rare, include excessive bruising, prolonged bleeding time, hyponatremia, serotonin syndrome, and extrapyramidal symptoms [64]. The risk of these reactions is increased with children with other medical problems requiring management with multiple medications or other medical interventions. Antidepressants should not be discontinued abruptly as it can result in discontinuation syndrome, which can include agitation, sleep disturbance, paresthesia, and dizziness.

### **Black Box Warning for Suicidal Ideation in Youth on Antidepressants**

In 2004, the FDA issued a black box warning on antidepressants due to an associated increase in suicidal ideation and behavior. The rate of the increase was 4% compared to 2% in patients receiving placebo when randomized clinical trials were analyzed in a series of meta-analyses. There were no completed suicides in the pooled trials [67]. The black box warning has been controversial as it has been associated with a decrease in antidepressant prescribing, particularly in the primary care setting, and a decrease in new diagnoses of depression [68]. However, the suicide rate has continued to rise steadily. More recent data show that the rate of use has returned to the rate prior to the warning [69]. Given the known association between suicide and severe depressive symptoms and the improvement of suicidal ideation with continued treatment with SSRI, the use of antidepressants when indicated outweighs the risk of increase in suicidal ideation with the initiation of treatment [4]. However, close monitoring and assessment of suicidal ideation is warranted whenever a child or adolescent is diagnosed with depression and started on an antidepressant. Of note, multiple studies indicate that paroxetine (Paxil) is of particular concern [70, 71].

**Table 10.6** Talking points for parents about initiation of antidepressants [65, 66]

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*Review indication for treatment:* Depression is an illness that has physical, cognitive, and behavioral effects. If depression is not treated, it can last close to a year or longer and impairs functioning at school and home. Depression also increases risk for suicide and other behavioral problems.

About 60% of children/adolescents will improve with treatment with an antidepressant. Even more children/adolescents respond with medication and therapy.

*Discuss treatment options:* There are two medications approved by the FDA for treatment of depression in children and adolescents. There are other antidepressants with studies to support their use that are also commonly used to treat depression in children/adolescents. The combination of medication and therapy is the most effective treatment for moderate and severe depression.

*Discuss treatment course:* It can take 4–6 weeks for your child to respond to antidepressant treatment once medication is increased to a treating dose. During that time, we will monitor symptoms and increase dose as needed. It is also recommended that you help your child continue healthy habits with a regular sleep schedule, regular exercise, and a well-balanced diet.

*Discuss potential side effects:* Antidepressants (SSRIs) are generally well tolerated. Side effects are reported by less than 20% of patients. The more common among side effects reported are stomach upset, weight gain, headache, and sleep changes.

Parents should be attentive to signs of increased anxiety, irritability, aggressiveness, or impulsivity. In a small number of instances, a child or adolescent might have extreme reactions to antidepressants as a result of genetic, allergic, drug interactions or other unknown factors.

*Discuss suicide risk:* In 2004, the FDA issued a warning (black box warning) after reviewing 23 studies of nine antidepressants. They found an elevated risk of suicidal ideation and behavior among those taking antidepressants. A later study showed an elevated but smaller risk. No suicides occurred in any of these studies.

Research suggests that any increased risk of suicidal thoughts or behaviors is most likely to occur during the first 3 months of treatment, with some studies showing that the risk is highest in the first 3–6 weeks.

Through careful monitoring, safety planning, and the combination of medication with psychotherapy, the risks for increased suicidal thoughts can be managed. *In the vast majority of cases of moderate to severe depression, the risk of SI posed by untreated depression is of greater clinical significance than the risk of SI associated with antidepressant medication.*

*Address emergency and safety planning:* The provider will work with you (the family), your mental health clinicians, and your other providers to develop an emergency action plan, called a “safety plan,” that is, a planned set of actions for family and physician to take if and when your child has increased suicidal thinking.

- A safety plan can be a simple agreed-upon understanding between physician and family in which the family is provided with a 24-h number available to deal with crises (number for on-call physician, mobile crisis team, or 911). Physician should discuss minimizing access to potentially harmful items in the home: lethal means of suicide, such as guns or large quantities of dangerous medications, including over-the-counter drugs, should be removed from the house or stored in an inaccessible location.
  - In the case of a crisis, it must be emphasized that antidepressants should not be discontinued abruptly as it can result in discontinuation syndrome which can include agitation, sleep disturbance, paresthesia, and dizziness.
-

## When to Refer

In cases of mild depression, psychotherapy is the first line of treatment. If significant stressors are present, psychotherapy and/or social service resources should also be considered. If symptoms are present in children under 6, referral for a comprehensive diagnostic behavioral health evaluation is recommended as more intensive parent guidance and family-focused intervention are likely warranted. If a patient has severe side effects from SSRI, does not improve with a second trial of an SSRI, or has complex psychiatric comorbidities, referral for psychiatric evaluation to clarify any diagnostic questions or further augment treatment may be necessary. Due to limited access to mental health providers, in cases with higher severity or complexity, referrals for specialized services should be made early as there may be a wait for enrollment in treatment, while symptoms are managed in the primary care setting.

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## Key Considerations for Follow-Up

Follow-up visits can be used to safely titrate the antidepressant to a therapeutic dose. It is important to note that many patients, about 60%, may have a partial or no response to their first trial of antidepressant. Common reasons for lack of response are inadequate dosing, inadequate duration, and intolerable side effects [64]. Initial titration for children should be a slow process, increasing by incremental doses every 1–2 weeks. Titration may be limited by side effects. An adequate trial is defined as 6 weeks at a treating dose; however, most patients have at least a partial response to an adequate dose in the first 2–4 weeks. If symptoms persist within therapeutic dose range, continue titration. Maximum dose for an individual patient is determined by response or therapeutic safety parameters. If symptoms have not remitted after 12 weeks at a tolerated maximum therapeutic dose, consider switching to another SSRI or atypical antidepressant. If side effects are intolerable or there is no response with the first trial of an SSRI, a trial of a second SSRI or SNRI is needed. Half-lives of sertraline, citalopram, paroxetine, and sustained-release bupropion are shorter in children than reported in adults, so they may be at greater risk for discontinuation syndrome or require more frequent doses of some medications to maintain steady state [72, 73]. Once a child or adolescent is having no or minimal depressive symptoms, the same treatment should be continued for at least 1 year. If there is a history of prior depressive episodes or the current episode is chronic and/or severe, it is recommended that treatment is continued for a longer period of time [3].

The decision to discontinue antidepressant treatment after sustained remission should be discussed with family and mental health providers. As the therapist is often the mental health specialist with the most frequent contact with the patient, their input can be very helpful. While most children and adolescents recover, an episode of major depression recurrence is common. Recurrence occurs in about 40% of children and adolescents over a 5-year period [46]. In the case of a

recurrence, reinitiating previously effective antidepressant treatment is recommended, though the response may vary from episode to episode.

In some cases of moderate to severe depression, depressive symptoms may interfere with a child's ability to fully participate in psychotherapy without a trial of an antidepressant first. In these cases, following the guidelines above, as well as obtaining permission to communicate with the child's mental health providers, is important for coordinated treatment decisions. Follow-up visits should also include asking the family and child directly about psychotherapeutic treatment progress. A meta-analysis conducted by Weisz and colleagues [46] found variability in long-term effects of psychotherapy for depressed adolescents beyond 1-year follow-up, suggesting periodic follow-up and assessment after treatment ends may be warranted.

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## Conclusion

Depression in children and adolescents often first presents in the primary care setting. Recognizing the symptoms early can lead to early interventions and decrease distress and impairment of function. Symptoms of depression can alter a child's cognitive, behavioral, and physical state. In assessing children and adolescents, it is important to engage the family in determining level of impairment and making a treatment plan. Treatment is likely to start in the primary care setting while the family is referred for specialized mental health treatment. This may include simple behavioral interventions and treatment with antidepressant medication as indicated. Antidepressant treatment has been shown to be effective in children and adolescents. Though generally well tolerated, parents and providers need to monitor for side effects. A safety plan should be established with the parents of all children and adolescents with depression.

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L. Kevin Chapman and Alphonso Nichols

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## Introduction

Anxiety disorders are the most prevalent types of psychiatric disorders in the USA, affecting both children and adults at staggering rates. Recognition of these disorders in the primary care setting can set the stage for timely diagnosis and appropriate therapeutic interventions as well as prevent potential misdiagnosis of mental illnesses with overlapping symptoms. There can be significant distress and impairment associated with anxiety disorders, and effective treatment can be life changing. Given the targeted nature of this text, this chapter will focus on the anxiety disorders that are most likely to be encountered in the pediatric primary care setting: social anxiety disorder, separation anxiety disorder, and generalized anxiety disorder.

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## Brief Review of Epidemiology and Pathophysiology

In the USA, anxiety disorders are the most common psychiatric conditions in both adults and children, affecting roughly 40 million Americans [1–3]. Though anxiety disorders are very treatable, only one-third of those suffering from an anxiety disorder receive treatment [4]. Moreover, 25% of adolescents will be diagnosed with an anxiety disorder in his or her lifetime [5]. Though anxiety symptomology is relatively consistent in its phenotypic expression, there are undoubtedly variations in the manifestation of these symptoms in children and adolescents for a number of reasons including developmental factors, cognitive factors, differences in child-specific antecedents (“triggers”)/maintenance factors, and other factors that vary from patient to patient.

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L. K. Chapman (✉) · A. Nichols  
Independent Practice, Louisville, KY, USA

## Diagnosis and Key Components of History

Anxiety disorders share more commonalities in presentation than disparities. Thus, children and adolescents presenting with separation anxiety, social anxiety, and worry (GAD) often present in a consistent fashion. All three of these disorders are often manifested through school refusal or premature departure from school [6], somatic complaints (stomachaches, heart palpitations, hot/cold flushes), irritability, sleep disturbance, restlessness, frequent reassurance seeking toward their parents, and avoidance behavior [6].

Significant alteration from previous observations of functioning is an important component to identify when assessing the child or adolescent's history since caregiver report is essential in aiding diagnosis. Since children of anxious parents are three to seven times more likely than children of non-anxious parents to have an anxiety disorder [1, 7, 8], being mindful of parental anxiety and potential parental modeling of distress is an important consideration when assessing child anxiety. Diagnostic criteria for all anxiety and related disorders require the symptoms to cause significant distress and impairment.

### Separation Anxiety Disorder

Separation anxiety disorder is characterized by excessive anxiety about being away from a loved one, particularly a caregiver. The child is often worried about a negative event happening to the caregiver or a negative event happening to the child. A child with normal separation concerns may express "missing" the caregiver when he/she goes on an extended business trip, whereas a child suffering from separation anxiety frets about the absence of a caregiver for an extended period of time on a frequent basis, even during the most mundane situations (e.g., if the child is invited to a sleepover, the child is at school and parent is driving several hours away for work, or the parent is away from the child for a few hours). The child with separation anxiety may also frequently worry about being kidnapped or refuse to attend school due to anxiety about something bad happening to the caregiver. Additionally, the child with separation anxiety may also experience nightmares and seek frequent reassurance about the parent's whereabouts.

### Social Anxiety Disorder

Social anxiety disorder involves a persistent fear and anxiety about social situations where negative evaluation may occur. Though it is normal to be wary of strangers and novel situations (such as when meeting a new person or being nervous about speaking in front of the class), the socially anxious child may do any of the following: cry excessively about presenting in front of the class to the point of being sick and not attending school, avoid sporting events due to anxiety about being made fun of by peers, have very little social interaction with peers in general, and complain of

somatic complaints weeks in advance before a presentation. Social anxiety may also manifest as significant performance anxiety before participating in sporting though the socially anxious child “plays well” during practice.

## Generalized Anxiety Disorder

Generalized anxiety disorder is characterized by significant anxiety that leads to excessive worry. Normal concerns that are not driven by chronic levels of anxiety lead to effective problem solving. For example, a child experiencing normal levels of anxiety may worry about an upcoming exam but view the anxiety as an emotion that is helpful by prompting the child to study. However, the child with chronic worry may worry about a number of areas, even if things are going well. For example, the worried child may worry about getting to school on time, worry about making mistakes on assignments, become “frozen” when making everyday decisions, and seek frequent reassurance from a caregiver about whether he/she will be able to engage in certain activities when on a trip. The worried child also experiences sleep disturbance, difficulty concentrating, fatigue, and irritability.

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## Confounders and Comorbidities

Due to the restlessness and impaired concentration often associated with both anxiety and impulsivity, ADHD is a significant differential diagnosis for anxiety in children and adolescents. Though restlessness is a symptom of both ADHD and anxiety, anxiety-associated restlessness is associated with more subjective distress, somatic complaints, and avoidance behaviors. The inattention often found in ADHD tends to be more consistent, particularly in school settings. Difficulty concentrating as a symptom of anxiety, however, tends to be the result of the mind being occupied by worried thoughts about school, loved ones, social relationships, and other factors. Depression is a frequent comorbid diagnosis with anxiety disorders in children and adolescents. Determining whether symptoms of depression are present in addition to anxiety is paramount when assessing the child or adolescent.

Anxiety in children commonly manifests with somatic symptoms such as headaches, abdominal pain, shortness of breath, chest pain, and dizziness. A thorough medical workup should be performed on each patient, and medical problems such as migraine headaches, celiac disease, Gastroesophageal reflux disease (GERD), mitral valve prolapse, asthma, and other medical disorders should be ruled out rather than assuming the symptoms are solely manifestations of anxiety. Comorbidity with such conditions and anxiety can most certainly occur, and children with chronic medical issues are at increased risk for mental illness.

Substance use should always be a consideration. Intoxication with stimulant prescription or street drugs and withdrawal from sedatives such as opiates to benzodiazepines to alcohol can very much mirror anxiety symptoms. If benzodiazepines are being abused, there may even be interdose anxiety that the patient is experiencing.

In certain patients, marijuana use can precede the onset of severe anxiety symptoms [9]. Patients with substance use disorders will many times not have the usual triggers that are associated with typical anxieties in children and adolescents. Symptoms may also be greatly out of proportion to what is typically seen and quite treatment resistant [10].

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## Screening and Measures

Given the frequent comorbidity of anxiety and depression, screening for the other is recommended whenever there is clinical suspicion of either. Table 11.1 displays commonly used screening assessment tools for anxiety and depression in children and adolescents. Additionally, all youth with anxiety symptoms should be screened for trauma, depression, and substance use disorders. Please refer to Fig. 15.1 in this text's Substance Use Disorder (SUD) chapter for the CRAFFT, the recommended SUD screening tool.

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## Initial Management

### Psychosocial and Behavioral Interventions

Behaviorally, it is important to reiterate the importance of eliminating avoidance behavior when managing anxiety and related disorders in children and adolescents. Avoidance works in the short-term, so it can be very reinforcing. The problem is that it is associated with significant impairment and robs the youth of the opportunity to realize that things would not turn out as badly as the youth thought they would. Thus, attending school, giving speeches in front of classmates, interacting with others, and eliminating worry concerns are necessary targets of treatment. Though the child or adolescent may report that he/she is unable to function in the particular social situation, assure the caregiver that gradual "exposure" back into the currently feared situation will be essential in eliminating significant distress and impairment.

Ideally, this is achieved in collaboration with a mental health professional trained in cognitive behavioral therapy (CBT), the gold standard psychological intervention for anxiety disorders (see Fig. 11.1). Of note, in collaborative care models, depending on licensure, training, and state regulations, the behavioral care manager may be able to initiate psychotherapy. Psychotherapy can be helpful as children who are prone to anxiety and related symptoms struggle in two specific areas: (a) negative, unrealistic thoughts about themselves, their emotions, and the world around them and (b) attempts to avoid anxiety-provoking situations as well as strong, negative emotions. As such, many children with anxiety have thoughts that include "thinking errors" that create more anxiety than necessary in many harmless situations. Examples include "mind reading" (e.g., "they will think I'm an idiot"), fortune telling (e.g., "I'm going to fail the exam"), and catastrophizing (e.g., "this always happens to me!" or "this is the worst paper ever!").

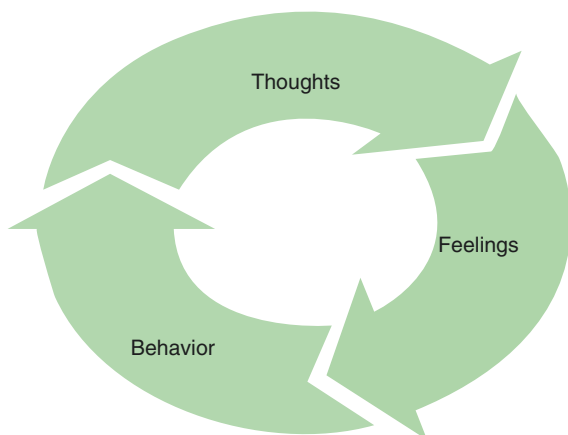
CBT contains an effective treatment component known as cognitive restructuring that teaches the child or adolescent that thoughts are "guesses" not "facts" in

**Table 11.1** Public domain anxiety symptom rating scales

Measure	Domain	Age validated and # of items	Completed by	Administration and scoring times training (none, unless otherwise indicated)	Languages available	Reference
Pediatric Symptom Checklist (PSC)	Interpersonal domains, psychosocial dysfunction	4–16 years 35 items	Youth	<5 min scoring 2 min	Translated in >20 languages	[11]
Acute Stress Checklist for Children	Acute stress disorder symptoms w/in the first month of traumatic exposure	8–17 years 29 items	Youth	5 min scoring: 1–2 min	English and Spanish	[12]
Penn State Worry Questionnaire for Children (PSWQ-C)	Worry	7–17 years 14 items	Youth	<5 min scoring: 2 min	English, Korean, Danish	[13]
Revised Children's Anxiety and Depression Scale (RCADS)—Youth and Parent Versions	Anxiety, depression	8–18 years 47 items	Youth and/or parent	5–10 min Excel scoring sheets online available for English versions in children grades 3 and up at <a href="http://www.childfirst.ucla.edu/resources.html">http://www.childfirst.ucla.edu/resources.html</a> Hand scoring: 5 min	English, Spanish, Danish, Dutch, Korean	[14]
Screen for Child Anxiety-Related Emotional Disorders (SCARED)—Youth and Parent Versions	Anxiety disorders	8–18 years 41 items	Youth and/or parent	10 min Scoring: 2 to 3 min	Arabic, Chinese, English, French, German, Italian, Portuguese, Spanish, Thai	[15]
Spence Children's Anxiety Scale	Generalized anxiety symptoms (DSM-IV)	8–15 years 45 items Preschool version for ages 2.5–6.5 34 items	Youth and/or parent	5–10 min Adobe reader X automatic scoring questionnaire available at <a href="http://www.scaswebsite.com/">http://www.scaswebsite.com/</a> Hand scoring: 5 min	English, Spanish, Chinese, Arabic, French, Russian preschool, German, Hindi, Portuguese preschool, and others	[16]



**Fig. 11.1** CBT model: the bidirectional relationship between thoughts, feelings/physical sensations, and behaviors



addition to understanding the connections between the thought, feeling/physical sensations, and resultant behaviors. Additionally, Socratic questions can be used to assist the child or adolescent in challenging unhelpful thoughts and creating more flexible thoughts used to ward off anxiety. Examples include “What’s the evidence that this negative event will occur?” “Is the negative prediction being driven by anxiety?” “Is the patient 100% sure this negative outcome will occur?” “What’s the worst that can happen and can the patient cope with that?” “What’s happened in the past?”

Relaxation and mindfulness techniques can be additionally helpful in alleviating much of the physiological arousal associated with anxiety and worry. Of note, this text’s Depression chapter includes a brief discussion of some apps that may be helpful adjuncts in these interventions. A mindfulness approach can be very helpful in assisting a child or adolescent to focus on the present moment rather than engage in worry, avoidance, or other behaviors driven by distressing emotional states. One strategy in assisting the child or adolescent with being more aware of his or her emotion in real time, or anchoring technique, is called nonjudgmental awareness. The child or adolescent begins with a few diaphragmatic breaths (e.g., inhale for 4 s, hold the breath for 5 s, and exhale for 6 s) followed by simply becoming “aware” of one’s thoughts, feelings/physical sensations, and behaviors as they are occurring in the present moment.

Finally, one of the most significant factors in effectively managing anxiety in children and adolescents is to provide the caregivers information about helpful strategies to implement at home. Please see Table 11.2 for key points to include while you are educating the patient’s family.

**Table 11.2** Selective serotonin reuptake inhibitors (SSRIs) for anxiety disorders [18–22]

Medication	Initial dose	Target dose	Maximum dose	Clinical considerations
Escitalopram (Lexapro)	5–10 mg	Children 10–20 mg Adolescents 10–20 mg	30 mg	FDA approved for social anxiety disorder from 10 to 17 years old. Generally accepted for effectiveness in GAD, lower risk of drug-drug interactions, intermediate half-life Available in liquid formulation
Fluoxetine (Prozac)	5–10 mg	Children 20 mg Adolescents 20–40 mg	30 mg in younger children 60 mg in adolescents	FDA indication for social anxiety disorder from ages 5 to 18, multiple studies showing effectiveness with GAD. Also approved for treatment of OCD in children 7 and up Long half-life, potential for drug-drug interactions Available in liquid formulation
Fluvoxamine (Luvox)	12.5 mg	Children 50–200 mg Adolescents 50–200 mg	200 mg in patients 8–11 y/o 300 mg in 11 y/o and up	FDA approved for generalized anxiety disorder from 8 to 17 years old. Multiple studies suggest effectiveness in social anxiety disorder and separation anxiety disorder. Drug-drug interactions due to inhibition of CYP1A2, CYP2C9, and CYP3A4. Consider lower doses in female patients. Divide into twice-daily dosing for doses greater than 50 mg per day total dose
Sertraline (Zoloft)	12.5–25 mg	Children 50–200 mg Adolescents 50–200 mg	200 mg	FDA approved for obsessive compulsive disorder from 6 to 17 years old. Multiple studies showing effectiveness in GAD and separation anxiety disorder and social phobia, including the CAM study. Intermediate half-life Available in liquid formulation
Citalopram (Celexa)	2.5–10 mg	Children 20–40 mg Adolescents 20–40 mg	40–60 mg	FDA approved for generalized anxiety disorder from 7 to 17 years old. Considered to be useful in social anxiety disorder and separation anxiety disorder. Fewer drug interactions and fewer side effects, potential for QTc in combination with doses over 40 mg per day or when used with pimozide Available in liquid formulation

(continued)

**Table 11.2** (continued)

Medication	Initial dose	Target dose	Maximum dose	Clinical considerations
Paroxetine (Paxil)	5–10 mg	Children 10–30 mg Adolescents 20–40 mg	50–60 mg	FDA approved for social anxiety disorder from 8 to 17 years old. Generally considered useful in the treatment of separation anxiety disorder and GAD. Short half-life; higher risk of discontinuation syndrome; requires a slower taper on discontinuation; slightly greater potential for weight gain; <i>may have higher risk of suicidality compared to sertraline and fluoxetine</i> Available in liquid formulation

## Pharmacologic Interventions

In the pharmacological treatment of anxiety in children, the goal is to decrease the overall burden of anxiety. While medications are certainly not the center of treatment for children, they can be helpful in decreasing the anxiety to the point where the patient can start to face it in their day-to-day life and deal with it in therapy. In child psychiatry, the mantra for medication treatment is “Start low, go slow.” This helps to minimize potential side effects of medications. Youth with anxiety disorders may be even more distressed by physical side effects than their anxiety disorder, particularly in the window before therapeutic effect has taken place.

Selective serotonin reuptake inhibitor (SSRI) antidepressants are first-line psychiatric medications for anxiety disorders in children and adolescents. Unfortunately, SSRIs and most of the other treatments for anxiety typically do not work immediately, and it is important to set expectations about the timeframe for effect and what patients should expect. Treating anxiety with medications is not like treating ADHD, where there is an almost immediate robust response to a therapeutic dose. At the onset of treatment, parents and children should be told that these medications must be taken daily, will work better over time, and may take 2–3 weeks to show any effect and up to 6 weeks to show their full effects at a given dose. As long as there are no unbearable side effects, it is important to keep taking the medication consistently to see if a response is achieved and push through the doses. Despite the daunting nature of the list of possible side effects, most people tolerate SSRIs and serotonin-norepinephrine re-uptake inhibitors (SNRIs) very well. Table 11.3 provides a quick reference for information about SSRIs.

Please note that due to the relative dearth of studies regarding medication in children and adolescents compared to studies in adults, pediatric prescribing is often “off label.” While this is acceptable and often quite necessary, it must be explained to parents and patients ahead of time [17]. Of note, all antidepressants used in children and adolescents carry a black box warning from the FDA regarding suicidal thoughts and behaviors. Please refer to the Pharmacologic Interventions section of

**Table 11.3** Non-SSRI medications for anxiety disorders [10, 18–24]

Medication	Medication class	Initial dose	Target dose	Maximum dose	Clinical considerations
Duloxetine (Cymbalta)	Serotonin and norepinephrine re-uptake inhibitor	20–30 mg per day	Children 40–60 mg Adolescents 40–60 mg	120 mg	FDA approved for generalized anxiety disorder for ages 7–17; also indicated for chronic pain and urinary continence; risk of elevated blood pressure; potential for drug-drug interaction via inhibition of CYP2D6; avoid use in hepatic disease
Venlafaxine XR (Effexor)	Serotonin and norepinephrine re-uptake inhibitor	37.5 mg	Children 150–225 mg Adolescents 150–225 mg	225 mg	FDA approved for generalized anxiety disorder from age 7 to 17. Acts as an SSRI at low dose; also indicated for chronic pain; use with caution with hepatic impairment. Can cause excessive sweating and tachycardia
Buspirone (Buspar)	Partial agonist of serotonin receptors	5 mg PO twice daily	15–60 mg/day divided BID	60 mg daily; consider lower dosing in younger children with lower body weight	<b>No FDA approval</b> for use in children and two RCTs in children w/ anxiety failed to detect effect; has one positive open-label study for social phobia; common side effects include dizziness, fatigue, drowsiness, nausea, headache, nervousness, xerostomia, and agitation

(continued)

**Table 11.3** (continued)

Medication	Medication class	Initial dose	Target dose	Maximum dose	Clinical considerations
Hydroxyzine	Antihistamine	Start 5–25 mg PO BID to TID or weight-based dosing 2 mg/kg/day divided q6–8 h	May use weight-based dosing of 2 mg/kg/day divided PO q6–8 h	Maximum dose of 100 mg per day total. Consider smaller maximum dose for younger children with lower body weight	<b>No FDA approval for treatment of anxiety in children; no RCTs for anxiety in children;</b> may be used scheduled or as needed for acute anxiety. Common side effects include xerostomia, drowsiness, fatigue, ataxia, weakness, dysarthria, headache, and agitation. Note: younger children are more likely to have a paradoxical reaction to hydroxyzine

this text's Depression chapter as well as this text's Medicolegal Issues in Prescribing Medications to Children and Adolescents chapter for additional information when starting an antidepressant in a child, adolescent, or young adult for any reason. The Depression chapter includes a discussion of common antidepressant side effects, their associated black box warning regarding suicidal ideation, and Table 10.6, which includes talking points for parents about initiation of antidepressants.

### Selective Serotonin Reuptake Inhibitors (SSRIs)

Due to their demonstrated efficacy in treating anxiety disorders and the fact that they are relatively well tolerated, SSRIs are the most widely used medications for anxiety disorders in children and adolescents. Common medication class side effects include headaches, nausea, vomiting, light-headedness, appetite changes, weight changes, sedation, palpitations, increased blood pressure, tremor, akathisia, sexual dysfunction, loose stool, and constipation. Monitoring for serotonin syndrome is indicated, especially when using higher doses and whenever there is polypharmacy.

### Serotonin-Norepinephrine Reuptake Inhibitors (SNRIs)

Two of the medications in this class are FDA approved for anxiety disorders in children and adolescents; however, SNRIs may not be as effective or well tolerated for comorbid child and adolescent depression as fluoxetine, an SSRI medication [25]. Common class side effects include headaches, nausea, vomiting, light-headedness, appetite changes, weight changes, sedation, palpitations, increased blood pressure,

tremor, akathisia, sexual dysfunction, loose stool, and constipation. Monitoring for serotonin syndrome is indicated, especially when using higher doses and whenever there is polypharmacy.

### **Additional Medication Classes for Consideration**

After first-line, FDA-approved treatments with relatively benign side effect profiles have been tried and have either not worked or caused intolerable side effects, alternative agents may be pursued. Note that the risk/benefit ratio and course of treatment necessitating these choices should be reviewed with families prior to their use.

Tricyclic antidepressants (TCAs) have plentiful studies supporting their use in anxiety disorders; however, overall they appear to be more effective in adults than in children and adolescents. They can be helpful for patients who have failed SSRIs and SNRIs. TCAs, however, are “dirtier” drug in that they tend to modulate receptors outside of serotonin and norepinephrine, such as anticholinergic receptors and histamine receptors. This can give them therapeutic advantages but also leaves them more prone to side effects, some of which are serious. TCAs used in children and adolescents include clomipramine, desipramine, and imipramine. Of note, TCAs can be fatal in overdose, which is an issue of clinical significance given the high rates of depression and anxiety comorbidity.

Benzodiazepines may interfere with learning, and they are also potential substances of abuse. Additionally, controlled trials do not support the use of benzodiazepines in children for anxiety [26, 27]. For these reasons, benzodiazepines are typically used either as short-term interventions for adjunctive treatment or for severe, functionally impairing anxiety symptoms. Compared to adults, adolescents are vulnerable to misusing benzodiazepines due to less well-developed executive functioning, decision-making, and impulse control. Also, the increased risk of death with the combination of benzodiazepines and other drugs of abuse, opiates in particular given the recent opioid epidemic, should be weighed prior to use. If there is a history of substance use/abuse in the patient, benzodiazepines should be avoided. Note that children, especially younger children, are more likely to have a paradoxical reaction to benzodiazepines. As with all drugs with the potential for abuse, formulations with faster onset and shorter duration of action can be more problematic.

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### **When to Refer**

Two primary factors determine when it is appropriate to refer the child or adolescent for additional treatment options. First, a referral is warranted when parental report indicates that the symptoms have created significant personal distress and impairment in the child’s functioning. This may be indicated by parental observation, teacher report, a decline in academic functioning, restricted social relationships, an increase in risky behavior, isolation, and other behaviors that are abnormal based on the caregiver’s typical observations. Second, subjective distress as noted by the

child or adolescent would indicate an additional reason to refer. Additionally, if initial interventions in the primary care setting do not yield an adequate treatment response, referral should be initiated.

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## Key Considerations for Follow-Up

Monitoring the effectiveness of treatment is an inexact science. As patients feel better, they generally report feeling calmer and less stressed. Additionally, at the time of diagnosis and treatment initiation, it is good to identify target symptoms to follow, such as somatic complaints, days of school achieved, number and severity of panic attacks in a given time span, improvement in sleep, or other markers that can be documented. As anxiety has likely kept patients from participating in their general interests and activities, a return to these exploits is seen as a great sign of progress. Rating scales can also be used at the beginning of treatment and along the course of treatment in order to measure the anxiety at baseline and its improvement as treatment moves forward. Short rating scales can be done in the waiting room prior to each appointment.

Determining whether the caregiver has followed recommendations for additional treatment is a key consideration when following up with the anxious child or adolescent. Considering there is a familial transmission of anxiety [1, 7, 8], inquiring as to whether the family has considered psychological and/or psychiatric treatment is essential due to the debilitating nature of avoidance behavior and functional impairment in the anxious family. Table 11.4 includes some key points for parental/family education about anxiety in children and adolescents.

**Table 11.4** Key points for parental/family education

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### Key points for parental/family education

*Encourage families to combat avoidance behaviors and social withdrawal/isolation*—Permitting ongoing avoidance reinforces the problematic behavior creating more anxiety and distress long term. Supporting and facilitating gradual exposure to anxiety-provoking situations are key.

*Educate families on the importance of relaxation at bedtime*—Anyone who is not well rested will have more trouble handling stressful events, and trouble sleeping often comes with anxiety disorders. Every night before bed, breathing exercises (inhaling through the nose for 5 s and exhaling out the mouth for 6 s) coupled with anchoring (saying the five senses in the present moment) may be helpful. Additionally, consistent implementation of a calming bedtime routine is also valuable.

*Be on the lookout for declines in academic functioning*—Preoccupation with worried thoughts may make it difficult to concentrate or attend to instruction in school. If/when a youth does start to struggle academically, the associated distress and/or avoidance behaviors may make it difficult for the youth to bring up the issue. Monitoring of grades and communication with school personnel can provide accountability that will help combat avoidance behaviors as well as allow for earlier identification and addressing of problems.

*Address comorbid depressed mood, if present*—Explain the role of social support, and capitalize on existing prosocial and supportive relationships among family members and peers. Additionally, behavioral activation and pleasurable activity scheduling are great ways to elevate mood.

*Emphasize the importance of structure and consistency*—Having a routine and planning specific times to complete tasks can help a child feel more safe and secure.

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## Summary

Anxiety disorders in children and adolescents often first present in the primary care setting. Recognizing the symptoms early can lead to early interventions and decrease distress and impairment of function. Symptoms of anxiety can alter a child's cognitive, behavioral, and physical state and lead to avoidance behaviors that are then reinforced by the short-term relief from anxiety they provide. Addressing avoidance is a key aspect of psychosocial treatment. While psychotherapeutic and behavioral interventions are the first-line therapeutic modalities for addressing anxiety symptoms, psychopharmacology can be helpful and, when symptoms are severe, is indicated. Comorbid depression is common with anxiety disorders, and all youth with anxiety disorders should be screened for SUDs and trauma.

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Hasani Baharanyi

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## Introduction

Attention deficit hyperactivity disorder is a neurodevelopmental disorder characterized by developmentally inappropriate inattention, hyperactivity, and impulsivity that interferes with a child's academic, occupational, and social functioning. ADHD affects approximately 5% of children and adolescents and 2.5% of adults. It is one of the most common pediatric chronic disorders seen in primary care clinics. Left untreated, ADHD hinders fundamental childhood tasks: learning, making friends, and working. Furthermore, ADHD persists. The majority of children who meet criteria for ADHD continue to have impairing symptoms in adulthood [1, 2]. Primary care physicians have an opportunity to recognize, diagnose, and treat this life-changing disorder. To do so requires a comprehensive evaluation and a thoughtful approach to management.

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## Brief Review of Epidemiology and Pathophysiology

The worldwide pooled prevalence of ADHD is 5.29% according to data from 102 epidemiological studies conducted in North America, Europe, Africa, and the Middle East [3]. It is more prevalent among boys than girls. Pre- and perinatal risk factors have been associated with ADHD including maternal stress, smoking or alcohol consumption during pregnancy, low birth weight, and prematurity. Environmental toxins (organophosphates, lead) and unfavorable psychosocial conditions (severe early-childhood deprivation, maternal hostility) have been

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H. Baharanyi  
Lorio Psych Group, Atlanta, GA, USA

Morehouse School of Medicine Adjunct Faculty, Atlanta, GA, USA  
e-mail: [drbaharanyi@loriopsychgroup.com](mailto:drbaharanyi@loriopsychgroup.com)

associated with the development of ADHD as well [4]. To date, the pathophysiology of ADHD has yet to be fully elucidated. Functional MRI studies suggest impaired functioning of the prefrontal cortex, striatum, and cerebellum. These regions of the brain are responsible for processing errors, response to stimuli, reacting to rewards, inhibition control, and motor timing [5].

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## Diagnosis and Key Components of History

In order for youth to be diagnosed with ADHD, they have to exhibit impairments in attention and/or hyperactivity/impulsivity that are not better explained by another illness. The DSM-5 Diagnostic Criteria for ADHD are included in Table 12.1.

It is not uncommon for parents to come into the PCP's office stating that they suspect that their son or daughter has ADHD. The parents may have observed that the child seems more hyper when compared to his peers. Or perhaps teachers have noted that the child is struggling to pay attention in class. The diagnosis and potential implications worry most parents. Before arriving at a diagnosis, answers to the following questions should be obtained:

- Does your child repeatedly get off track?
- Is your child easily distracted?
- Is your child often forgetful?
- Is your child constantly on the go?
- Does your child avoid work that requires mental effort?
- Does he or she need constant supervision to complete work?
- Can your child wait his or her turn?
- Does your child fidget often?
- Is your child very talkative?
- Is your child easily distracted or sidetracked?
- Does your child often lose things?
- Does your child make careless mistakes on assignments? [6]

Children can be asked questions as well:

- Do you get easily distracted?
- Are you easily bored?
- Can you usually finish what you start?
- Is it hard to pay attention in class?
- Do you find yourself daydreaming or "spacing out"?

This is by no means an exhaustive list yet it covers some of the core symptoms of ADHD. If answered affirmatively, clinicians should ask how long symptoms have been present, as the diagnosis requires the presence of symptoms before age 12. It is also important to understand what exacerbates or mitigates symptoms, as this can point to potential differential diagnoses and comorbidities as well as inform treatment interventions. Collateral is key as ADHD symptoms can vary depending on the setting and activity, and the diagnosis requires symptoms in two or more settings [6]. Hence observations from teachers, coaches, administrators,

**Table 12.1** DSM-5 diagnostic criteria for attention deficit hyperactivity disorder

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A. Persistent pattern of inattention, hyperactivity, and impulsivity that interferes with functioning for development as characterized by 1 and/or 2

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1. Inattention: Six or more of the following symptoms have persisted for at least 6 months to a degree that is inconsistent with developmental level and that negatively impacts directly on social and academic/occupational activities

Note: The symptoms are not solely a manifestation of oppositional behavior, defiance, hostility, or failure to understand tasks or instructions

(a) Often fails to give close attention to details or makes careless mistakes in schoolwork, at work, or during other activities

(b) Often has difficulty sustaining attention in tasks or play activities

(c) Often does not seem to listen when spoken to directly

(d) Often does not follow through on instructions and fails to finish schoolwork, chores, or duties in the workplace

(e) Often has difficulty organizing tasks and activities

(f) Often avoids, dislikes, or is reluctant to engage in tasks that require sustained mental effort

(g) Often loses things necessary for tasks or activities

(h) Is often easily distracted by extraneous stimuli

(i) Is often forgetful in daily activities

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2. Hyperactivity and impulsivity: Six (or more) of the following symptoms have persisted for at least 6 months to a degree that is inconsistent with developmental level and that negatively impacts directly on social and academic/occupational activities

(a) Often fidgets with or taps hands or feet or squirms in seat

(b) Often leaves seat in situations when remaining seated is expected

(c) Often runs about or climbs in situations where it is inappropriate

(d) Often unable to play or engage in leisure activities quietly

(e) Is often “on the go” acting as if “driven by a motor”

(f) Often talks excessively

(g) Often blurts out an answer before a question has been completed

(h) Often has difficulty waiting his or her turn

(i) Often interrupts or intrudes on others

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B. Several inattentive or hyperactive-impulsive symptoms were present prior to age 12 years

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C. Several inattentive or hyperactive-impulsive symptoms are present in two or more settings (e.g., at home, school or work, with friends or relatives, in other activities)

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D. There is clear evidence that the symptoms interfere with or reduce the quality of social, academic, or occupational functioning

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E. The symptoms do not occur exclusively during the course of schizophrenia, another psychotic disorder, and are not better explained by another mental disorder

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Combined presentation: if both criterion A1 and criterion A2 are met  
Predominantly inattentive presentation: if criterion A1 is met but not A2  
Predominantly hyperactive-impulsive presentation: if criterion A2 is met and criterion A1 is not met for the past 6 months

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and/or tutors are very beneficial. Finally, gathering information about how the child’s life is impacted and to what degree is an important piece of information. Though a child may check off many boxes for ADHD symptoms and even meet criteria for a diagnosis, the level of impairment may vary and should guide the intensity of intervention.

## Confounders and Comorbidities

ADHD is linked to a host of associated features and negative outcomes. Mild delays in language, motor, or social developmental can occur with ADHD as can low frustration tolerance and irritability. Academic impairments are common with some studies showing that children with ADHD struggle with reading, spelling, and math [2]. Executive functioning skills such as working memory, inhibitory control, attention maintenance, and response inhibition are impaired as well [7]. Socially, ADHD raises the risk of grade retention, arrests, convictions, incarcerations, illicit substance use, terminated employment, and accidents [8, 9].

During the initial evaluation, clinicians should ask the parents and/or child about past head injuries, seizures, asthma, and thyroid dysregulation. A child who has symptoms of sleep disordered breathing such as snoring, frequent nighttime awakenings, and daytime fatigue should be referred for a sleep study (polysomnography). Generally, no lab work is required in the workup for ADHD unless concerning physical symptoms are present.

Comorbid psychiatric disorders are the rule in ADHD. The diagnosis is associated with conduct, oppositional, depressive, and anxiety disorders [10, 11]. Additionally, long-term studies of individuals with ADHD reveal that by early adulthood, ADHD is associated with an increased risk of suicide attempts and bipolar disorder [9].

Other psychiatric disorders present with poor concentration, impulsivity, and academic setbacks. Distinguishing between these disorders and ADHD is necessary as inappropriate treatment can worsen the child's symptoms. Table 12.2 contains ways that clinicians can make that distinction.

## Learning Disorders and Intellectual Disability

A child with a learning disorder or intellectual disability may seem inattentive because he or she has trouble understanding number sense, reading comprehension, and reasoning skills that form the foundation of future learning. Without adequate support, the child can feel left behind, bored, distracted, and frustrated. Input from parents and teachers is vital. They may report that the child writes letters backward or struggles with mathematical concepts even when he/she appears to be focused. A red flag for these diagnoses is if symptoms are much more pronounced in academic settings. Clinical suspicion for a learning disorder should arise if symptoms are more pronounced in a cluster of subjects that rely on a particular skill set. For example, a child who has what appears to be ADHD but has impairment that is much more pronounced in social studies, English, and history classes compared to his symptoms in math, science classes, or at home may have a reading disability.

In cases where both ADHD and a learning or intellectual issue are present, it is imperative to help the family with follow-through in the assessment and treatment process for both. After starting ADHD medication, the child may be less of a management issue, reducing teacher complaints and caregiver distress, but still not progressing academically as he/she could if appropriate educational interventions were

**Table 12.2** ADHD differential diagnosis quick reference

Disorder	Possible area of overlap	Distinguishing characteristic
Depressive disorders	Poor concentration, irritability, declining grades, oppositional behavior	Adolescent symptom onset; co-occurring anhedonia; social isolation; changes in appetite, sleep, or energy; episodic, weeks to months
Substance use disorders	Poor concentration and attention, restlessness, irritability, impulsivity, declining grades	Adolescent symptom onset, sudden symptom onset, markedly fluctuating symptom presentations
Anxiety disorders	Impaired concentration and attention, restlessness, irritability	Source of distraction is internal—worried thoughts; symptom fluctuations in stressful situations; focus may respond to reassurance; somatic complaints
Post-traumatic stress disorder	Impaired concentration and attention, restlessness, irritability, possible impulsivity	Traumatic exposures corresponding with symptom onset; presence of nightmares and flashbacks and increased startle responses
Bipolar disorder	Impaired concentration and attention, restlessness, irritability, talkativeness, impulsivity	Episodic in nature with symptoms representing a deviation from baseline functioning; may be accompanied by an inflated self-esteem and decreased <i>need</i> for sleep

in place. A psychoeducational evaluation is the best way to diagnose a learning disorder. In situations where psychoeducational testing is not immediately available, it is reasonable to treat inattention and see how that impacts the child's academic performance; however this is not a substitute for a psychoeducational evaluation when indicated, even when improvement is noted.

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## Screening and Measures

As the discussion of differential diagnosis demonstrates, youth may have symptoms of ADHD for a number of reasons. No scale is diagnostic, but can be helpful for identifying a need to explore ADHD symptoms. Additionally, they can be helpful in tracking treatment response if/when interventions are started. Table 12.3 includes select public domain ADHD rating scales.

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## Initial Management

### Psychosocial and Behavioral Interventions

Psychosocial and behavioral interventions can be of benefit in youth across age ranges and at all stages of the ADHD symptoms continuum. In cases where symptoms warrant pharmacologic intervention, while the medications may widen the space between

**Table 12.3** Public domain ADHD symptom rating scales

Measure	Age validated and # of items	Completed by	Administration and scoring times training (none, unless otherwise indicated)	Languages available
Vanderbilt ADHD Rating Scale—parent and teacher versions	6–17 years 55 items	Parent or teacher	10 min	English, Spanish
Vanderbilt ADHD Rating Scale—teacher	6–17 years 43 items	Teacher	10 min	English, Spanish
Strengths and Weaknesses of Attention Deficit Hyperactivity Symptoms and Normal Behaviors (SWAN)	8–18 years 18 items	Parent or teacher	5 min Scoring: 1–2 min	English, Spanish

impulse and action, giving the patient more time to reflect on consequences, they do not create compliance nor do they control behavior. Thus, they are most effective when used in conjunction with other strategies. In situations where significant oppositional symptoms are present, referring to the strategies discussed in the oppositional defiant disorder chapter of this text will be of benefit. Data on behavioral interventions for ADHD are mixed with studies showing the most support for parent training [12, 13]. In this particular treatment modality, caregivers learn how to recognize antecedents of behavior, set expectations, give rewards, and discipline effectively. Table 12.5 includes key points for parental/family education about ADHD.

With the understanding that parent training may not be readily available in all communities, clinicians can encourage general principles of the intervention for families with children with ADHD. Children with ADHD benefit from predictable structure and consistency. They need rules communicated clearly and consistently. In giving commands, it is helpful to limit the number of instructions; do so with direct eye contact so that it is clear the parent has the child's attention; then have the child repeat what they have heard. Visual aids such as calendars, posters, and checklists can help them recall tasks. In school and at home, children with ADHD respond well to a token system in which they earn something small (e.g., stars on chart) for desired behavior that are later exchanged for rewards. For work, parents and teachers can break assignments into 15–30-min segments, providing breaks in between.

Children with ADHD learn best when there are as few environmental distractions as possible. At school, they should be seated away from the windows and disruptive classmates. At home, work should be completed in quiet areas with the television, phones, and tablets turned off. To bolster social skills, emphasis should be placed on waiting one's turn, sharing, and appreciating another person's perspective, with the adults around the child being intentional in recognizing and praising the child when these behaviors occur. Also, a parent ought to ignore minor disruptive behavior and generously praise preferred behavior. When discipline is necessary, age-appropriate time-outs (1 min for each year old) or time-limited loss of privileges are preferred over harsh verbal or physical punishments.

## Psychopharmacologic Interventions

### Stimulants

The use of stimulants in ADHD is supported by a large number of studies that demonstrate their efficacy. Of note, in the preschool-age population, however, stimulants are generally not as effective. For this reason behavioral interventions are the first-line treatment in this population. For those young children (aged 3–5) whose impulsivity and hyperactivity cause significant impairment even after behavioral interventions, dextroamphetamine and dextroamphetamine-amphetamine can be used in combination with parent training and behavioral therapy. For the treatment of ADHD in school-age, adolescent, and transitional-age youth, stimulant therapy has a robust evidence base for improvements in self-regulation, sustained attention, and attentional control [14, 15]. There are two types of stimulants: amphetamines and methylphenidates. Both types have short- and long-acting formulations. There is evidence to suggest that long-acting formulations are associated with higher remission rates [16] and decreased risk for abuse.

### Titration and Dosing

After starting a stimulant, allow at least 1 week at specific dose to determine its effects before increasing dose. The onset of action ranges anywhere from 15 to 60 min depending on the medication. Timing the dose so that it's working by the beginning of the school day is the most effective strategy. In general children should avoid taking stimulants at night given their potential to disrupt sleep.

Even though extended-release stimulants are designed to last for the entire school day, some teachers and parents note that the medication appears to stop working in the afternoon. A comparison of ADHD symptoms in the morning and afternoon by the teachers may reveal that the medication is wearing off resulting in a return of functional impairment. In this case, start with a low dose of the immediate-release stimulant within the same class after lunch, and increase the dose at weekly intervals until the symptoms have improved.

Older sustained-release methylphenidate stimulants like Ritalin SR may still require afternoon dosing, while newer longer-acting formulations such as Concerta or Vyvanse may obviate the need for afternoon dosing. In youth whose appetites are affected at lunch and dinner by a longer-acting stimulant, medication such as Ritalin SR may be helpful. At times youth become irritable or depressed as the stimulants wear off. It is more likely to occur with short-acting stimulants and can be managed by spacing the doses closer together, prescribing a small dose as the larger dose is wearing off, or by switching to a longer-acting stimulant [17].

### Management and Parental Education Re: Potential Side Effects

Up to 20% of patients taking stimulants may experience bothersome side effects. The most common side effects are appetite loss, insomnia, and mood changes [18]. Less common side effects include psychotic symptoms such as paranoia and hallucinations [19]. In general, a prescribing clinician should start with a short-acting stimulant to ensure tolerability and then switch to a long-acting stimulant. This



allows for decreased exposure to the medication should a bad reaction occur. Generally, stimulant side effects can often be managed by lowering the dose, changing to a different formulation, or switching to another medication, as there are many FDA-approved stimulant formulations. Of note, methylphenidate extended release (Concerta) should be avoided in patients with gastrointestinal (GI) narrowing or constipation because of risk of intestinal obstruction as it does not change shape in the GI tract [20].

### **Stimulants and Growth**

Though some studies have shown stunted growth due to treatment with stimulant medications [21], this is not a consistent finding. In fact, a recent population-based longitudinal study found no association between stimulant treatment of childhood ADHD and deficits in adult height or significant adverse impact on growth throughout childhood and adolescence [22]. If present, the growth-related side effects of stimulants may be offset by taking breaks on weekends and holidays; however, the benefit of taking a break must be weighed against the risk of untreated symptoms, especially if the youth engages in unsafe behavior.

### **Cardiovascular Considerations**

Stimulant use has been associated with increases in blood pressure and heart rate [23]. However, regular screening with an ECG prior to the use of stimulants is typically not warranted unless family and personal history indicate cardiac disease [24]. A family history of severe palpitations, fainting, exercise intolerance, sudden death, cardiomyopathy, arrhythmias, or tachycardia warrants administering an ECG. Consultation with a cardiologist is indicated if abnormalities are seen on the ECG. Similarly, a child's personal history of chest pain, arrhythmias, hypertension, or syncope warrants consultation with a cardiologist prior to prescribing stimulants [25]. If, while taking a stimulant, a child develops tachycardia ( $\geq 130$  beats/min in school-age child and  $\geq 100$  beats/min in adolescents) or hypertension ( $\geq 95$ th percentile of SBP and DBP based on age, sex, and height), lower dose, switch to a different stimulant class, or switch to a nonstimulant.

### **Stimulant Treatment and Substance Use Disorders**

Per the Monitoring the Future national survey on drug use, in 2016 the past year, mixed amphetamine salts (Adderall) misuse had been relatively constant, with 6.2% of 12th graders reporting past-year use, though methylphenidate (Ritalin) use had declined from 5.1% in 2004 to 1.2% in 2016 [26]. When youth with ADHD take stimulant medications as prescribed, they are not at increased risk of substance use disorders. In fact, treatment of ADHD has been found to lower the risk of substance abuse in youth with ADHD [27]. For adolescents at risk of substance abuse, longer-acting stimulants such as extended release formulations of methylphenidates (e.g. Concerta, Metadate CD, Ritalin LA, Focalin XR), extended release formulations of amphetamine (e.g. Adderall XR, Vyvanse) have lower abuse potential. Lisdexamfetamine (Vyvanse) has the added benefit of being a prodrug that has to be swallowed and passed through the GI tract before it becomes active. Likewise, no matter which medication is selected, parents must supervise their adolescent's

medication to prevent diversion or misuse. In cases where there is a suspicion of diversion, drug screens can be used to verify that the patient is taking the medication rather than selling it. Table 12.5 includes key talking points for discussions with guardians about stimulants.

### **Nonstimulant ADHD Medications**

Alpha-2 agonists are used as alternatives to or in combination with stimulants to treat ADHD. While generally less effective than stimulants, they can be considered first line for children with ADHD and comorbid tic and anxiety disorders [29]. They are also used for aggressive patients with ADHD. The extended-release formulations of guanfacine (Intuniv) and clonidine (Kapvay) are approved by the FDA for the treatment of ADHD. Common side effects include sedation, dry mouth, dizziness, and constipation. Rarely, alpha-2 agonists can lead to bradycardia and hypotension. Should these symptoms emerge, the dose should be lowered or the medication should be tapered off.

Atomoxetine (Strattera) is an FDA-approved nonstimulant for the management of ADHD. It typically takes 2–4 weeks to take effect. Atomoxetine has been found to effectively treat the core symptoms of ADHD but may not be as effective as stimulants [30–32]. It is used to treat ADHD in patients who have comorbid anxiety and tic disorders or who don't respond well to stimulants. It does not have the potential for abuse, so it may also be considered in patients with a history of stimulant abuse disorder. Common side effects of atomoxetine include dry mouth, nausea, suppressed appetite, and nausea. It carries an FDA black box warning for suicidal thinking in the pediatric population. Lastly, bupropion (Wellbutrin) is an antidepressant that has been found to reduce symptoms of ADHD in children and adults [33, 34]. Though not FDA approved for ADHD, it can be used as a third-line agent. Medications and dosages for ADHD are included in Table 12.4.

### **Aggression and ADHD**

Aggression associated with ADHD is often the impetus for a family presenting for help. In many cases, a child's aggression subsides once inattention, hyperactivity, and impulsivity are treated with the right stimulant. Alpha-2 agonists such as Intuniv or Kapvay used as monotherapy or in combination with stimulants reduce aggression as well. Understanding the triggers for a child's aggressive behavior is important, as aggression may be a maladaptive way to express frustration, get attention, escape a situation, or obtain a desired object. Once the function of the aggression is appreciated, the above-mentioned environmental modifications can be applied effectively. In addition, self-regulation skills such as counting to ten, deep breathing, and progressive muscle relaxation can help the youth manage their own feelings. Some children with ADHD struggle to comprehend the perspective of others and/or problem-solving. These skills have to be taught, modeled, and reinforced regularly.

In the case of severe aggression that is unresponsive to the above pharmacologic and behavioral interventions, low-dose risperidone (0.25 mg–2 mg/day) or aripiprazole (2 mg–10 mg/day), two atypical antipsychotic medications, can be used.

**Table 12.4** Medications for ADHD

Medication	Pediatric dose	Action duration (h)	Ages FDA approved for ADHD	Delivery system/ notes
<i>Methylphenidates</i>				
Focalin/ dexmethylphenidate	2.5 mg BID–10 mg BID	3–4	6–17, adults	Continuous- release tablets
Methylin CT	2.5 mg BID–20 mg TID	3–4	6–17, adults	Chewable tablets
Methylin oral solution	2.5 mg BID–20 mg TID	3–4	6–17, adults	Grape-flavored liquid
Ritalin	2.5 mg BID–20 mg TID	3–4	6–17, adults	Immediate-release tablets
Ritalin SR	10 mg QAM–60 mg QAM	8–12	6–17, adults	Continuous- release tablets
Aptensio XR	10 mg QAM–60 mg QAM	8–12	6–17, adults	ER capsules; 40% IR, 60% ER
Concerta	18 mg QAM–72 mg QAM	10–16	6–17, adults	Initial release and then continuous capsule
Cotempla XR-ODT	17.3 mg QAM– 51.8 mg QAM	8–12	6–17	Disintegrating tablets
Daytrana patch	10 mg QAM–30 mg QAM	8–12	6–17	Continuous- release patch
Focalin XR/ dexmethylphenidate XR	5 mg QAM–30 mg QAM	8–12	6–17	Capsules of 50% immediate release and of 50% delayed-release beads
Metadate CD	20 mg QAM–60 mg QAM	8–12	6–17, adults	30% immediate- release beads and 70% delayed- release beads
QuilliChew	20 mg QAM–60 mg QAM	8–12	6–17, adults	Chewable ER capsules
Quillivant XR	20 mg QAM–60 mg QAM	8–12	6–17, adults	Oral solution
Ritalin LA	20 mg QAM–60 mg QAM	8–12	6–17, adults	50% immediate- release beads/50% delayed-release beads
<i>Amphetamines</i>				
Dexedrine	3–5 y/o: 2.5 mg QAM–20 mg BID 6–16 y/o: 5 mg QAM–20 mg BID	3–5	3–16	Tablets
Dexedrine Spansules	5 mg QAM–40 mg QAM	6–10	6–16	Sustained-release capsules
Liquadd, ProCentra	5 mg QAM–20 mg BID	3–5	3–16	Liquid

**Table 12.4** (continued)

Medication	Pediatric dose	Action duration (h)	Ages FDA approved for ADHD	Delivery system/ notes
Adderall	3–5 y/o: 2.5 mg QAM–20 mg BID 6–16 y/o: 5 mg QAM–20 mg BID	6–8	3–17, adults	Mixed salt of l- and d-amphetamine
Adderall XR	6–12 y/o: 5 mg QAM–30 mg QAM 13–17 y/o: 10 mg QAM–40 mg QAM	8–12	6–17 adults	50% IR, 50% ER
Adzenys XR-ODT	6–12 y/o: 6.3 mg QAM–18.8 mg QAM; 13–17 y/o: 6.3 mg QAM–12.5 mg QAM	8–12	6–17 adults	ER orally disintegrating tablets
Mydayis	12.5 mg QAM–24 mg QAM	10–12	13–17, adults	ER formulation
Vyvanse	30 mg QAM–70 mg QAM	8–12	6–17, adults	ER capsule
<i>Nonstimulant medications</i>				
Intuniv	1–4 mg daily	24	6–17	Extended-release guanfacine
Kapvay	0.1 mg–0.4 mg daily	8–12	6–12	Extended-release clonidine
Strattera	Dosage varies <sup>a</sup>	24	6–17, adults	Norepinephrine reuptake inhibitor
Tenex	1–4 mg daily	17	Not FDA approved for ADHD	Tablets
Clonidine	0.003–0.005 mg/kg/day PO divided TID–QID	6–20	Not FDA approved for ADHD	Tablets
Wellbutrin	1.4–6 mg/kg/day	6–9	Not FDA approved for ADHD	SR (12 h) and XL (24 h) versions exist

<sup>a</sup>Strattera dosing: weight < 70 kg, start 0.5 mg/kg/day, target 1.2 mg/kg/day; weight > 70 kg, 40 mg–100 mg daily

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**Table 12.5** Talking points for parents about treatment with stimulants for ADHD

<i>Review indication for treatment</i> —ADHD is a chronic illness that has physical, cognitive, and behavioral effects. While academic concerns are often a presenting concern, social deficits can be impairing as well. Impulsivity, when severe, can place the adolescent at risk for harm or juvenile justice system involvement. Studies indicate that the first stimulant treatment will be effective in reducing ADHD symptoms in 70% of children.
<i>Discuss treatment options</i> —There are many FDA-approved medication options. For preschool-age children, however, the first-line treatments are behavioral interventions focusing on environment and parenting. For school-age children and adolescents even, when medications are used, behavioral interventions should be implemented.
<i>Discuss treatment course</i> —At a therapeutic dose, the impact of stimulant medications can be seen quickly, within a week. Behavioral interventions may take more time to show effect but, with consistent implementation, will yield results over time. Consistency is the key.
<i>Discuss potential side effects</i> —Stimulants are generally well tolerated. Parents should be attentive to signs of increased anxiety, irritability, or aggressiveness.
<i>Emphasize the importance of breakfast</i> —To compensate for potential mid-day appetite suppression, children should have a high-protein breakfast in the morning and healthy snacks throughout the day [28].
<i>Educate about SUDs and ADHD</i> —Some parents have concerns that the treatment of ADHD with stimulants will increase their child's risk of developing a substance use disorder. The opposite is true as treatment of ADHD has been found to lower the risk of substance abuse in ADHD [27].

However, this off-label use carries the risk of weight gain, hyperlipidemia, diabetes, gynecomastia in males, and extrapyramidal symptoms. Potential benefits must be weighed against these numerous risks. This text's Autism Spectrum Disorder chapter includes additional information regarding the use of these medications.

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## When to Refer

Many pediatricians successfully manage ADHD in their practices. Consult with a child and adolescent psychiatrist if a child with ADHD presents a threat to himself or others, has family history of bipolar disorder or schizophrenia, has been hospitalized for the treatment of a psychiatric illness, presents with complex diagnostic issues, has a history of abuse, or is being treated with two or more psychotropic medications [35].

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## Key Considerations for Follow-Up

During follow-up appointments, parents and patients should be asked about the specific symptoms that prompted treatment. How is the child's focus? Have teachers noticed a difference in behavior? Is the child better able to sit still? How are his or her grades? Have there been any recent suspensions or detentions? How is the child getting along with others? In addition, data in the form of follow-up parent and teacher rating scales should be collected. The parents and the child should be asked about

**Table 12.6** Key points for parental/family education

<i>Provide a description of ADHD symptoms</i> —It is important for families to know that ADHD is a psychiatric illness with biological underpinnings that are not the child’s fault. When caregivers understand that the child’s difficulty completing schoolwork, paying attention, sitting still, or behaving in other ways as desired is not just the child being lazy or oppositional.
<i>Encourage families to remain active</i> —Putting the child’s energy to productive use pays off. Physical activity can help with ADHD symptoms and should become a part of the family routine, when possible.
<i>Emphasize the importance of organizational aids and routine</i> —Children with ADHD are likely to have more difficulty getting and staying organized than their same-aged peers and will need more help as a result. Organizational aids, structure, and accountability (things such as binder or homework checks) can be helpful.
<i>Identify family strengths and psychosocial supports</i> —Explain the role of social support, and capitalize on existing pro-social and supportive relationships among family members and peers. Also encourage the family/caregivers to catch the youth doing good, as youth with ADHD can be on the receiving end of frequent criticisms and redirections.
<i>Address concerns about treatment</i> —Although individual psychotherapy, family therapy, pharmacotherapy, or some combination may be warranted, families may experience worries and hesitation about beginning treatment. Worries may derive from stress and uncertainty, concerns about side effects, stigma, and/or cultural experience. Listen carefully to families’ concerns, welcome questions, and provide information in a way that is open, accurate, and clear.
<i>Education them about redirection</i> —Even when treated, youth with ADHD may still have a lot of energy. Telling them to “stop” will be less effective than redirecting their energy to a preferable behavior.
<i>Provide guidance on giving effective commands</i> —Directions that are concise, clear, concrete, and made with eye contact are more likely to be followed.
<i>Encourage patients to obtain a comprehensive assessment</i> —Parents must gather as much medical, educational, and psychiatric information about their child as possible. Every child is unique, and the more that is known about child’s specific challenges, the better suited the interventions will be. Psychological/psychoeducational evaluations provide a broad assessment of the child’s cognitive and emotional functioning as well as individualized recommendations. They are highly recommended if there is clinical suspicion of a comorbid intellectual disability or learning disorder.
<i>Make them aware of the child’s educational rights</i> —Children with ADHD can receive academic support in the form of extended test time, small group instruction, behavioral plans, and designated breaks. This text’s chapter on interfacing with the school system and the website <a href="http://www.wrightslaw.com">www.wrightslaw.com</a> are helpful resources.
<i>Communicate regularly with school</i> —Caregivers should regularly call, email, or meet with their child’s teachers and school administrators to discuss academic progress and accommodations.
<i>Encourage parents to make use of respite care and/or professional help</i> —Children do their best when their parents are emotionally healthy. Caring for a child with ADHD can be stressful. Parents should explore and utilize opportunities for respite. In cases where they have symptoms of mental illness, an evaluation may be warranted to help parents effectively manage their own anxiety, depression, or inattention for the benefit of the child.
<i>Learn the tools of successful behavioral management</i> —Identify parent training programs in the community through local parent information and resource centers <a href="http://www.parentcenterhub.org/find-your-center/">www.parentcenterhub.org/find-your-center/</a> .

side effects. Finally, vital signs should be measured with special attention paid to the child's weight, blood pressure, and heart rate [36]. Table 12.6 includes some key points for parental/family education about ADHD in children and adolescents.

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# Oppositional Defiant Disorder

# 13

Yolanda Graham

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## Introduction

Oppositional defiant disorder (ODD) can be a costly illness for the child and the parent. Children with disruptive behavior disorders have more expensive office visits, prescription medications, and emergency room visits compared to those with physical illnesses [1]. Indeed, ODD is the most significant predictor of caregiver strain, accounting for up to 90% of doctor visits for parents and negatively impacting parental mental health and work productivity [1]. It is no surprise that parents of these children present to pediatric offices seeking advice on management and treatment options.

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## Brief Review of Epidemiology and Pathophysiology

Oppositional defiant disorder (ODD) was first introduced as a psychiatric disorder in the *Diagnostic and Statistical Manual (DSM)-III* in 1966. Despite the common myth that all adolescents go through a difficult period of being oppositional, the prevalence rate of ODD is only 3.3% in the general population. There is, however, a lifetime prevalence of up to 11%. ODD is slightly more common in boys before puberty but equally common in boys and girls after puberty [2]. This represents a dramatic shift from 20 years ago when the diagnosis in boys far exceeded girls [3]. ODD is considered a childhood diagnosis that can persist throughout adolescence. While there is no minimum age limit for the diagnosis, ODD symptoms are usually present prior to age 8 years, and the diagnosis is more severe when children meet full criteria prior to age 10 years. Approximately 30% of children with ODD will go on to develop conduct disorder in adolescence or antisocial personality traits in

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Y. Graham

Mental Health Services, Devereux Advanced Behavioral Health, Kennesaw, GA, USA

e-mail: [YGRAHAM@devereux.org](mailto:YGRAHAM@devereux.org)

adulthood, but 67% are free of symptoms 3 years after treatment [4]. Because ODD is considered a childhood diagnosis, the diagnosis should be officially removed at age 18, even if symptoms have not remitted.

The etiology of the disorder is multifactorial—heritability, parenting styles, and other psychosocial factors have been well documented. Changes in anatomical structure and brain functioning have also been associated with the disorder. There is no known cause for oppositional defiant disorder, though the genetic risk is 61% [5]. The etiology is felt to arise from a complex set of protective and risk factors [5]. The ability of parents to match their parenting style to the child's temperament, especially during the crucial years of autonomy and separation (around age 3 years), is a vital determinant of later response to rules and structure. Parents who fail to set consistent rules early in life have more difficulty in establishing authority as children get older. This is especially important for PCPs working with parents of small children. On the other hand, parents who have a harsh and punitive parenting style are often modeling aggressive and conflictual communication styles, leading to higher rates of oppositional behavior.

A difficult temperament, baseline under-arousal, exposure to toxins or nicotine in utero, and nutritional and vitamin deficiencies have all been associated with the development of oppositional behaviors [6, 7]. Poverty, social disadvantage, criminality, and mental health problems in the biological parents are also known risk factors [8]. Depressed mothers have more difficulty demonstrating positive parenting skills, which can lead to power struggles and rebellious and oppositional behaviors. Care should be taken by the primary care provider (PCP) in assessing and supporting mothers who appear to be depressed [9].

Despite these risk factors, what makes it really difficult for children with oppositional defiant disorder is their tendency to misinterpret social cues. They perceive mal-intent in non-threatening situations and have more difficulty processing social information, recognizing emotions and expressing empathy [10, 11]. They are hypervigilant to slight and expect consequences before they occur. They are literally “on edge,” defensive, staking their claim. They have trouble delaying gratification and actually expect praise and reward for aggressive behavior. They don't understand why others fail to see their point of view. These deficits are compounded by the fact that children with ODD tend to have lower IQs and impaired executive functioning [10, 11]. They generate fewer solutions overall when problem-solving and have difficulty connecting their actions to possible consequences.

The challenge in helping them is they actually feel they are right and their response is justified. Their failure to accept responsibility for their behaviors and externalization of blame are a result of their inability to accurately process social cues and problem-solve appropriate responses. Hypoactivity in the “hot” areas of the brain, responsible for processing emotions and affect on a cognitive level, and in the “cool areas,” responsible for self-regulation, problem-solving, inhibition, working memory, flexibility, and generating solutions in the face of stress, has been shown in neuroimaging studies of children with ODD and aggression [8].

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## Diagnostic Criteria and Key Components of History

Children with oppositional defiant disorder tend to be argumentative, irritable, easily annoyed, and resentful. They have difficulty accepting responsibility for their own actions, blame others, hold on to grudges, deliberately annoy others, and can be vindictive and spiteful. They intentionally break the rules and then argue incessantly about it. These symptoms have to be present on most days for at least 6 months in order to be considered problematic, and they have to negatively impact the child's ability to function in his/her family, school, or other important areas of their lives. Most children begin with symptoms in one area (e.g., they are oppositional at home but not school) but progress to more areas when left untreated. The more areas in the child's life the behavior presents itself, the more severe the disorder.

The diagnosis of oppositional defiant disorder is a clinical one and is based upon age, symptom presentation, and whether full DSM-V criteria are met. A thorough history should be obtained, with a particular focus on recent life stressors such as bullying, environmental changes, or abuse as well as mental health and medical comorbidities. The diagnosis should be made only after excluding natural developmental shifts, learning/social issues, and other psychiatric diagnoses.

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## Comorbidities and Confounders

Comorbidity with ODD and other disorders is common. Children with ODD have been shown to have higher rates of ADHD (35–50%), unipolar depression (14–30%), bipolar disorder (6–50%), anxiety, and substance abuse [12, 13]. Approximately 33% of children with ODD subsequently develop conduct disorder (CD), which includes more severe behaviors and less remorse for behaviors; some progress to meet the criteria for antisocial personality disorder (ASPD) in adulthood. Greater functional impairment and higher levels of aggression have been associated with these comorbidities. A younger age of onset is predictive of criminal behavior, incarceration, more prolonged histories, and other comorbidities. It is important to ensure that underlying disorders are appropriately diagnosed and treated, which greatly reduces the presence of oppositional behaviors.

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## Screening and Measures

Unlike many other childhood psychiatric disorders, ODD symptoms rarely fly under the radar. These symptoms can, however, be manifestations of other underlying mental illnesses that are not as obvious. For these reasons, screening for disorders such as ADHD, mood disorders, anxiety disorders, trauma, and even learning or intellectual problems is important when a family presents with a chief complaint of oppositional behaviors. There are two public domain rating scales that can be useful in assessing ODD symptoms and treatment response. The Disruptive Behavior Disorder Rating Scale (DBDRS) can be used in ages 5 and up. It is a 45-item measure completed by

the parent or teacher and takes approximately 5–10 min to complete and less than 5 min to score. Another measure, the Mojave Child and Adolescent Symptom Rating Scale—ODD, is an eight-item measure. Compared to the DBDRS, this scale has limited psychometric information available regarding its use; however, it can be helpful as it provides clear examples regarding symptom severity for core ODD symptoms. The Achenbach Child behavior Checklist (CBCL) is more thorough in assessing ODD and co-morbid disorders; however it is not public domain. There are three versions available—youth self report, parent rating, teacher rating—each averaging 100 questions and requiring 25–30 minutes to administer and score.

## Initial Management

### Psychosocial Interventions

Intervention for ODD should always begin with an evidence-based psychosocial therapeutic intervention before consideration is made for higher level interventions, including medications. The National Institute of Clinical Excellence (NICE) released guidelines for psychosocial treatments in 2013 showing that all treatments led to a small to moderate effect size, with none showing superiority over others [14]. These treatment strategies include individual therapy, group therapy, family therapy, psychoeducation, social skills training, anger management, emotion awareness, problem-solving, and perspective taking.

In general, the younger the child the more focus is placed on parent training. Parent training sessions teach parents to positively reinforce behaviors, ignore minor negative behaviors, and choose battles, as well as how to use age-appropriate consequences such as time-out and loss of rewards/privileges. Teaching parents these strategies leads to reduced parental stress and improved communication between parents and children, counteracting harsh and punitive parenting styles [15]. As children get older, more focus is placed on skill training, cognitive processing, problem-solving, and increasing social supports. The most commonly available, validated treatment models are listed in Table 13.1. With a mental health collaborative care model, some of the interventions, such as cognitive behavioral therapy and the collaborative and proactive solutions, could possibly be implemented in the primary care setting; however, most of these interventions will require referral to another agency. This information is provided to guide in the referral process.

**Table 13.1** Evidence-based therapies for oppositional defiant disorder

Elementary school children	Middle school children	High school children
Parent-child interaction therapy (PCIT)	Collaborative and proactive solutions (CPS)	Multisystemic therapy (MST)
Parent management training (PMT)	Cognitive behavioral therapy (CBT)	Functional family therapy (FFT)
	Multifamily psychoeducational psychotherapy (MF-PEP)	High-intensity wrap-around services

## Parental and Family Education

Given the frank reality that evidence-based therapies are not available in all areas (or accessible to all families even when they are), it is important to know that any type of behavioral, cognitive, social skills training, or any type of parent management training, is better than none. Pediatricians can begin the therapeutic process in the office by helping parents to understand why children are oppositional and what they can do to mediate their child's responses. Here are ten tips that have been shown to reduce defiant behaviors:

1. Children need structure—Creating a regular sleep, exercise, and meal routine are all important. Children are more irritable and have trouble processing and learning new information when they do not get enough sleep. Foods that are high in sugar and carbohydrates lead to “highs and lows” in terms of mood and temperament. Exercise provides a healthy outlet for expending energy and stimulates natural endorphins. Creating structure early in life sets the stage for later expectations as children get older.
2. Speak in a calm manner—Parents get angry when children present as defiant. It is easy to get into the habit of yelling, but it's important to remember that parents are role modeling expected communication patterns. In other words, the parent is displaying to the child that it is okay to yell when angry.
3. Be clear in your communication—Don't ask a question that could result in a yes or no response when your expectation is a yes. In this case, it is better to give a directive rather than ask a question.
4. Promote the positive—Parents of children with ODD often fall into the trap of focusing only on the negative. It is important to praise good behavior, being as specific as possible about what is praiseworthy and why. This really changes the nature of the parent-child interaction.

No matter how challenging the child's behavior, there is always some component worthy of praise. Parents can even set their own goals for how many times they would like to praise their child each day, then praise themselves when they reach their goal.

5. Be clear on your expectations—Chore charts, posting rules, and drawing up contracts are helpful. Positive reinforcement through praise, points, stars, privileges, allowance, etc. gives the child tangible proof that they are doing what is expected and something worth working for. There's no need for argument—either the expectation is met or not met—same with the reward.
6. Offer alternatives—Kids with ODD struggle with feeling “forced” to do something. Often there is more than one way to achieve the same outcome so offer at least one alternative whenever possible (e.g., you can wear the red shirt or blue shirt; you can go out Friday night or Saturday night).
7. Express empathy—Most children, whether they have ODD or not, feel that adults fail to understand them. Expressing empathy at what they might be feeling does not negate your own feelings or change the expectations, but it does help the child to feel understood and less alone.

8. Describe how you want your child to act, not how you don't want them to act— It focuses them on what is positive rather than what is negative, and for children who have difficulty problem-solving, it helps them to be more successful.
9. Consistent consequences—Even the most well-meaning parent can deliver harsher consequences when angry. Choose your child's most problematic behaviors, and develop age-appropriate consequences with your child when you are not angry. This provides your child with clear expectations and helps to mediate the interaction at the time the behavior occurs.
10. Be good to yourself—Caring for a child with ODD can be exhausting at times. It is important for caregivers to allow themselves a “time-out” when needed, to allow respite periods where both the child and the parent receive a break, and to do things for themselves that are replenishing.

Remember, children with ODD have mastered the power struggle and exerting control. They have nothing to lose since they feel they have already lost. Successfully navigating this period requires parents to avoid engaging in the power struggle in the first place. The goal is to raise healthy, productive adults who are able to problem-solve and operate within societal expectations, not children who comply out of anger and fear, holding onto resentments to take out on others. Being structured and consistent and finding creative ways to offer praise seem more time-consuming; however, this is not really the case considering the amount of time spent on arguments, punishments, and managing stress levels.

## Pharmacologic Interventions

There are no medications to “cure” and no FDA-approved psychotropic medications for ODD. When medications are prescribed, they are most commonly prescribed to treat comorbid psychiatric disorders and their related symptoms. Given the high rates of comorbidity with other disorders (especially ADHD and mood disorders) that result in higher levels of aggression and functional impairment, it is important that treatment providers understand how and when medications can prove useful in this population.

### ODD and ADHD Medications

Psychostimulants have been shown to have a moderate to large effect on reducing oppositional behaviors in children with combined ODD and attention deficit hyperactivity disorder (ADHD). A strong recommendation in favor of their use was issued by a multidisciplinary consensus group [16]. Methylphenidate has shown superiority in some studies but no preference over amphetamines in others [16, 17]. In general, amphetamine and methylphenidate derivatives have a similar mechanism of action with a similar side effect and efficacy profile (approximately 85% effective). A trial should be initiated with a medication within one class, and most PCPs develop comfort with 1–2 medications within the same class. A dose-response relationship has been suggested, and efforts should be made to maximize the dose

within the first class of stimulants prior to switching classes. If there is a lack of response to a therapeutic dose, a second trial should be instituted with another class then titrated to a therapeutic dose. The best guide for an initial choice of stimulant class should be a positive family history of response. For more information on stimulants, please refer to this text's ADHD chapter.

The alpha-2 agonists, clonidine and guanfacine, received a conditional recommendation in favor of their use in children with ODD and ADHD. They are generally used as second-line agents to reduce impulsivity in children with ADHD, either as an adjunct, when there has been a partial response to stimulants, or as monotherapy when stimulants are not tolerated. Clonidine has been shown to have a small effect and guanfacine to have a moderate effect in children with ODD and ADHD [18]. Two studies have shown guanfacine to be superior to placebo in children but not adolescents, suggesting a possible age-related response [19, 20]. Caution should be used when prescribing these agents as there is a risk of rebound hypertension and tachycardia with missed doses or if the medication is discontinued suddenly.

Atomoxetine (Strattera) has received a conditional recommendation as a first-line agent for use in children and adolescents with combined ODD and ADHD, generally when stimulants are not tolerated or effective [18]. Atomoxetine has a different side effect profile than stimulants and is sometimes preferred by parents who have concerns about stimulant use. The chemical structure of atomoxetine is similar to that of antidepressants. While atomoxetine failed to show significant changes in depression in the FDA clinical trials, it likely confers mild to moderate benefit in this area and may prove a useful regimen in children with ODD and ADHD with significant irritability. Treatment providers should be aware that there is a slightly higher risk of suicidal thoughts with atomoxetine, but it is otherwise well tolerated with no abuse potential. No studies to date have demonstrated an increased benefit of combining psychostimulants with atomoxetine, and monotherapy treatment for a disorder should be the preferred treatment method whenever possible.

To summarize, the quality of evidence for psychotropic medication in combined ODD and ADHD is highest for stimulants, followed by atomoxetine, guanfacine, then clonidine. All three classes of medication seem to impact core ADHD symptoms over other behavioral problems. Bupropion may be a good option when there is a combination of ADHD, ODD, and mood symptoms. Improvement in ADHD symptoms alone leads to improvements in the externalizing behaviors commonly seen in ODD.

### **ODD and Mood Stabilizers**

Evidence for other mood stabilizers and antipsychotics has demonstrated low- or very-low-quality evidence for improving behaviors in children with ODD. Despite the limited research supporting efficacy, the use of these agents to treat oppositional and aggressive behaviors has become more widespread. Mood stabilizers and antipsychotics are often used as monotherapy or in combination with other agents, depending upon the level of comorbidity.

Several studies have found lithium carbonate to be effective in reducing aggression [21, 22], but others have failed to demonstrate any benefit for



lithium vs. placebo [23]. Most of these studies were done with an all-male population of conduct-disordered youth, either open label or retrospective. Despite the mixed results, lithium is still considered a viable alternative for aggression and irritability related to ODD, with or without the diagnosis of a separate mood disorder. Management with lithium requires regular lab work and monitoring. The risk of possible side effects (e.g., diabetes insipidus, acne, hypothyroidism, changes in kidney functioning) must be weighed against any potential benefit prior to making a decision to prescribe lithium off label in this population.

Divalproic acid (Depakote) is another mood stabilizer often used in the pediatric population for mood lability, irritability, or aggression. Divalproic acid is an anti-convulsant found to be effective in reducing mood swings (e.g., bipolar disorder, disruptive mood dysregulation disorder, schizoaffective disorder), and reducing mood symptoms has been shown to reduce oppositional behaviors. Two placebo-controlled studies have demonstrated a large magnitude of effect with the use of divalproic acid in ODD, but the quality of the evidence was poor [24, 25]. This, combined with the side effect burden associated with divalproic acid, including the risk of polycystic ovarian syndrome in girls, has led to only a conditional recommendation [16]. Additionally, this medication is a known teratogen, and birth control must be in place when it is used. Again, routine lab work is required with divalproic acid.

There was only one placebo-controlled trial involving carbamazepine (Tegretol) in the treatment of ODD, which was a small study with negative results [26]. Carbamazepine can lead to major blood dyscrasias and is generally not recommended in the treatment of ODD. It appears to be more effective in children with mood disorders associated with explosive episodes.

### **ODD and Antipsychotics**

The atypical antipsychotics have experienced an increase in off-label use in treating ODD over the past 10 years. While they were once considered much safer and more effective than first-generation antipsychotics (decreased risk of extrapyramidal symptoms), the negative impact on metabolic functioning in children has raised great concern. They are often prescribed to “turn down the dial” on aggression or raise the threshold for frustration tolerance by blocking dopamine transmission. Unfortunately, these medications have been associated with increases in weight, abdominal girth, triglycerides, and cholesterol. Any use of atypical antipsychotics in this population is considered off-label, unless the child has a concomitant diagnosis of autism spectrum disorder (ASD), mood disorder, or psychosis.

Risperidone (Risperdal) has the best evidence for reducing conduct problems and aggression in youth with ODD with and without ADHD, with average and sub-average intellectual functioning [27]. Risperidone has shown moderate to large effect sizes but has received only a conditional recommendation because of its side effect profile [16]. In addition to the side effects listed above, risperidone can increase prolactin levels, leading to galactorrhea and gynecomastia. There has only



been one study of quetiapine (Seroquel) treatment in children with ODD. It was a nonrandomized design with a small patient population. The effect size for quetiapine was large, but it received only a conditional recommendation due to the limited research available and the possible side effect burden [27].

More information regarding clinical considerations in using atypical antipsychotic medications, including monitoring recommendations, can be found in the Pharmacologic Intervention section of this text's Autism Spectrum Disorders Chapter.

Evidence for haloperidol (Haldol) is limited, with one study showing positive outcomes. The study was placebo-controlled but small and of poor quality [21]. First-generation antipsychotics are not generally recommended in children due to the risk of extrapyramidal symptoms (e.g., stiffness in joints, eyes, tongue), including the potentially irreversible development of tardive dyskinesia.

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## When to Refer

Intervention for ODD should always begin with an evidence-based psychosocial therapeutic intervention, the vast majority of which will require referral to a mental health specialist. Diagnostic uncertainty or the identification of a comorbid psychiatric illness during the evaluation process can also prompt referral. Prognosis is worsened for children with an earlier age of onset (prior to age 10 years) and those who later develop conduct disorder, so these youth likely need to be referred for specialty services earlier.

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## Key Points for Follow-Up

Psychosocial interventions should continue through all phases of treatment to improve prognosis, and medications should only be prescribed in conjunction with therapeutic supports. The use of rating scales can assist in measuring treatment response over time. This can prove helpful as sometimes in the heat of the moment, it can be hard for youth and their families to appreciate the progress they have made, particularly if there was a recent conflict or stressor. It is promising that the majority of children with ODD have a resolution of their symptoms by late adolescence or early adulthood. As noted above, prognosis is worsened for children with an earlier age of onset (prior to age 10 years) and those who later develop conduct disorder. With this in mind, youth in these categories may warrant more frequent follow-up, particularly if specialized mental health services are not in place. As caregiver strain is frequently encountered, it is also important to ask about parental stress, supports, and respite care. As usual, monitoring for side effects of any psychiatric medications, especially if on an atypical antipsychotic is an important aspect of follow-up. Please refer to [Table 14.5](#) regarding monitoring frequency when on an atypical antipsychotic.

## Summary

ODD is a childhood disorder often arising from a complex interaction of genetics, temperament, parenting styles, and a host of psychosocial factors. Early intervention dramatically improves the prognosis, not only for the identified child but for other children in the home. Focusing treatment efforts on the parent and the child has proven beneficial in reducing parental stress and strain. There are a variety of evidence-based treatment models for ODD, with a focus on parenting skills in early childhood, cognitive behavioral therapy in middle childhood, and executive functioning or problem-solving approaches in later adolescence. Failure to adequately treat other psychiatric disorders often leads to oppositional behaviors; comorbidity with ODD is the norm rather than the exception.

While no class of psychotropic medication specifically targets ODD, medications can be helpful in reducing symptoms associated with other diagnoses.

ODD occurs most commonly with attention deficit hyperactivity disorder, with multiple studies demonstrating improvement in both disorders with stimulant treatment. Combining pharmacotherapy (second-generation antipsychotics or mood stabilizers) with multimodal psychotherapy leads to greater reductions in aggression and emotional dysregulation in children with ODD who also demonstrate mood problems or irritability. Most promising in terms of outcomes is that the majority of children with ODD have a resolution of their symptoms by late adolescence or early adulthood.

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Michael A. Ellis

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## Introduction

The diagnosis of autism spectrum disorder (ASD) includes within it multiple neurodevelopmental disorders that are characterized by restricted, repetitive behaviors and interests; and deficits in the domains of social interaction and communication. Children with ASD have varying degrees of impairments within these different domains. The most important task of the primary care physician is to identify these signs and symptoms early and to make the diagnosis of ASD or refer to a provider who can make a definitive diagnosis. Early diagnosis has been shown to significantly improve outcomes on multiple measures and is currently the best way to change the trajectory of the lives of children with ASD.

Since 1–2% of children will be diagnosed with autism spectrum disorder (ASD), primary care physicians must be competent at recognizing the signs and symptoms of ASD, as well as initiating or recommending medical and behavioral treatments. Primary care physicians are on the frontlines and as such have the enormous opportunity and responsibility of helping children achieve their highest potential by recognizing ASD symptoms and referring to the appropriate specialists and

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M. A. Ellis

Mercer University School of Medicine, Macon, GA, USA

Philadelphia College of Osteopathic Medicine (PCOM)—GA Campus, Suwanee, GA, USA

Child and Adolescent Psychiatry, The Bradley Center, St. Francis Hospital,  
Columbus, GA, USA

e-mail: [miellis@augusta.edu](mailto:miellis@augusta.edu)

therapists. Because the autism spectrum is quite broad, it requires a significant amount of training and experience in order to recognize and treat properly. In this chapter, we will concisely discuss what primary care physicians need to know to be competent in the early detection of ASD as well as practical interventions for the primary care setting.

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## Brief Review of Epidemiology and Pathophysiology

According to the Centers for Disease Control and Prevention (CDC), the prevalence rate has increased in 12 years (2002–2014) from 1 in 150 children to 1 in 59. Another less scientific survey found the prevalence to be 1 in 45 children [1]. ASD is about 4 times more common in males (1 in 38) than females (1 in 152), and it occurs in all racial, ethnic, and socioeconomic groups [2]. Recent rigorous studies have shown the heritability of ASD to be 37–50%. Full siblings of children with ASD have a risk of 10–20% [3]. This information can be used to help families with genetic counseling. There are known medical and genetic causes of ASD as well as numerous environmental factors that confer an increased risk for ASD. It is well-known that rubella infection, exposure to thalidomide or valproic acid in the first trimester, and untreated phenylketonuria are associated with increased risk of ASD. Other factors include multiple pregnancy, prematurity, and advanced paternal age at conception. However, there are currently no environmental factors that can predict the diagnosis.

Childhood vaccination as a potential cause of ASD has been a very controversial and contentious issue. A small case series was published in the *Lancet*, linking autism to the measles-mumps-rubella (MMR) vaccine. Although this article was later retracted, this study reinforced what many lay people had already feared. Fortunately, vaccines as a cause of ASD have since been extensively studied and disproven by many recent large, high-quality studies. A 2013 study found no link between the number of vaccines a child was given and the risk for ASD [4]. Another study in 2015 found that the MMR vaccine was not associated with autism even in siblings of children with autism (those at higher risk) [5].

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## Diagnosis and Key Components of History

The impairments seen in those with ASD are generally classified into three main areas: communication, social reciprocity, and repetitive or restricted interests. In 2013, the *Diagnostic and Statistical Manual of Mental Disorders*-fifth edition (DSM-5) merged the communication and social interaction behaviors into one category and the restricted and repetitive interests into a second category. For purposes of discussion, we will discuss these three domains separately. Please refer to the DSM-5 for specific ASD criteria.

Most commonly, the first sign that alerts the parent or primary care physician to possible ASD is a deficit in communication. This is typically a significant language delay or inappropriate use of language by the age of 18–24 months. The child may

**Table 14.1** Autism spectrum disorder red flags

Red flags related to communication	<ul style="list-style-type: none"> <li>Delayed speech and language skills</li> <li>Repeats words or phrases over and over (echolalia)</li> <li>Uses few or no gestures (e.g., does not wave goodbye)</li> <li>Does not point or respond to pointing</li> <li>Gives unrelated answers to questions</li> <li>Reverses pronouns (e.g., says “you” instead of “I”)</li> <li>Talks in a flat, robot-like, or sing-song voice</li> <li>Does not understand jokes, sarcasm, or teasing</li> </ul>
Red flags related to social skills	<ul style="list-style-type: none"> <li>Does not respond to name by 12 months of age</li> <li>Avoids eye contact</li> <li>Does not share interests with others</li> <li>Prefers to play alone</li> <li>Only interacts to achieve a desired goal</li> <li>Has flat or inappropriate facial expressions</li> <li>Is not comforted by others during distress</li> <li>Avoids or resists physical contact</li> <li>Does not understand personal space boundaries</li> <li>Has trouble understanding other people’s feelings</li> </ul>
Red flags related to unusual interests and behaviors	<ul style="list-style-type: none"> <li>Lines up toys or other objects</li> <li>Gets upset by minor changes</li> <li>Likes parts of objects rather than whole objects (e.g., wheels)</li> <li>Has obsessive interests</li> <li>Plays with toys the same way every time but inappropriately</li> <li>Is very organized</li> <li>Has to follow certain routines</li> <li>Flaps hands, rocks body, or spins self in circles</li> </ul>

be mute, have a delay in language acquisition, or have a significant regression in language. Even if a child with ASD has language, he or she may have echolalia (repeating words or phrases previously heard), or the language may not be functional. In those with ASD without a language delay, there may be only a focus on their specific interests and no concern regarding the listener’s responses. The child will also likely fail to initiate or maintain conversations. Table 14.1 can guide you in your questioning of the parent to elicit the diagnosis [6].

Social reciprocity is also impaired in those with ASD. This is the typical “give and take” of social interaction. This requires the child to be able to take another person’s perspective, which is very difficult for those with ASD. Youth with ASD may not empathize well for this reason. They have difficulty establishing relationships with same-age peers. The child with ASD has an inability to maintain joint attention, read and respond to nonverbal cues, and share socially. An early red flag of such difficulty is the inability to point to a desired object at 18 months. Direct eye contact is often poor and avoided by the child with ASD. Research has shown that neurotypical children look at adults’ eyes when interacting, while a child with ASD typically looks at adults’ mouths the majority of the time [6].

The repetitive and restrictive behaviors in ASD can be isolating and difficult for the child and the entire family. Those with ASD have a rigid insistence on structure and routine and may tantrum if these are not followed or achievable. The reliance on

a nonfunctional routine can be extremely difficult for the family. For example, a child with ASD may tantrum if the parent takes a different route to school or if the parent takes the child on an unusual or unexpected errand after school. Parents will likely complain of this when they present to your office. The child with ASD may have nonfunctional repetitive movements such as hand flapping, spinning, or rocking. They may have a preoccupation with the parts of objects rather than an appreciation for the whole/what the object represents and often do not play with toys appropriately. For example, the child with ASD might spin the wheels on a toy car repetitively or line toy cars up without ever pretending to drive them. Children with ASD often have very restricted interests in activities and food preferences. They are often very picky eaters. They may be hypersensitive and/or hyposensitive to any or all of the five senses [6].

Those on the autism spectrum will not have every symptom and sign of ASD, and they will typically vary significantly in the severity of various signs and symptoms. As a result, diagnosing children with a stereotypical picture or set of symptoms in mind may not work. The red flags mentioned will help guide diagnosis, but there can be a great deal of variability in how children present. When you are not sure of the diagnosis, you should consult or refer the child to a child psychologist, child psychiatrist, or developmental pediatrician.

The most common questions to ask are the following: “Did your child have a speech delay such as not using a 2 word sentence by 24 months?”, “Does your child often fail to respond when you call his or her name?”, “Does your child prefer to be alone or is he/she often off by him/herself when other peers are together?”, “Does he/she fail to give eye contact?”, “Is he/she inflexible?”, “Does your child tantrum if he/she is unable to follow the same routine or schedule?”

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## Confounders and Comorbidities

There are multiple known medical and genetic conditions that can cause ASD or ASD-like symptoms. These include fragile X syndrome, Angelman syndrome, neurofibromatosis, tuberous sclerosis, chromosome 15 duplication syndrome, lead exposure, and Rett syndrome. Despite advances in genetic techniques (chromosomal microarray), approximately 75% of ASD cases have no currently identifiable genetic abnormality. It is also important to be aware that other mental health/neurological disorders can mimic ASD [7]. See Table 14.2.

The first step in evaluating a child with suspected ASD is a complete physical evaluation. This exam should especially focus on identifying any neurological abnormalities such as hypotonia, macrocephaly, dysmorphic features suggestive of other syndromes, toe walking, and neurocutaneous skin findings such as café au lait or ash-leaf spots consistent with neurofibromatosis or tuberous sclerosis. Thorough medical history and family medical/psychiatric histories should be obtained, focusing on behavioral and developmental issues [6].

**Table 14.2** ASD differential diagnosis quick reference

Disorder	Area of overlap	Distinguishing characteristic
Sensory impairments/ deafness	Does not respond when name called; may have communication difficulties	No significant delays in social skills and joint attention; no repetitive, restricted interests/behaviors; uses nonverbal communication
Intellectual disability	Intellectual impairment in many but not all with ASD	No significant repetitive, restricted interests/behaviors; will demonstrate capacity for social reciprocity
Obsessive-compulsive disorder	Obsessions and compulsions may appear similar to circumscribed interests and repetitive behaviors	Obsessions and compulsions are bothersome and not enjoyable
Anxiety disorders/ selective mutism	Social and communication impairments	Social communication impairments are only situational (not constant as is the case with ASD)
Reactive attachment disorder	Difficulty attaching to caregiver; inappropriate social behaviors	Has no significant delays in communication or socialization; no repetitive, restricted interests/behaviors
Mood disorders/ bipolar disorder	Tantrums/rages/irritability; emotional dysregulation	No significant impairments in communication; capacity for social reciprocity; no repetitive, restricted interests/behaviors
Language disorder	Struggle with language and therefore social and communication deficits may be present	Able to point for interests and uses gestures
Schizophrenia	Social impairments, odd patterns of thinking	Generally no deficits in communication unless highly disorganized; usually has delusions and hallucinations

**Table 14.3** Common comorbid disorders with autism spectrum disorder

Anxiety disorders, especially social anxiety disorder
Attention deficit hyperactivity disorder
Intellectual disability
Tic disorder/Tourette’s disorder
Major depressive disorder
Insomnia/sleep disorders
Bowel disorders – especially constipation
Seizure disorder

Most children and adolescents with ASD do have or will have a comorbid diagnosis. At times, these comorbidities are as problematic as the ASD itself. It is important to recognize these comorbidities and either treat them or refer them to the appropriate provider that can treat with medication and/or therapies [6]. See Table 14.3.



**Table 14.4** Public domain screening tools for ASD

Measure	Age validated and no. of items	Completed by	Administration and scoring times Training (none, unless otherwise indicated)	Languages available
Communication and Symbolic Behavior Scales and Developmental Profile (Infant Toddler Checklist)	<18 months 25 items	Parent	5–10 min Scoring: 5 min	English, Spanish
Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT-R/F)	16–30 months 20 items	Parent	5–10 min Scoring: <2 min. PDF for scoring also publicly available	Translated in >20 languages
Childhood Autism Spectrum Test	4–11 years 39 items	Parent	10 min Scoring: 5 min	English, Dutch, French, Greek, Persian, Slovak, Slovenian, Spanish, Swedish

## Screening and Measures

In 2007, the American Academy of Pediatrics (AAP) recommended that pediatric clinicians screen all 18- through 24-month-old children for ASD. This is crucial since early identification allows for parents to get early access to intensive behavioral treatments, such as applied behavioral analysis (ABA), that can improve outcomes in language, IQ, academic performance, and adaptive behaviors. Children suspected of having ASD through screening should be further evaluated by diagnostic testing with a developmental pediatrician, a psychological evaluation by a child psychologist, or a diagnostic evaluation with a child psychiatrist. To aid pediatric clinicians in this process, the AAP developed Caring for Children with Autism Spectrum Disorders: A Resource Toolkit for Clinicians (Autism Toolkit at [www.aap.org](http://www.aap.org)) [6].

Of note, the primary goal of the M-CHAT-R/F was to maximize sensitivity, meaning to detect as many cases of ASD as possible. Because of this, some children who score as at risk for ASD using this measure do not actually have ASD.

The screening test used depends upon the age of the child. Please see Table 14.4.

## Initial Management

### Psychosocial and Behavioral Interventions

According to the evidence base, every child with ASD should receive applied behavior analysis (ABA) therapy. ABA uses learning principals to bring about

positive and meaningful change. It decreases problem behaviors and reinforces positive behaviors. It also seeks to improve adaptive skills, academics, language, socialization, etc. The complication in children getting the ABA therapy is that many insurance providers either will not cover this at all or will cover a very limited number of hours and only until a set age. It cannot be stressed enough that the only evidence-based treatment for the core symptoms of ASD is ABA therapy. Every attempt should be made to refer the child for this service. Many states now have autism laws mandating that insurance providers cover this therapy at some level.

Children and adolescents can benefit from social skills groups offered by psychologists in many communities. There are other therapies that should be recommended on an individual basis. Parent skills training can be recommended to help the parent more effectively manage difficult behaviors, although often this is handled in ABA therapy as well. Adolescents or high-functioning children may benefit from individual psychotherapy especially when there is significant depression or anxiety present. Many interventions, such as speech and occupational therapies, should also be provided at school.

Children with language delays should be referred immediately to an audiologist even before a diagnosis of ASD is made. Laboratory and other diagnostic testing should be guided by physical exam findings and medical history. For those diagnosed with ASD, testing for fragile X, lead exposure, and genetic testing is standard of care. More recently a chromosomal microarray is recommended by the American Academy of Pediatrics, but insurance providers may not always cover this. The use of neuroimaging, EEG, and metabolic testing should generally be reserved for situations when the exam and history warrant such testing. More advanced genetic testing may also be advisable, especially if dysmorphic features are present. This may require a referral to a geneticist, if further expertise is needed or doing so is a requirement of insurers [6].

Table 14.5 contains key points for parental/family education after an autism spectrum diagnosis is made.

## Pharmacologic Interventions

There are many symptoms and disorders comorbid or associated with ASD that can be treated with medications. Although not an exhaustive list, the most common symptoms or comorbidities that can be treated are those of attention deficit hyperactivity disorder (ADHD), irritability, aggression, self-harm behavior, obsessive-compulsive disorder (OCD) or OCD-like behaviors, insomnia, depression, and anxiety. The medications most likely to be used to treat ADHD are stimulants and nonstimulant ADHD medications. Atypical antipsychotics are the most common medications used to treat significant irritability, aggression, agitation, and/or self-harm behavior associated with ASD. Selective serotonin reuptake inhibitors (SSRIs) are the most likely medications used to treat depression, multiple types of anxiety, and OCD. Additionally, SSRIs are of potential benefit in treating insistence on sameness as well as repetitive behaviors. Also, there are multiple medications used to treat the common problem of insomnia. These will be further discussed in the following sections.

**Table 14.5** Key points for parental/family education

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*Provide a description of autism spectrum disorder symptoms*—It is important for families to know that ASD is a psychiatric illness with biological underpinnings that are not the child or the parents' fault. This may help them take a more empathetic stance toward the youth's difficulty understanding social boundaries, regulating their emotions, throwing tantrums, or ceasing repetitive behaviors.

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*Encourage parents to make use of respite care and/or professional help*—Children do their best when their parents are emotionally healthy. Caring for a child with ASD can be stressful. Parents should explore and utilize opportunities for respite, including use of informal supports like family members. In cases where caregivers have symptoms of mental illness, an evaluation may be warranted to help parents effectively manage their own anxiety or depression for the benefit of the child.

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*Emphasize the importance of structure and routine*—Without the perspective-taking tools available to them that their neurotypical peers have and can use in making sense of interactions/the world around them, children with ASD will be more reliant on structure and routine.

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*Recommend the indicated therapies*—As the gold standard treatment for ASD, it is important that youth receive ABA therapy if possible. Also emphasize the role of speech/occupational/possibly physical therapy in optimizing functioning. Social skill training can be helpful for the youth, and parent management can be helpful for the parent.

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*Recommend connection with local community autism support group*—In addition to social support such organizations can be a source of education and inside information regarding the navigation of local resources. The Autism Speaks website is also a valuable resource.

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*Encourage patients to obtain a comprehensive assessment*—Psychological/psychoeducational evaluations provide a broad assessment of the child's cognitive and emotional functioning as well as individualized recommendations. They are highly recommended in cases of ASD so that educational interventions can be tailored appropriately.

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*Make them aware of the child's educational rights*—Children with ASD can receive individualized academic support. This text's chapter on interfacing with the school system and the website [www.wrightslaw.com](http://www.wrightslaw.com) are helpful resources.

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*Encourage parents to make use of available government resources*—Youth with ASD may qualify for SSI/disability benefits or Medicaid waiver programs which can provide patients and families with more resources to pursue therapeutic interventions.

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## Stimulants for ADHD in ASD

Stimulant medications are the most efficacious of the medications used to treat ADHD. When stimulants are used in children with ADHD without ASD, they have a response rate of 70–80%. However, research has shown that these medications are less effective and are more likely to cause side effects in those children who also have ASD. In these children, the response rate is closer to 50%. The largest side effect seen in those with ASD is irritability. However, the most worrisome side effect is increased aggression or agitation. If the child with ASD has these symptoms on a stimulant, the medication will likely need to be abruptly discontinued. For this reason, the “start low and go slow” approach with stimulants in children with ADHD and ASD is recommended [8, 9].

Although all of the medications that are FDA-approved to treat ADHD are typically used to treat those with ADHD and ASD, the only stimulant that has had significant research and proven efficacy in those with autism is methylphenidate.

Because the DSM-5 has now allowed the diagnosis of both ASD and ADHD separately in those with ASD, the use of stimulants in those with ASD and ADHD is no longer off-label.

Methylphenidate is a psychostimulant medication that is moderately efficacious in treating ADHD in children with ASD. According to the research, it is particularly effective for hyperactivity [3]. Although all of the many formulations of methylphenidate contain the same chemical compound, each is released differently into the patient's system such that one of these compounds may be more effective or better tolerated than another.

Since the evidence base in treating ADHD in those with ASD is with methylphenidate, one of the methylphenidate compounds should be used as a first-line agent. However, if the child fails a trial of a methylphenidate product, then one should try an amphetamine-based stimulant, paying attention to the length of action of the specific compound. Please refer to the ADHD chapter of this text, particularly Tables 12.4 and 12.5, for additional information regarding stimulants.

### **Nonstimulant ADHD Medications**

The nonstimulants can be used as a first-line medication for ADHD treatment. However, due to them being overall less effective at decreasing ADHD symptoms when compared to stimulants, they are generally used after stimulant trials have failed or in combination with a stimulant. Also, the nonstimulant medications take longer to evaluate effectiveness, taking 2–4 weeks to show significant therapeutic effects. These nonstimulant medications include guanfacine, guanfacine ER (Intuniv), clonidine, clonidine ER (Kapvay), and atomoxetine (Strattera).

All of these nonstimulants except atomoxetine are blood pressure medications, and so it is important to check blood pressure regularly, especially when titrating. Although hypotension is possible, it is not common and rarely causes a need for discontinuation. Sometimes sedation can be a problem and prompt discontinuation.

Studies of guanfacine have shown improvements in hyperactivity, inattention, insomnia, and tics in those with ADHD and ASD. Response rates in these different studies ranged from 24% to 58%, especially for hyperactivity. Studies of guanfacine ER (Intuniv) have also shown improvements in irritability in those with ASD. Less often, this medication can also cause irritability. Other potential side effects are sedation, sleep disturbances, constipation, headache, and bed-wetting. This medication has a relatively benign side effect profile. There has been a randomized, double-blind, placebo-controlled trial of guanfacine extended-release showing efficacy in controlling ADHD symptoms, especially hyperactivity, in those with ASD [9].

Atomoxetine (Strattera) is a different type of nonstimulant. It is a selective norepinephrine reuptake inhibitor that is FDA-approved for ADHD in children and adults. It is moderately effective for the treatment of hyperactivity and possibly inattention in those with ASD. One study showed a 60% response rate with improvements in conduct, hyperactivity, learning, and inattention. Another study showed a 75% response rate with additional improvements in irritability, social

withdrawal, stereotypy, and repetitive speech. The most common side effects are fatigue, nausea, and decreased appetite [2]. This medication is not typically prescribed as a first-line medication by most physicians but probably works quite well in a certain proportion of those with ASD. Generally, the response is not as high as with stimulants, and it does take 2–4 weeks to notice significant improvement with this medication [9].

### **Atypical (Second-Generation) Antipsychotic Medications**

The only two medications that have been approved by the FDA specifically for those with ASD are risperidone (Risperdal) and aripiprazole (Abilify). Risperidone was approved in 2006 to treat irritability in those with ASD, while aripiprazole was approved in 2009. Risperidone is FDA-approved starting at age 5 and aripiprazole at age 6. These two medications are specifically approved for impairing irritability, aggression, self-injury, and severe tantrums associated with ASD [8].

One study that led to the FDA's approval of risperidone for irritability in children with ASD was able to show a 69% response rate with a 57% decrease in irritability. Doses in the study ranged from 0.5 mg to 3.5 mg per day with an average dose of about 2 mg per day. A study in adults was able to show improvement in aggression, irritability, anxiety, depression, and repetitive behaviors with a 57% response rate [9].

Short-term (8 weeks) and long-term studies (52 weeks) have proven aripiprazole to be effective in reducing irritability in those with ASD. Dosages for aripiprazole in these studies ranged from 2.5 mg to 15 mg per day [6, 11]. One study found that it was generally safe and well tolerated even after 1 year, but there were, on average, abnormalities noted in lipids/cholesterol and blood sugar. For example, there was a 5% increase in cholesterol and a 2% increase in blood sugar. About 10% of those in the study discontinued aripiprazole secondary to side effects of weight gain or aggression. However, after 52 weeks irritability remained improved [8].

Although there are numerous other atypical antipsychotics, they are not FDA-approved for ASD, and, more importantly, there are not any randomized, double-blind, placebo-controlled trials proving their effectiveness in treating ASD-associated behavioral problems. In fact, lurasidone (Latuda) recently proved ineffective in treating those with ASD in a large trial. Nonetheless, other atypicals may be used as third-line agents if the child fails trials of risperidone and aripiprazole. These other atypical antipsychotics are quetiapine (Seroquel), ziprasidone (Geodon), paliperidone (Invega), iloperidone (Fanapt), asenapine (Saphris), and cariprazine (Vraylar) [9].

Due to the fact that aripiprazole and ziprasidone are regarded as the most “weight-neutral” medications in their class, ziprasidone (Geodon) is often used in practice when a child is gaining too much weight on risperidone or even aripiprazole. In clinical experience, some patients are successfully treated for irritability and tantrums with ziprasidone with less weight gain than on risperidone; however, there have not been any large randomized, double-blind, placebo-controlled trials of ziprasidone for ASD. As a result, one should probably not use ziprasidone as a first-line medication.

**Table 14.6** Evidence-based medications for autism spectrum disorder

Medication	Quality of evidence	Target symptoms	Dosage ranges	Risk (relative) of metabolic syndrome/ weight gain
Risperidone	High (FDA-approved); positive studies	Irritability, agitation/ aggression, self-injurious behavior, tantrums	0.25–3 mg; for irritability associated with ASD in 5–16yo	Medium
Aripiprazole	High (FDA-approved); positive studies	Irritability, agitation/ aggression, self-injurious behavior, tantrums	2–15 mg; for irritability associated with ASD in 6–18yo	Low
Paliperidone	Low; positive studies	Irritability, agitation/ aggression, self-injurious behavior, tantrums	3–6 mg (<51 kg) 3–12 mg (>51 kg); based on pediatric schizophrenia in those >12 yo	Medium
Ziprasidone	Low; positive studies	Irritability, agitation/ aggression, self-injurious behavior, tantrums	Only approved for any indication in adults, Range 20–160 mg divided BID	Low
Olanzapine	Low; positive studies	Irritability, agitation/ aggression, self-injurious behavior, tantrums	2.5–20 mg; based on schizophrenia/ bipolar >12 yo	High
Quetiapine	Low; negative studies	Irritability, agitation/ aggression, self-injurious behavior, tantrums	50–600 mg divided BID; based on bipolar disorder in those >9 yo	Medium
Lurasidone	Low; negative studies	Irritability, agitation/ aggression, self-injurious behavior, tantrums	20–80 mg; based on schizophrenia in those >12yo; take with food	Low

One small study showed quetiapine was poorly tolerated and minimally effective in children with ASD. In small studies, paliperidone and ziprasidone appeared promising but more studies are needed [11]. Please see Table 14.6 regarding the evidence base for atypical antipsychotics in ASD and dosing. Those atypical antipsychotics not mentioned in this chart have no evidence for use in ASD.

Due to significantly high rates of metabolic syndrome (or weight gain in general) on atypical antipsychotics, it has been suggested by some experts that metformin should be started early in treatment to prevent metabolic syndrome and to reduce or halt the rate of weight gain. If a child continues to gain a significant amount of

weight, but the atypical antipsychotic cannot be discontinued due to severe aggression, self-injurious behavior, or extreme irritability, then one should strongly consider the addition of metformin. Research shows that the earlier that metformin is started, the greater the reduction in weight and/or the rate of weight gain. Another strategy is switching to a different atypical antipsychotic that might cause less weight gain than that caused by risperidone. For example, one could taper this medication and titrate ziprasidone (Geodon) or aripiprazole (Abilify). There is some risk, however, of the second atypical antipsychotic not working as well.

### **SSRIs**

In those without ASD, selective serotonin reuptake inhibitors (SSRIs) are commonly used to treat depression, obsessive-compulsive disorder, social anxiety disorder, generalized anxiety disorder, panic disorder, and other disorders. As those with ASD are also at an increased risk for these disorders, they should be monitored and treated with SSRIs when appropriate. Those with moderate or severe depression or severe anxiety should be referred to a psychologist or counselor and likely to a psychiatrist for close monitoring.

It was once thought that SSRIs might treat the repetitive and restrictive behaviors seen in those with ASD. The thinking was that this behavior was similar to OCD, and thus SSRIs should help reduce these symptoms, but research has proven that these symptoms are not the same as typical OCD. As a result, SSRIs are not effective for these behaviors in children with ASD. In fact, in ASD repetitive and restrictive interests are usually enjoyable or at least not bothersome to the youth as they would be if they were obsessive and part of OCD. If a child is bothered by obsessions or compulsions, he or she may have OCD and may benefit from an SSRI. According to research, SSRIs, specifically fluoxetine (Prozac), might be helpful in adults with ASD that have repetitive and restrictive behaviors, even though these same people may not be helped with SSRIs as children in the absence of comorbid OCD.

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### **When to Refer**

Youth should be referred for additional specialty care if the ASD diagnosis is unclear. In these cases, a child psychologist, child psychiatrist, or developmental pediatrician can be helpful. Referral to a child psychiatrist can be indicated if/when medication management is needed, but this may vary depending on PCP comfort/training with psychiatric prescribing for this population. In all cases, youth should be referred for a hearing test, speech therapy, occupational therapy, and physical therapy (at least initial evaluation). Additionally, evaluation and therapy with applied behavior analysis should always be recommended; however, there is a recognition that the family may not be able to follow through if this is not covered by insurance. Referral to a local autism support group is recommended as this can be a valuable source of emotional and resource support. The Autism Speaks website is a good source of information on autism and resources. Children younger than 3 years of age should be immediately referred to an early intervention program. Children older than 3 years



**Table 14.7** Monitoring youth on antipsychotics

Assessments	Frequency
Lifestyle monitoring	Every visit
Height, weight, BMI percentile	Baseline and at least annually (best at every visit)
Blood pressure, pulse	Baseline, at 3 months, and every 6 months
Fasting glucose, HbA1C, lipids	Baseline, at 3 months, and every 6–12 months
Liver function tests	Baseline, at 3 months, and every 6–12 months
EPS, akathisia	Baseline, during titration, at 3 months, and annually
Dyskinesia, tardive dyskinesia	Baseline, at 3 months, and annually
Electrolytes, blood count, renal function	As needed or appropriate unless on clozapine
Prolactin	Only if symptomatic
EKG	If on ziprasidone during titration and at max dose

need referral to the special education department in their school district. Discuss with the parent the need for an Individualized Education Program (IEP) at school and for a special needs advocate to help with this process [6].

## Key Considerations for Follow-Up

At every visit, it is important to determine if the patient and family are taking full advantage of all treatment modalities and recommendations. The importance of early intervention and compliance in positively altering the trajectory of the disorder should be reiterated to parents. Medication adherence should also be assessed. If on an SSRI, always ask about suicidal thoughts. Safety issues such as severe tantrums, aggression, and elopement should be followed and tracked. If there is elopement present, recommend a GPS tracker. As caregiver strain is frequently encountered, it is also important to ask about parental stress, supports, and respite care. As usual, monitoring for side effects of any psychiatric medications, especially if on an atypical antipsychotic, is an important aspect of follow-up. Please see Table 14.7 regarding monitoring frequency when on an atypical antipsychotic.

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A. Benjamin Srivastava, Steven L. Jaffe, and Mark S. Gold

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## Introduction

Substance use disorders (SUDs) are one of the foremost public health problems in the United States, and their manifestations in children and adolescents warrant careful consideration [1]. Adolescent substance use is associated with medical and psychiatric problems, high-risk behavior including high-risk driving and unsafe sex, poor scholastic performance and lost future productivity, family dysfunction, and injurious behavior including suicide and homicide [2]. Costs associated with underage drinking total \$68 billion yearly; an additional \$14.4 billion is associated with substance-related juvenile justice programs [2]. Clearly, identification, evaluation, and treatment of substance use disorders in children and adolescents are of paramount importance for maximizing individual potential and mitigating disease burden on both individual and public health levels.

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## Brief Review of Epidemiology and Pathophysiology

Overall, adolescent substance use is quite prevalent in the United States, with 59% of adolescents having tried alcohol, 24% having used illicit drugs, and nearly one third trying cigarettes [3]. Most individuals who eventually transition from substance use to an actual substance use *disorder* begin experimenting with drugs and alcohol during adolescence. Specifically, 90% of adults in the United States with a

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A. B. Srivastava (✉) · M. S. Gold  
Department of Psychiatry, Washington University School of Medicine,  
Saint Louis, MO, USA  
e-mail: [a.srivast@wustl.edu](mailto:a.srivast@wustl.edu)

S. L. Jaffe  
Department of Psychiatry, Emory University School of Medicine, Atlanta, GA, USA

substance use disorder started using before age 18 [2]. Of individuals who experiment with addictive substances prior to age 18, 25% develop SUDs, while only 0.04% of individuals who experiment after age 21 develop SUDs [2]. Figure 1.1 in this text's chapter on resilience includes many risk and protective factors for substance use.

Several epidemiological surveys measure adolescent substance use, with perhaps the most well-known being the Monitoring the Future (MTF) study [3]. Of note, MTF is a cross-sectional study for students enrolled in school. Many of the teenagers with the most severe substance use disorders are not in school and instead are in the juvenile justice system, in treatment centers, or on the streets [4]. Therefore many of the teens with the most problematic alcohol and drug use may not be captured in the MTF data. Additionally, the National Survey on Drug Use and Health (NSDUH) has collected data on illicit drug, tobacco, and alcohol use in the United States among individuals 12 and older and has been conducted yearly since 1971 [5, 6]. The bulk of evidence demonstrates that use, misuse, and substance use disorders of all substances have been declining over the past 1–2 decades in adolescents. See Table 15.1 for additional details of these studies' findings.

In contrast with the overall trend of decreased use, e-cigarette use is ever increasing [7]. Several studies associate antecedent e-cigarette use with later cigarette use (once monthly); however, whether these users go on to develop tobacco use disorder (i.e., smoke cigarettes regularly) is not clear [8, 9]. Additionally, the overall decline in marijuana use notwithstanding, in Colorado, which legalized recreational marijuana in 2012, marijuana-related emergency department visits, marijuana-related suspensions and expulsions, and marijuana-related legal problems have all increased in prevalence among teenagers [10]. Though on a population level, substance use, misuse, and use disorders among children and adolescents are declining, nearly 90% of adolescents with a diagnosable substance use disorder do not receive treatment, which has been relatively consistent since 2003 [11].

Decades of preclinical and clinical research has provided extensive evidence regarding the pathophysiology of substance use disorders. Though many models exist, the “three phases” model proves helpful in understanding the pathophysiology of addiction and will be briefly reviewed here [12]. In the binge/intoxication phase, all drugs of abuse result in phasic dopamine (DA) release, producing a “reward” phenomena parallel to, though stronger than, that produced by natural stimuli necessary for survival (e.g., food, sex). With time and repeated use, dopamine receptors desensitize, resulting in a decreased sense of reward when the drug is taken. In the withdrawal/negative affect phase as a consequence of decreased dopamine release and receptor downregulation from natural stimuli as well as drugs of abuse, there is a profound state of anhedonia. Thus, any period of abstinence results in anxiety, dysphoria, and anhedonia. In this stage, the act of drug taking transitions from *impulsive* (i.e., pleasure seeking) to *compulsive* (relief of underlying stress). In the preoccupation/anticipation phase, prolonged substance use is associated with decreased dopaminergic tone in the prefrontal cortex. The resulting clinical manifestation is thus inability to resist temptation to use (i.e., when cued or

**Table 15.1** Epidemiology of adolescent substance use disorders

Substance	Trends	Surveys
Alcohol	12th grade past year use decreased from 75% in 1997 to 55.6% in 2016	Monitoring the future
	10th grade past month use decreased from 65.3% in 2000 to 38% in 2016	
	8th grade past year use decreased 46.8% in 1994 to 17.6% in 2016	
	Binge drinking declined among 8th graders, from 13.3% in 1996 to 3.4% in 2016, as well as 12th graders, from 31.5% in 1998 to 15.5% in 2016	
Tobacco	Decline in smoking 22.2% among 12th graders in 1996 to 4.8% in 2016 and in 10th graders, from 18.3% in 1996 to 1.9% in 2016	Monitoring the future
	Perception of availability of cigarettes decreased, with 62.9% of 10th graders reporting ease of obtaining cigarettes in 2016 compared with 91.3% in 1996	
Marijuana	Perception of harm continues to decline, daily use among all grades declined as well (from 3.6% to 2.5% of 12th graders and 1.3% to 0.7% of 10th graders from 2011–2016 and 1.1% to 0.7% from 2015–2016 for 8th graders)	Monitoring the future
	Prevalence of cannabis use disorder has decreased from 15.8% in 2002 to 13.2% in 2013	NSDUH
Opioids	Heroin use among 12th graders declined to 0.3% in 2016 from a peak of 0.7% in 2010	Monitoring the future
	Prescription opioid misuse also declined among 12th graders, from a peak of 9.5% in 2004 to 4.8% in 2016	
Stimulants	Cocaine use among 10th graders peaked at 4.9% in 1999 and has decreased to 1.3% in 2016	Monitoring the future
	Past year mixed amphetamine salts (Adderall) misuse has been relatively constant, with 6.2% of 12th graders reporting past year use, though methylphenidate (Ritalin) use has declined from 5.1% in 2004 to 1.2% in 2016	
Sedative/hypnotics	Ever use down from peak prevalence of 7.9% in 2001 to 5.2% in 2015; slight increase to 5.5% in 2016	Monitoring the future

stressed), failure to stop using despite known consequences, and continued use despite attempts and desire to do otherwise.

## Developmental Factors

The earlier someone starts using substances, the more likely he or she is to develop a substance use disorder. The young brain's plasticity renders it particularly vulnerable to the impact of substances. Additionally, because frontal lobes are not fully developed in adolescence, compared to the adult brain, the adolescent brain is more prone to underestimate risks and fail to think through long-term consequences. All of these biological factors coincide with adolescence as a time of increased

independence from the family and increased peer influence. Psychologically, adolescents are undergoing several significant life transitions and charged with making more decisions. If they have not developed adaptive coping skills to assist with their stressors, substance use may fill that gap, especially if their peers use substances.

One of the most controversial constructs in psychiatry is the “gateway hypothesis,” the idea that the use of certain widely available drugs that are perceived as “less harmful” (e.g., marijuana, alcohol, tobacco) may lead to the use of “harder” drugs (e.g., opioids, cocaine, etc.) [13]. The sequence of cigarettes/alcohol to marijuana to harder drugs was proposed [14]. The theory has historically been supported by epidemiological evidence; however studies have yielded conflicting findings, and though early initiation generally predicts later, more pathological use, direct causality cannot be confirmed from these studies [13, 15].

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## Diagnosis and Key Components of History

The primary care provider (PCP) should evaluate for both risk and protective factors. Risk factors include but are not limited to trauma, family history of substance use, poor parental supervision, low academic achievement (see later), untreated ADHD (see later), and perceived acceptance of substance use among peers [16]. Protective factors include but are not limited to parental rule setting and enforcement, family meal time, open discussion in the family of the dangers of substance use, having a parent in recovery, involvement in religious and/or community programs, and opportunities for prosocial involvement in the community [16]. For more information on SUD protective and risk factors in youth, please refer to Fig. 15.1 in this text’s chapter, Considerations on Resilience in At-Risk Youth.

Per the recommendations of the American Society of Addiction Medicine (ASAM), primary care physicians should screen patients as soon as they are old enough to be interviewed without the presence of a parent (typically ages 11–13) [17]. Though the parent/guardian will accompany the patient to the appointment, the parent or guardian should be asked to leave the room prior to taking a substance history [17]. The primary care provider should educate the patient that information shared will only be told to the parent if there are safety concerns [17].

In the interview with the patient, one should begin with open-ended questions about substance use in the family and his/her peer group and then proceed to more specific questions about the use of alcohol and marijuana. It is very important to then ask about the use of pills. This should involve asking specifically about opiates especially by brand and colloquial names (e.g., Percocet®, Vicodin®, “Roxys and Oxys”) and benzodiazepines (e.g., Xanax®, Valium®, Ativan®, and Klonopin®). Physical dependency is not uncommon, and withdrawal seizures can be life-threatening [18]. All adolescents should be asked whether they have ever taken an unknown pill at a party. One can then proceed to asking about psychedelics, cocaine, and heroin. DXM (dextromethorphan) used in cough medicines is also becoming a popular way to get high (“Robo tripping”) [19].

When taking a substance abuse history, given the reluctance of some patients to fully disclose their histories even in confidence, asking both the child and parent about changes in academic performance, behavioral problems at school, changes in interest in extracurricular activities, fighting, and medical issues might be helpful [17]. In particular, declining grades may be the very first indicator of addiction for

## The CRAFFT Interview (version 2.0)

To be orally administered by the clinician

**Begin:** “ I ’m going to ask you a few questions that I ask all my patients. Please be honest. I will keep your answers confidential.”

### Part A

**During the PAST 12 MONTHS, on how many days did you:**

- |                                                                                                                                                                  |                                                                       |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------|
| 1. Drink more than a few sips of beer, wine, or any drink containing alcohol ? Say “0” if none.                                                                  | <input style="width: 100px; height: 20px;" type="text"/><br># of days |
| 2. Use any marijuana (pot, weed, hash, or in foods) or “synthetic marijuana ” (like “K2” or “Spice”)? Say “0” if none.                                           | <input style="width: 100px; height: 20px;" type="text"/><br># of days |
| 3. Use anything else to get high (like other illegal drugs, prescription or over-the-counter medications, and things that you sniff or “huff”)? Say “0” if none. | <input style="width: 100px; height: 20px;" type="text"/><br># of days |

**Did the patient answer “ 0” for all questions in Part A?**

Yes

No



**Ask CAR question only, then stop**

**Ask all six CRAFFT\* questions below**

### Part B

	No	Yes
<b>C</b> Have you ever ridden in a <b>CAR</b> driven by someone (including yourself) who was “high” or had been using alcohol or drugs?	<input type="checkbox"/>	<input type="checkbox"/>
<b>R</b> Do you ever use alcohol or drugs to <b>RELAX</b> , feel better about yourself, or fit in?	<input type="checkbox"/>	<input type="checkbox"/>
<b>A</b> Do you ever use alcohol or drugs while you are by yourself, or <b>ALONE</b> ?	<input type="checkbox"/>	<input type="checkbox"/>
<b>F</b> Do you ever <b>FORGET</b> things you did while using alcohol or drugs?	<input type="checkbox"/>	<input type="checkbox"/>
<b>F</b> Do your <b>FAMILY</b> or <b>FRIENDS</b> ever tell you that you should cut down on your drinking or drug use?	<input type="checkbox"/>	<input type="checkbox"/>
<b>T</b> Have you ever gotten into <b>TROUBLE</b> while you were using alcohol or drugs?	<input type="checkbox"/>	<input type="checkbox"/>

**\*Two or more YES answers suggest a serious problem and need for further assessment. See back for further instructions →**

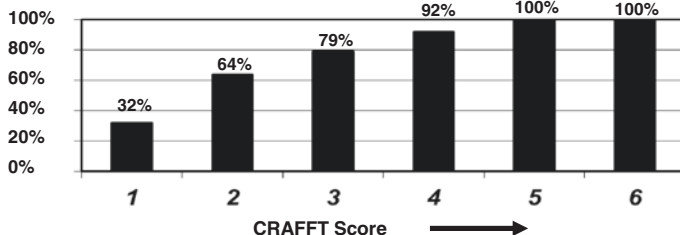
**NOTICE TO CLINIC STAFF AND MEDICAL RECORDS:**

The information on this page is protected by special federal confidentiality rules (42 CFR Part 2), which prohibit disclosure of this information unless authorized by specific written consent. A general authorization for release of medical information is NOT sufficient.

**Fig. 15.1** CRAFFT 2.0 <http://www.ceasar.org>

**1. Show your patient his/her score on thisgraph and discuss level of risk for a substance use disorder.**

**Percent with a DSM-5 Substance Use Disorder by CRAFFT score\***



\*Data source: Mitchell SG, Kelly SM, Gryczynski J, Myers CP, O’Grady KE, Kirk AS, & Schwartz RP. (2014). The CRAFFT cut-points and DSM-5 criteria for alcohol and other drugs: a reevaluation and reexamination. *Substance Abuse*, 35(4), 376–80.

**2. Use these talking points for brief counseling.**



**1. REVIEW** screening results  
For each “yes” response: *“Can you tell memore about that?”*



**2. RECOMMEND** not to use  
*“As your doctor (nurse/health care provider), my recommendation is not to use any alcohol, marijuana or other drug because they can: 1) Harm your developing brain; 2) Interfere with learning and memory, and 3) Put you in embarrassing or dangerous situations.”*



**3. RIDING/DRIVING** risk counseling  
*“Motor vehicle crashes are the leading cause of death for young people. I give all my patients the Contract for Life. Please take it home and discuss it with your parents/guardians to create a plan for safe rides home.”*



**4. RESPONSE** elicit self-motivational statements  
Non-users: *“If someone asked you why you don’t drink or use drugs, what would you say?”* Users: *“What would be some of the benefits of not using?”*



**5. REINFORCE** self-efficacy  
*“I believe you have what it takes to keep alcohol and drugs from getting in the way of achieving your goals.”*

**3. Give patient Contract for Life.** Available at [www.crafft.org/contract](http://www.crafft.org/contract)

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(617) 355-5433 [www.ceasar.org](http://www.ceasar.org)

For more information and versions in other languages, see [www.ceasar.org](http://www.ceasar.org).

**Fig. 15.1** (continued)

which the parents express concern and might provide an opportune time for intervention and prevention of disease progression [20]. Additionally, parents or teachers may suspect substance use given previously mentioned behaviors, changes in mood, and being caught with drug paraphernalia, and this collateral information may be indispensable [17]. Obtaining consent to talk to other friends and school administrators may be prudent [17]. Though collateral is often requisite, an important point is that teens may readily admit marijuana, benzodiazepine, and alcohol use but not consider it harmful or problematic [3].

## Differentiating Substance Use from Substance Use Disorder

A key task for the primary care provider is to differentiate substance use (experimentation or sporadic use without consequences), problematic substance use (use with consequences that are starting to appear or are sporadic), and substance use disorder (a continued pattern of use despite adverse consequences psychologically, medically, and/or socially) [16]. Ultimately, this process should be informed by use of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM) criteria for substance use disorders. Of note, while the DSM requires that the substance use and associated symptoms be present for a year's duration in order to meet diagnostic criteria, this time frame may be too long to wait to diagnose and begin interventions in youth given their biological, psychological, and social vulnerabilities. Questions regarding tolerance, withdrawal, loss of control, declining interest in recreational activities, and negative impacts of the substance on mood, concentration, relationships, and school (and if applicable, job) performance should be asked. The physician must pay attention to the presenting signs and symptoms, family history, longitudinal course, and laboratory evaluation while keeping the clinical criteria and potential differential diagnoses and co-occurring illnesses in mind [21].

For all stages of substance use, it is important to understand *why* the youth is using. Do they just like being high? Do they perceive that it helps them with anxiety or stress? Does it diminish flashbacks from a traumatic event? Is it something they do out of boredom? Are they using at this point just to avoid withdrawal symptoms? Understanding why can point to possible co-occurring mental illnesses. It is also needed to inform effective therapeutic interventions.

## Physical Exam and Laboratory Tests

Children and adolescents are less likely to display stigmata of chronic alcohol/drug use, though a full physical exam may reveal telling signs (septal perforations from cocaine use, track marks from IV drug use, etc.) [17]. Also, looking for obvious and subtle signs of intoxication and withdrawal is crucial. Urine drug screens can be helpful, though in some circumstances more comprehensive testing (hair, nail clip-pings) may be necessary [17]. The urine drug screen will be best at detecting marijuana use because the substance is stored in lipids and therefore stays in the body



longer compared to other drugs of abuse. A single “joint” can have a positive screen for up to a week after last use, while more frequent use may result in a positive screen for up to a month after last use. Most other drugs of abuse will show up in urine drug screens for only 2–3 days after last use [22].

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## Comorbidities and Confounders

The majority of youth with SUDs will have other co-occurring mental illnesses. Screening for and evaluation of psychiatric disorders, particularly ADHD, depression, anxiety, trauma and stress-related disorders, and eating disorders, are imperative [17, 23, 24]. To provide one example of the interplay between SUD and other mental illness, cannabis use is likely to antedate severe adolescent anxiety [25]. If/when co-occurring mental illness is discovered, the creation of two timelines, one for initiation/progression of substance use and another for onset/progression of psychiatric symptoms/diagnoses such as depression and anxiety, can bring some clarity. This approach can help with teasing out whether substance use is causing other symptoms or if substances were started in an attempt to self-medicate or cope with preexisting psychiatric symptoms. Either way, one complicates the presentation and treatment course of the other, so both should be identified and addressed.

---

## Screening and Measures

Adolescents, high-risk preadolescents, and youth with known mood, anxiety or trauma, and stress-related disorders should be screened for SUDs. The CRAFFT 2.0 is a screening tool for SUD, and it has high sensitivity and specificity [26] (Fig. 15.1). The provider simply asks the listed questions. The first question is about past year substance use (# of days used alcohol, marijuana, and other drugs). If none, anticipatory guidance based on risk and protective factors should be given, and the physician should only ask the additional CRAFFT screening question about riding in a car (“CAR”) with someone who has been high or using drugs. If this car question is answered “yes,” a discussion on the dangers of impaired driving should ensue, and a safety plan should be made for alternative transportation. Of note, while almost all adolescents recognize that alcohol impairs driving, they often don’t realize that marijuana also impairs driving [27]. We have found the following message helpful in making this point: “If you are drunk, you run the red lights. If you are high, you stop at the green lights.” It is important to make youth aware that marijuana impairs driving by a different mechanism and that a small amount of alcohol combined with smoking marijuana causes marked driving impairment [28].

If the patient has used substances, the physician should then ask the remaining CRAFFT questions. If the total CRAFFT score is greater than 2, this is suggestive

of a substance use disorder and requires further exploration. The physician should ask about detailed use of each substance, recommend cessation, emphasize alternative modes of transportation if impaired driving/riding is an issue, educate the patient about the risks of substance use, and reinforce positive behavior and self-efficacy (*see* Fig. 15.1) [29].

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## Initial Management

### Safety Considerations

Safety first. It is imperative to obtain information regarding the type and frequency of substances used. Certain drugs of abuse, such as alcohol and benzodiazepines, can be deadly in withdrawal if they have been used on a regular basis. Intoxication with other substances of abuse can be associated with serious medical problems including the possibility of death. The combination of benzodiazepines and opiates is especially risky. If a patient took unidentified pills, err on the side of assuming the worst. If vital sign instability, disorientation, or other signs of medical complications from substance use or withdrawal are present, emergency evaluation should be strongly considered. An additional safety consideration is that SUDs place youth at risk for exposure to infectious diseases from needle sharing or, in some cases, from sex work that is being done in order to fund their substance use. Thus, youth should be asked about these high-risk behaviors and tested accordingly.

### Psychosocial and Behavioral Interventions

If the patient does not demonstrate behavior concerning for problematic substance use, but is using or is at risk, praise and reinforcement of good decisions and behavior should be offered [17]. If the patient has not used but is around friends who use, precautionary advice should be given [17]. If the child has used substances but does not have a disorder, emphasizing cessation while providing information is indicated. This is helpful because youth's appreciation of the risks of substance use is a protective factor. Candid discussions about additional risks the youth may have because of family history can be helpful. Any psychiatric comorbidities should be addressed. Dialogue with the family is useful for the identification of risk and protective factors, and the subsequent education should include strategies to decrease/mitigate risk factors and bolster protective factors. Cessation should also be recommended. Table 15.2 includes key points for parental/family education.

If the youth has a substance use disorder but does not recognize a need for change, the appropriate intervention is education regarding the potential consequences of substance use coupled with changes in the home or community environment that bolster protective factors and decrease risk factors. In treating all youth

**Table 15.2** Key points for parental/family education

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*Help families see their potential as protective factors*—Appropriate parental supervision and involvement in prosocial activities are protective factors against SUDs. While it is true that the opinions and influence of peers take on greater significance as youth enter into adolescence, the youth's perception of the parent's approval of substance use has also been identified as a risk factor.

*Educate families about co-occurring mental illnesses*—It is rare that SUDs occur in isolation in youth. Additionally, SUD remains a more highly stigmatized mental illness compared to others. The youth's path to recovery will be hard, if not impossible, if co-occurring mental illness is not addressed. Explaining the relationship between SUD and other mental illnesses can help families understand how the child got there and what needs to be done to help them move forward.

*Identify potential risks of the SUD*—SUDs increase the youth's risk of harming themselves or others. Additionally, they are at risk of overdose leading to medical complications or possibly death depending on the substance used.

*Identify potential risks in the home*—Access to lethal means, especially guns, should be restricted or eliminated. Also, any old or surplus prescription or over-the-counter medications with abuse potential should be promptly and properly removed from the home.

*Educate the family about the perils of enabling and the need for natural consequences*—When it comes to deciding to change behavior, the tipping point for people with SUDs is when they perceive that the consequences of use outweigh the benefits. When families shield youth from natural consequences of their use, they are undermining the youth's motivation to change.

*If opiate use is a concern, educate parents about naloxone (Narcan)*—Timely administration of naloxone can be lifesaving. Parents and youth should be educated about its use when it is co-prescribed. The following page <https://www.drugabuse.gov/related-topics/opioid-overdose-reversal-naloxone-narcan-evzio> includes a helpful, short video describing the rationale and use of intranasal naloxone. Families and youth must know that if/when naloxone administration is needed, the overdose still requires emergency hospital care even if the youth responds because of naloxone's relatively short half-life.

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with substance use disorders, intervention must be informed by an understanding of *why* the youth is using. If/when the youth recognizes the need to change and is ready to discuss a cessation or reduced drug use plan, knowledge of the youth's reasons for using can help inform the treatment plan. This knowledge facilitates the PCP's support of the youth in problem-solving around more adaptive strategies to address the purpose for which they were using substances. Additionally, understanding the circumstances of the substance use can help family and providers identify additional resources. These resources can take the form of mental health interventions or environmental changes.

SBIRT, which stands for screening, brief intervention, and referral to treatment, has proven efficacy in treating substance use disorders in the primary care setting [30] and is a useful starting point. Components of brief intervention that can be performed by the primary care physician include feedback, education, recommendation, negotiation, and follow-up. Feedback involves communicating risk and/or discussing manifested consequences of continued substance use. Education involves relaying how consequences are relevant to the adolescent. Recommendation involves imploring the patient to forgo all substance use for a specified period. Negotiation is invoked when the recommendation is declined and involves suggesting a commitment to reduced intake or other harm-reductive measures. Agreement

involves a mutually assured contract to the treatment plan. Follow-up involves future appointments to gauge progress [16].

The long-term treatment goal of adolescents with substance use disorders is life-long abstinence; however, recidivism is high, and addiction itself is a chronic, relapsing disease [17, 23]. Thus, harm reduction, or, in other words, decreasing the risk associated with the substance by decreasing the amount used or the situations when it is used, may be an “intermediate” goal that eventually leads to long-term recovery. Contingency-parent management and psychotherapy may be useful for both harm reduction and long-term sobriety.

In contingency-parent management, the primary care provider can assist the parents and the patient with the development of a plan that sets appropriate limits and also includes consequences for substance use along with rewards for good decisions/use of healthier coping mechanisms. The management plan uses positive and negative social and material reinforcements, especially related to the safe use of a car, to promote positive behavior. This intervention can be delivered during brief intervention and outpatient therapy [31]. Family therapies and cognitive behavioral therapies have evidence for the treatment of adolescent SUDs but generally require the involvement of a clinician with mental health expertise [32].

### **Marijuana and Perceived Risk of Harm**

A major issue in the risk for marijuana use disorder is that many adolescents consider it to be a harmless drug [27]. When this is the case, there is an important role for patient education regarding marijuana’s potential harmful effects including the development of cognitive problems, especially short-term memory deficits, as well as attentional and motivational issues [33]. For example, one study showed a loss of six IQ points in a follow-up of regular users beginning in adolescence [34]. Figure 15.2 can be a useful demonstrative aid for such conversations.

### **Pharmacologic Interventions**

Evidence for psychopharmacologic treatment of adolescent SUDs (e.g., buprenorphine for opioid use disorder, naltrexone for alcohol use disorder) is limited and generally within the purview of an addiction specialist [35]. If the patient uses opioids, especially heroin, the PCP should strongly consider prescribing naloxone by nasal spray or injection to be used in case of an overdose [36]. In sum, compared to adults, evidence for pharmacotherapy across different substance use disorders is limited, and as a result pharmacotherapy is infrequently used in this patient population. Further, adolescents rarely use drugs in isolation, and no pharmacotherapy has shown demonstrated efficacy for the most commonly abused drug (marijuana), further limiting the utility of pharmacotherapy [35]. Of note, however, in a randomized controlled trial of the supplement N-acetylcysteine (NAC) in cannabis-dependent adolescents, compared to those receiving placebo, participants receiving NAC had more than twice the odds of having negative urine cannabinoid test results during treatment. Additionally the supplement was well tolerated [37].

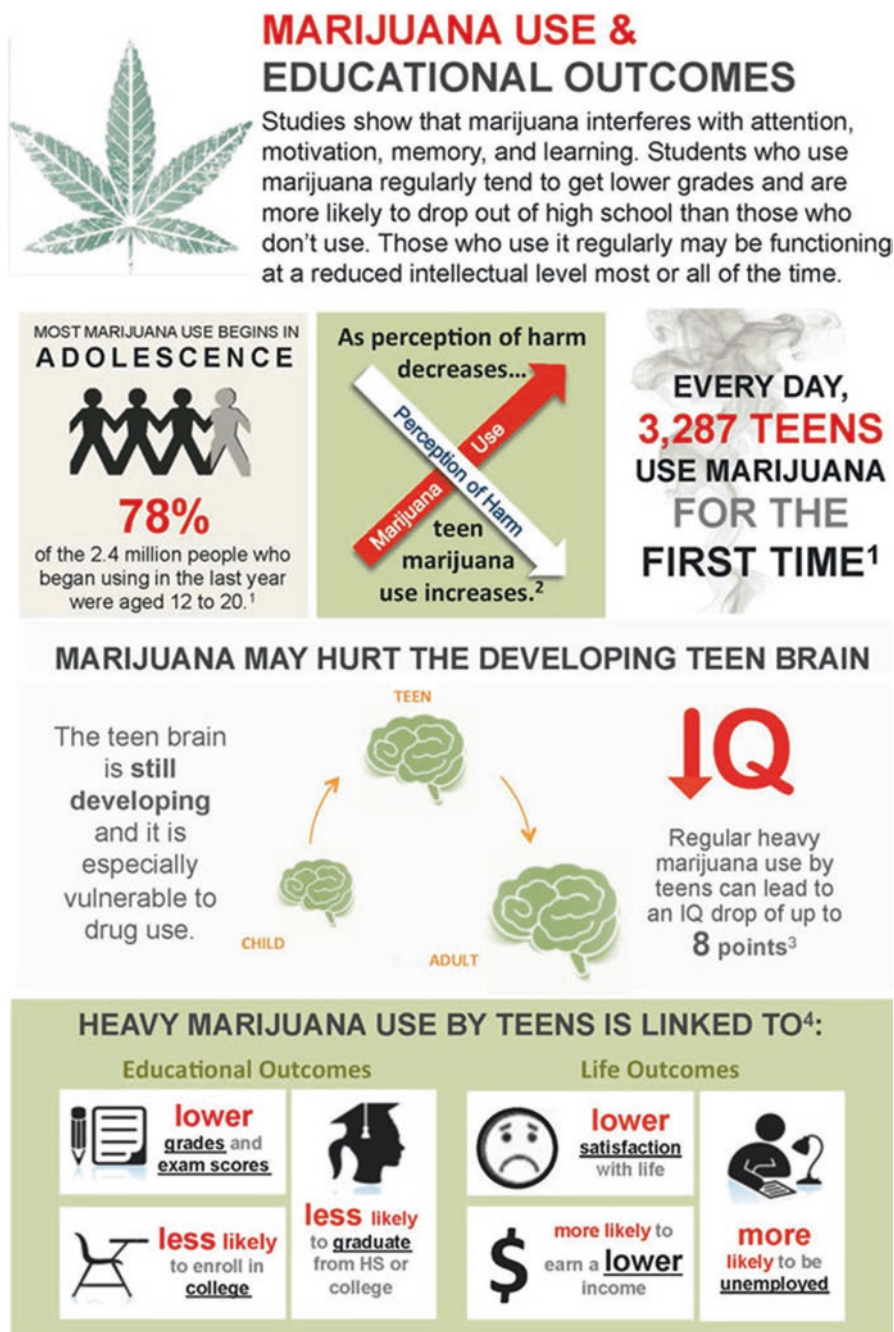


Fig. 15.2 Source <https://teens.drugabuse.gov>

### **Psychiatric Medications for Co-occurring Illness in Youth with SUD**

Co-occurring psychiatric illnesses, particularly anxiety disorders, mood disorders, ADHD, and trauma and stress disorders, should be addressed and may benefit from medication treatment. Stimulant medications used for ADHD can be abused and carry FDA warnings to that effect. This may be concerning to patients and/or their families, especially if their child has a SUD or if there are other people with SUDs in the family. They can be reassured by education that studies show ADHD treatment with psychostimulants and/or atomoxetine is actually associated with a *reduced* risk of substance-related problems compared to the risk in those with untreated ADHD [38]. In general, longer-acting formulations are less likely to be abused than immediate release ones and are preferable in cases where there is risk of or known SUD [39].

While concern remains about suicidality with selective serotonin reuptake inhibitors and its FDA black box warning, interim evidence has shown that these medications are appropriate and at times lifesaving for children with affective and anxiety disorders [40]. Please refer to this text's Table 10.6, Talking Points re: Antidepressant Medication Treatment Initiation, for additional information. The SSRIs do not have abuse potential; however, the benzodiazepines do and are potentially fatal in overdose, especially when used with opioids. For this reason, this class of medications should be avoided.

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### **When to Refer**

Patients and families should be referred to specialty services, if available, whenever a diagnosable substance use disorder is discovered. There are frequent co-occurring mental illnesses, and symptom presentation may fluctuate in response to changes in substance use patterns. Referrals for specialized services should be made early as there may be a wait for enrollment in treatment while symptoms are managed in the primary care setting.

---

### **Key Considerations for Follow-Up**

When patients with Substance Use Disorders are not convinced that they need to change their substance use, subsequent visits should be used to assess risks, attempt to reduce harm through environmental interventions, and provide ongoing education and dialogue. When a patient has agreed to change his/her substance use, tracking substance use by the patient (or family) report and/or the use of urine drug screens is an important aspect of treatment. Accountability can be a great motivator. The plan developed as part of the SBIRT intervention can be followed up for adherence and adjusted as needed. Just as important as tracking substance use is the tracking of co-occurring mental illness symptoms. Employing measurement-based care can be helpful in this setting. Finally, given the conceptualization of SUD as a chronic issue, all future visits should include screening for substance use of any kind and efforts to decrease/mitigate risk factors and bolster protective factors.



## Summary

Substance use disorders among adolescents are common and can be a harbinger of lifelong disability. Though the prevalence is declining across substance types, many SUDs in youth remain untreated. Drugs and alcohol impair the brain during a crucial period of brain development, and thus intervention during this time becomes even more pressing. Further, intervening on the use of tobacco, marijuana, and alcohol may prevent the use of “harder” drugs such as opioids and cocaine. The primary care provider can play a crucial role in the prevention of SUDs, and when SUDs are present, facilitate early identification, start treatment, and refer to appropriate services. Following more acute treatment, the PCP again becomes a focal point of the patient’s recovery, monitoring progress in recovery and carefully assessing relapse risk in order to promote long-term sobriety and wellness.

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# Appendix A

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## Quick Notes on CPT Coding

### 5 Coding Tips

1. **It's complicated, and that's an understatement.**

Whether an existing code is reimbursed or not, and at what rate, varies by state, insurance, insurance plan, provider credentialing and training, and, in some circumstances, treatment setting.

2. **But figuring it out is worth it.**

Reimbursement is key to sustainability, and primary care practice managers may not be familiar with the codes applicable to mental health and/or integrated care. The development of a sustainable model must be informed by the realities of the practice environment and will probably require some work on the front end.

The practice manager should:

- Explore the codes with possible applicability.
- Know the clinic population payor mix.
- Identify which codes are reimbursable.
- Know which credentials are eligible for reimbursement.

3. **Just because you can use a psych code does not mean that you should.**

PCPs can use psychiatric diagnostic evaluation and psychotherapy codes but probably shouldn't. If the PCP has not received and documented additional training in mental health relative to what he/she received in medical school, the third-party payor could deny payment and/or the PCP could be at increased risk medicolegally. (Of note, care managers, as part of an integrated care team, may be able to bill and receive reimbursement for these codes depending on the factors listed in 1 and 2.)

4. **Provider-to-provider telephone consults and collaborative care codes may not pay now, but documenting their use could pay off later.**

Though these codes are included in the CPT manual and reflect the growing recognition of the need for reimbursement to catch up with integrated care practice models, PCPs still may not be reimbursed. By documenting these

codes' applicability, even if there is no reimbursement, you may be able to help payors and other decision-makers understand their clinical relevance and in turn help to build the case for reimbursement.

#### 5. Consider using E & M codes with time as the controlling factor

In many primary care visits during which patient's mental health conditions are addressed, the PCP spends at least half of the time on counseling and coordination of care. This allows for E & M coding based on time rather than meeting the documented complexity requirements for history, exam, or decision-making. Providers must include the time spent face-to-face with the patient, that more than half the time was spent on counseling and care coordination, and detail the content covered in counseling as well as actions taken in coordination.

Established patient E & M code	Face-to-face minutes average (range)
99211	5 (3–7)
99212	10 (8–12)
99213	15 (13–20)
99214	25 (21–32)
99215	40 (33+ min)

## Codes to Consider and Explore

### Psychiatric Collaborative Care Management Services

These codes are for use in the context of collaborative care teams that include the treating physician, a behavioral care manager (staff with a masters/doctoral level education or specialized training in behavioral health), and a psychiatric consultant.

99492—Initial psychiatric collaborative care management (first 70 min in the first calendar month)

99493—Subsequent psychiatric collaborative care management (first 60 min in a subsequent month)

99494—Initial or subsequent psychiatric collaborative care management (each additional 30 min in a calendar month of behavioral healthcare manager activities)

### Interactive Complexity Codes to Be Used by Psychiatrists or Other Qualified Mental Health Professionals

This add-on code can be reported in conjunction with the ones for diagnostic psychiatric evaluation, psychotherapy, and group psychotherapy. It will often be applicable in pediatric mental health settings as these complexity factors are typically present when the patient has other individuals legally responsible for their care (as in the case with minors who have guardians). This code can also be used when a

sentinel event, such as the identification of abuse or neglect requiring a report to a state agency, occurs.

90785—Psychotherapy complex interactive

### **General Behavioral Health Integration Care Management**

These services are performed by clinical staff for a patient with a behavioral health condition that requires care management services (can be face-to-face or non-face-to-face) of 20 min or more in a calendar month. This cannot be used in the same month as the psychiatric collaborative care management services codes.

99484—Care management services for behavioral health conditions

### **Interprofessional Telephone/Internet Consultations**

This code is an assessment and management service in which a patient's treating physician or other qualified healthcare professionals request the opinion and/or treatment advice of a physician with specific specialty expertise. This can include review of records, the medical consultative verbal/Internet discussion, and written report to the patient's treating/requesting physician or other qualified health professionals.

99446–99449—Depending on time spent

### **Standardized Screening Measures**

Of note, currently there are often reimbursed billing codes for the use of screening instruments. While the use of these codes can help to recoup the cost of staff time and materials, it will not result in large reimbursements as no physician work value is factored into them. These codes are as follows:

96110—Developmental screening with scoring and documentation, per standardized instrument (For example, MCHAT)

96127—Brief emotional/behavioral assessment with scoring and documentation, per standardized instrument (For example, PHQA, PSC, Vanderbilt Rating Scales, SCARED)

96160—Administration of patient-focused health risk assessment instrument with scoring documentation, per standardized instrument (For example, CRAFFT 2.0)

### **Potential Resources**

1. Professional organizations—If you or a member of your team is a member of the American Academy of Pediatrics or the American Academy of Child and Adolescent Psychiatry, these organizations have resources for members and can also be contacted to assist with specific coding questions.
2. SAMHSA-HRSA Center for Integrated Health Solutions (CIHS)—This is a national training and technical assistance center that promotes the development of integrated primary and behavioral health services. There are clinical practice tools and resources for integrating mental health, substance use, and primary care. Additionally, the center offers free one hour consults with subject matter experts.

# Appendix B

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