Persons with intellectual and developmental disabilities (IDD) often come to the attention of mental health services, including those in emergency and other crisis settings, inpatient psychiatric settings, and outpatient clinics, to name a few. This article is one of two originally conceptualized by the National Association of State Mental Health Program Directors on behalf of the Substance Abuse and Mental Health Services Administration. In this article, we describe diagnostic and treatment considerations for persons with IDD, including those pertaining to co-occurring mental illness. In the second article, we provide information related to systems and policy developments that can afford opportunities and present challenges in the delivery of care for persons with IDD (1).

**CONCEPTUALIZING IDD: THE NEURODEVELOPMENTAL DISORDERS**

Neurodevelopmental disorders are a category of disorders described in *DSM-5* (2). This category includes a group of often co-occurring conditions, with onset in the developmental period—usually manifesting before a child enters primary school—and is characterized by deficits in “personal, social, academic, or occupational functioning” (2).

Included in this category are intellectual developmental disorder, autism spectrum disorder (ASD), attention-deficit hyperactivity disorder (ADHD), and other communication, motor, and learning disorders. Neurodevelopmental disorders are distinct from the neurocognitive disorders, which are
characterized by a loss in cognitive functioning from a prior level (e.g., Alzheimer’s dementia) that may emerge at any age. Intellectual functioning may or may not be impaired in the neurodevelopmental disorders, and it is therefore important to understand the total abilities of the individual being served to best address his or her needs.

**Intellectual Developmental Disorder**

According to DSM-5 criteria for intellectual developmental disorder, an individual with this disorder needs to meet requirements in three areas: deficits in intellectual functioning, deficits in adaptive functioning, and onset of the deficits occurring in the developmental period (2). Although DSM-IV focused on IQ scores as a cornerstone of the definition, in DSM-5 the severity of the intellectual developmental disorder is classified as mild, moderate, severe, or profound based on adaptive functioning in conceptual, practical, and social domains, and the focus on IQ scores alone for diagnosis has been deemphasized (2).

The shift in thinking regarding an emphasis on adaptive functioning reflects studies indicating that IQ test scores, although helpful as an approximation of domains in functioning, are inadequate to capture the full picture of deficits and strengths that together make up an individual’s adaptive functioning (3). Related to current standards of focusing on strengths rather than deficits, the use of adaptive functioning provides a more comprehensive snapshot, without reliance on only a number or an IQ test score, which that can lead to stigmatization and labeling or even an underestimation of the individual’s capabilities (Table 1).

Intellectual developmental disorder, according to DSM-5, has an overall general population prevalence of approximately 1%, with the prevalence of severe intellectual disability estimated at 0.006% (2, 4). Although estimates of the distribution of mild, moderate, severe, and profound intellectual developmental disorder vary in the literature, some estimate that of the population of persons with intellectual developmental disorder, 85% would be classified as having mild, 10% as having moderate, 4% as having severe, and 1%–2% as having profound intellectual developmental disorder (5). Although no consistent racial differences in the prevalence of intellectual developmental disorder have been noted, a gender difference appears to exist; studies have shown that males have a higher likelihood of being diagnosed as having both mild and severe intellectual developmental disorder (6).

**Autism Spectrum Disorder**

ASD is a neurodevelopmental disorder with onset in the early developmental period and is characterized by the presence of persistent deficits in social communication and social interaction in multiple contexts, as well as restricted and repetitive patterns of behavior, interests, or activities that cause clinically significant impairment in several areas of functioning, including personal, social, academic, or occupational (2).

As with intellectual developmental disorder, adaptive functioning is a key consideration with ASD. Some individuals with ASD exhibit marked deficits in socialization and communication that impair their ability to function adaptively, highlighting the possible discrepancy between cognitive capabilities that can be measured via IQ and level of support an individual requires (7). In screening for ASD, developmental screenings and comprehensive evaluations are often conducted. The American Academy of Pediatrics recommends that all children be screened for developmental delays and disabilities during regular well-child pediatrician visits at 9, 18, and 24 months (8).

According to DSM-5, in recent years the prevalence of ASD has been estimated at 1% of the population (2). Recent 2014 data from the Centers for Disease Control and Prevention (CDC) indicate that the prevalence may be as high as 1 in 59 children (9). No clear answer has yet been offered as to why ASD prevalence rates seem to be increasing; some point to changing ASD diagnostic criteria, and others postulate that higher rates reflect increased awareness and early identification of this disorder or underestimation of the prevalence in the past (10, 11).

**Other Neurodevelopmental Disorders**

Although not the focus of this article, other neurodevelopmental disorders include ADHD and communication, motor, and specific learning disorders (i.e., those affecting math and reading.)

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**TABLE 1. Examples of areas of difficulty in adaptive functioning domains among persons with intellectual and developmental disabilities***

<table>
<thead>
<tr>
<th>Domain</th>
<th>Areas of difficulty</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conceptual skills</td>
<td>Reading, writing, and language; telling time; handling money; executive functioning (planning, strategizing, and setting priorities); memory</td>
</tr>
<tr>
<td>Practical skills</td>
<td>Activities of daily living, such as bathing, toileting, and self-care; instrumental activities of daily living, such as telephone use, paying bills, grocery shopping, and transportation; skilled vocations; Legal decisions</td>
</tr>
<tr>
<td>Social skills</td>
<td>Interpersonal skills, social responsibility and cues, following rules, understanding risk (leading to decreased wariness or gullibility)</td>
</tr>
</tbody>
</table>

* Summarized from DSM-5 and American Association on Intellectual and Developmental Disabilities diagnostic information.

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**Editor’s Note:** This article is part of a series based on the Technical Assistance Coalition working papers, which were originally written for NASMHPD and funded by SAMSHA. Matthew L. Goldman, M.D., M.S., is series coordinator and has helped curate these papers for publication in Psychiatric Services.
CO-OCCURRING CONDITIONS: PREVALENCE AND MANIFESTATIONS

Many conditions co-occur within the neurodevelopmental disorders, ranging widely in psychiatric, neurodevelopmental, and physical domains. In the mid-1900s, one school of thought generally subscribed to the idea that individuals with a developmental disability could not also have a mental illness and that any behavioral issues were instead a result of intellectual disability (12). However, research has shown the opposite to be true and has suggested that the prevalence of mental illness among persons with developmental disabilities is higher than in the general population (12). Psychiatric disorders have been shown to be three to four times higher among individuals with IDD, compared with the general population, and include illnesses such as major depressive disorder, bipolar disorders, psychotic disorders, anxiety disorders, impulse control disorders, major neurocognitive disorders, and stereotypic movement disorder (13).

Psychiatric disorders may manifest differently among individuals with intellectual developmental disorder, compared with the general population. The National Association for the Dually Diagnosed, in collaboration with the American Psychiatric Association, has greatly contributed to the field by compiling the Diagnostic Manual—Intellectual Disability, which suggests how psychiatric diagnosis can be adapted in working with people with IDD (14). Other neurodevelopmental disorders, such as ASD and ADHD, are also frequently comorbid with IDD (13). Although numerous studies show that ASD and IDD co-occur, the actual prevalence rates of IDD in ASD vary widely in the literature, ranging from 16.7% to 84% (15). Extreme individual variation in IQ has been noted among those with a diagnosis of ASD, requiring that sample size be quite large to achieve any approximation of accuracy. More recent studies may put the co-occurring prevalence rates around or below 50% (15, 16). The close and often co-occurring relationship between IDD and ASD is also significant because individuals with IDD and ASD may have different needs and comorbidities, compared with individuals with IDD or ASD alone. Individuals with comorbid ASD and IDD may have higher rates of repetitive, restrictive, or self-injurious behaviors and may have a poorer prognosis (17). Awareness of the possibility of co-occurring psychiatric and neurodevelopmental disorders among individuals with IDD is important, because these co-occurring disorders may be targets for interventions that can affect behaviors, functioning, and outcome.

Traumatic brain injury (TBI) can also co-occur with IDD. Consequences of TBI can include impaired thinking, memory, and cognitive function; decreased hearing or vision; and even personality changes or emotional symptoms, such as depression, aggression, or impulse control issues (18).

In addition, it is helpful to be aware that sensory deficits (visual, tactile, auditory) are often undetected coexisting issues and that addressing such deficits can improve the quality of life of persons with IDD. Appropriate screening for and awareness of such deficits as possible added challenges can open windows to more effective treatment interventions.

More than 800 recognized syndromes listed in the Online Mendelian Inheritance in Man database (www.omim.org) are associated with intellectual disability, including the chromosomal abnormality trisomy 21, or Down syndrome, and the X-linked abnormality fragile X syndrome (19). Other genetic disorders associated with intellectual disability include but are not limited to Klinefelter syndrome, Williams syndrome, and tuberous sclerosis. Although these associations do exist, many regard genetic disorders as frequently associated with IDD, even though for most persons with IDD, no specific genetic abnormalities are found (19). Other nongenomic conditions associated with IDD can be due to preterm birth or perinatal in-utero exposures or teratogens (agents that affect the fetus), such as cigarette smoke or alcohol. Fetal alcohol syndrome (FAS) is a well-established condition that often results in developmental disability, and CDC studies have identified the prevalence of FAS as 0.2 to 1.5 for every 1,000 live births in certain areas of the United States (20).

PERSONS WITH IDD IN THE MENTAL HEALTH SYSTEM: CONSIDERATIONS AND CHALLENGES

Early Recognition
As noted above, one of the critical elements of working with individuals with IDD is to recognize that a person in services may have neurodevelopmental challenges and that adaptive functioning can vary among individuals. In identifying and working with persons with IDD, attending to the complexities of racial biases in how individuals may be recognized, diagnosed, supported, or treated is equally important. More work is also needed to understand how structural issues that lead to health disparities affect this population. Because there is tremendous heterogeneity within the IDD population, a cookie-cutter approach does not work well. Children in the mental health system with concomitant neurodevelopmental disorders should have a unique individualized educational plan (IEP) that addresses both mental health issues and IDD. Information about the IEP can inform practitioners who may be less familiar with a youth new to their services. Among adults and older adults who visit emergency services, who reside in nursing homes, or who present in any setting in the mental health system, individuals with IDD may not be the best source for providing their history of disorders and care. Gathering collateral information about them when they are in a care or support setting is important. Identifying whether the person has a guardian provides further information about the individual and the level of supports needed and can facilitate gaining proper consent from the guardian for particular treatments when needed.

Recognizing Trauma: Trauma-Informed Care, Supports, and Systems
It is especially important to consider the impact of trauma when caring for individuals with IDD. Research has indicated
that individuals with IDD are more likely to be victimized and that children with moderate to severe intellectual disabilities are more likely to be neglected, sexually abused, emotionally abused, and physically abused, compared with children without such disabilities (21). In addition, children with speech or language disorders also appeared to be at increased risk of physical and emotional abuse, as well as neglect (21). Because of a potentially reduced capacity to process information, including traumatic memories, those with IDD may be at higher risk of developing posttraumatic stress disorder, compared with the general population (22). Complicating this picture further is research indicating that exposure to environmental stressors may also be higher in the IDD population. For instance, exposure to poverty is higher among individuals with intellectual disability, compared with their nondisabled peers, as is violence in the family and social isolation, which can also lead to decreased resilience in the face of other adverse life events and can compound the negative effects on an individual’s life (23, 24). Negative life events were found to be significantly predictive of psychological trauma after 6 months in one study focusing specifically on individuals with intellectual disability (25).

For some persons with IDD, limited ability to communicate about traumatic experiences, as well as limited knowledge or social skills, may result in difficulty integrating their perception of traumatic events and their emotional response, which may result in affective aggression or behavioral dysregulation (26). In addition, there is often a perception that a person with IDD is not a reliable witness; one study found that jurors tend to perceive witness statements by a child with IDD as inherently unreliable (27). Ongoing victimization can result if an individual is not believed to be a reliable historian and his or her statements are not taken seriously. Specialized interviewing techniques for investigators are important to ensure the best assessment of victimization. Although challenging behavior in the IDD population is not uncommon, a subset of the externalizing behaviors may be a result of trauma (28).

Despite data showing higher rates of trauma among persons with IDD, there is still a lack of research on integration of trauma-informed care in organizations and systems providing support for the IDD population (29). At a systems level, to provide trauma-informed care means operating with the awareness of the pervasiveness of trauma as well as its impact.

**Person-Centered Care, Self-Determination, and Decision-Making Supports**

Person-centered care aims to shift from viewing individuals with IDD as persons with deficits and needs within a system to focusing on their strengths, capabilities, and potential to contribute to their community. Person-centered care aims to develop collaborative support with individuals with IDD, focused on community presence and participation, positive relationships, respect, and competence (30). The concept of self-determination in the IDD population within this person-centered framework has been an area of significant focus in recent years. Self-determination is viewed by many as a fundamental human right—the right of an individual to manage his or her own life without unnecessary interference from others and to have more choice and control over life-affecting decisions (31). Individuals with IDD must have opportunities that enable them to exert control in their lives and to be self-advocates; having such opportunities is a strong predictor of self-determination (32). Studies investigating the impact of self-determination on individuals with IDD have found that those who were more self-determined or received more education on self-determination were more likely to be participatory and independent in performing community activities, more likely to have a higher quality of life, and more likely to be working for pay at higher hourly wages (33–36). Therefore, increased education on self-determination among individuals with IDD will continue to be important; such education includes but is not limited to decision making, problem solving, goal setting and attainment, self-advocacy, self-regulation, and self-awareness (37).

Issues of decision making are also important to consider for individuals with intellectual developmental disabilities, especially in a person-centered care construct. As a broad overview, generally adults are presumed competent to make their own decisions, unless a court of law finds them to be incompetent. If someone is found incompetent, a potential next step is guardianship, which is a legal process in which a court appoints an individual to make decisions in the best interests of the person who has been determined to lack capacity. Decisions made by guardians can include some or all decisions about health care, living arrangements, property, and other personal life decisions (38). Because guardianship is often considered to be the most restrictive option with the aim to protect a vulnerable person, other, less restrictive options prior to guardianship should also be considered—and considered first before moving toward guardianship. These include power of attorney, advance directives, special needs trust, or special bank accounts with cosigners (38).

Although guardianship is still used routinely, it is important to realize that some individuals question the idea of guardianship and the notion of a person’s being granted decision-making powers for someone else, and the effect it may have on the individual’s autonomy and independence (39). Recent disability research has moved toward an idea of supported decision making, which is a process in which instead of having an assigned guardian or substitute decision maker, an individual with IDD is supported by a circle of trusted others in making decisions for him- or herself, allowing the person to retain his or her right to make decisions (40). Supported decision making leaves the individual with IDD as the ultimate decision maker such that he or she is able to participate in society on an equal basis with others who make their own decisions (41). Those who help an individual with IDD with supported decision making may include peer supports, community services staff, personal ombudspersons, and personal assistants; good advance planning also has a role (42). Suggestions about how to more fully implement supported decision making include increasing education on...
decision-making skills, even in primary schools; providing more professional development; and educating families, judges, and the public on the abilities of individuals with IDD (43). In addition, providing an individual an opportunity to participate in the decision-making and planning process of transitioning from being a child with IDD to being an adult can also be important and should be focused on the individual's preferences, needs, strengths, and desires (38, 44).

Although advocates for supported decision making in lieu of legal guardianship are champions of this approach, some critics of supported decision making argue that more research is needed to delineate the similarities and differences between supported decision making and alternative surrogate decision makers before wide-scale, systemic changes are implemented (45). Either way, decisional capacity and deficits must be considered and addressed as individuals with IDD are seen in care systems.

**HABILITATIVE TREATMENT, MEDICATIONS, AND OTHER SUPPORTS**

According to the Centers for Medicare and Medicaid Services, habilitative services are “Health care services that help a person keep, learn or improve skills and functioning for daily living” (46). After the *Olmstead* decision in 1999, most persons with IDD now live in the community. Federal waivers that provide support to persons with IDD living in the community require state assurances that the health and safety of these individuals are preserved through the ongoing provision of habilitative, medical, and support services. Federal waivers may provide for the housing needs of these individuals, or they may be supported in their own or family home. Habilitative services provided through waiver programs may include necessary staffing, supported employment, and assistance via coordination services. Additional habilitative services provided through federal waivers or state Medicaid plans may include physical and occupational therapy, speech-language pathology services, and other services for people with disabilities in various inpatient or outpatient settings (46). The supports described below are those most directly related to mental health care, but they do not reflect the total array of supports that may be needed or might be available.

**Behavioral Supports**

Behavioral supports are important at all stages of life, although some have suggested that individuals ages 16 to 22 have the greatest need for support, compared with the other age groups, suggesting that this period is an important area of focus (47). Among persons with IDD, challenging behavior can present for a multitude of biopsychosocial reasons, with functions including attention seeking, escape, access to tangible items, or automatic behaviors. Challenging behavior can present as aggression toward others or the environment, impulsivity, self-injury, or behaviors that are seen as socially unacceptable and may affect an individual's adaptive functioning in the community. For example, an individual may engage in repetitive head banging to escape from an undesirable task or to seek attention. Although the data vary, some have estimated that the prevalence of behavior problems among persons with comorbid ASD and IDD is approximately 50% and that levels of severity of problem behavior can range from minor and time limited to severe, chronic, and potentially life threatening (48, 49).

Provision of appropriate behavioral supports requires an analysis of the environments, the relationships, and the requirements placed on an individual. Given the prevalence of trauma in the lives of persons with IDD, the analysis should consider abuse, neglect, medical pain, or comorbidities, as well as irritation at staff turnover in the home. Behavioral supports include a variety of strategies that creatively avert challenging behaviors.

From a behavioral perspective, maladaptive or challenging behavior serves the purpose of getting a need met. All behavior, challenging or adaptive, can be construed as a learned behavior that has been historically reinforced by meeting a need or achieving a goal in some way. The task is to understand how challenging behaviors have been reinforced, perhaps inadvertently, and to change the reinforcement schedule to favor adaptive behaviors. Persons with IDD may have little pragmatic language or may lack the ability to communicate their needs. They may have receptive difficulty interpreting ordinary language, common idioms, social cues, tone of voice, facial expressions, or any other communication shortcuts. Again, regardless of verbal expressive abilities, what is said is less important than what is communicated in an array of nonverbal ways. Given these constraints, it is better to ask, “What does the behavior usually achieve?”

A biopsychosocial approach is an essential first step for the psychiatric clinician endeavoring to understand behavior and will be discussed in greater detail below; however, person-centered behavioral interventions would ideally occur prior to pharmacological intervention (50). Because systems now aim to prevent use of restraints, effective behavioral supports clarify the function of the behavior, are culturally appropriate, and are designed to meet the specific needs of the individual, with goals of removing environmental precipitants of challenging behaviors, emphasizing the idea of choice, and focusing on social integration (51).

Applied behavior analysis (ABA) is often linked to ASD, but the overarching principles involved in ABA are useful in intervening in all kinds of challenging behavior. Functional behavior assessment (FBA) is an umbrella term that consists of a variety of methods to hypothesize the function of a behavior. These include indirect measures, direct observation, and an experimental functional analysis method, which implies a strictly controlled experimental condition designed to understand the function of a challenging behavior by manipulating an independent variable. In FBA, an appropriately trained clinician observes the individual in multiple natural environments, interviews caretakers, and organizes data to reduce the challenging behavior. Shawler et al. (52) found that use of FBA to treat self-injury has dramatically increased since the 1990s and has continued to grow steadily.
Over the years, as the focus and literature base for identifying the function of behaviors has grown, additional models, such as those focused more on maximizing positive behaviors and incorporating the relationship with the individual, have been evolving, moving far away from the previously accepted use of aversive stimuli (53). Both ABA and positive behavior support approaches examine behavior and help the individual function more optimally in his or her environment. Positive behavior interventions and supports, used in school systems originally, has been extended to the IDD population and the population of persons with serious mental illness in state hospitals and other parts of the mental health continuum of care.

A review of more than 100 studies involving young people with co-occurring ASD and IDD and challenging behaviors found that behavioral interventions, such as those described above, resulted in more than 86% of individuals benefiting from treatment; 65% were characterized as “responders,” whose problem behavior was reduced by more than 80% (48). In addition, use of behavioral intervention strategies with a consequence-based structure and clear limits (i.e., withdrawal of privileges), along with reinforcement of positive behaviors as described above, is often recommended (80). Mental health professionals should work with individuals with appropriate training in FBA to achieve the best possible gains for individuals being served.

Pharmacologic and Nonpharmacologic Therapeutic Supports

Appropriate and effective pharmacologic supports depend on accurate and detailed assessments leading to plausible diagnostic hypotheses. The biopsychosocial model can facilitate this approach. During the first psychiatric encounter in an emergency, urgent, or nonacute setting, a critical task is to get an understanding of the baseline of the person with IDD. Subsequent clinical inquiry emphasizes psychosocial changes, symptoms or behavioral changes indicative of medical issues, trademark behaviors and their function, history of trauma, and, finally, any evidence that may support the assignment of a diagnosis of a mental or substance use disorder.

The impact of psychosocial stressors tends to be underestimated in this population. The effects of changing group living environments, changing staff, lack of access to family, seeing siblings achieve adult milestones, and losing parents to death and old age tend to be minimized. There is a definite role for psychotherapy in understanding the emotional response of the person with IDD and assisting the person to process events and his or her responses. Any diagnostic hypothesis has to be put in context. Knowing if the person has reacted to a similar stressor in an equivalent way in the past builds an understanding of his or her behavioral function. Medical conditions can also be overlooked among individuals who are not well equipped to localize pain, describe symptoms, or assist the clinician in other ways to identify a somatic condition. Behavior to achieve a function is discussed above. For some individuals, aggression and property destruction or disruption, as well as self-injurious behavior, might be a method of expressing pain or distress from a medical condition. Empirical data on this linkage are lacking, yet impacted wisdom teeth, migraine headaches, severe premenstrual syndrome, peptic ulcer disease, and gastroesophageal reflux disease are all common medical conditions that can be very painful or distressing and that do not manifest outwardly, even to observant treatment providers. Suspicion of painful conditions should be followed up with proper medical attention.

Gaining a sense of the usual temperament and personality style of the person with IDD helps to filter possibilities. Trauma and its impact on personality and temperament are more challenging to identify and address in this group, compared with more neurotypical individuals, and often confound pharmacologic treatments. Arriving at a psychiatric diagnosis also depends greatly on accurate data transfer from the home environment. Data about sleep, weight changes, or shifts in appetite can be helpful clues indicating psychiatric illness, if these data have not been obscured by other pharmacologic interventions.

A major departure from an individual’s baseline, which cannot be convincingly attributed to other factors, may at least warrant an empiric trial of a psychotropic agent expected to address the identified symptoms. This is best done with the support of a behavioral plan developed after careful analysis (described above) and with a review of data on behavioral targets that the clinician anticipates will be affected by the medication. Most often these targets are physical aggression, property destruction or disruption, verbal aggression or disruption, elopement, and sexually inappropriate behavior. All these behaviors tend to arouse strong emotions among caretakers, highlighting why it is important to have data rather than anecdotal report. No clinician should prescribe medications as part of a long-term treatment plan to simply and solely suppress undesired behavior.

If medications are ultimately deemed appropriate, they are best initiated by conducting empiric trials, using data-driven feedback. It is critical for the prescriber to maintain an open mind that allows constant reassessment of information at hand. Strong collaboration should be practiced between clinical team members, including psychiatrists, direct support professionals, clinicians, family, and the person in treatment, so that treatment is person centered. Medications can be associated with significant risk and adverse outcomes. Persons with IDD should not be unnecessarily exposed to these risks, especially because the evidence base for psychopharmacology in this population is limited.

An important consideration is the risk of polypharmacy, which may lead to complex drug-drug interactions and erosion of the individual’s quality of life. Although the quality and quantity of research on this subject are limited, low-dose antipsychotics, such as risperidone, are the most commonly used pharmacologic intervention, followed by antidepressants and mood stabilizers (54). Many medications investigated in studies on this topic are being used off-label—that is, not for the indication approved by the Food and Drug
Administration (55). The National Core Indicators published a report in 2012 examining use of medications in public IDD systems (56). The final data set included 8,390 adults, and the study found that 53% of them were taking medication to address one of three mental health conditions (mood, anxiety, or psychosis) or behavioral challenges—or a combination of those issues. Given the complexity of prescribing medications for this population, whether those medications were actually indicated is difficult to know. This difficulty highlights the challenge of prescribing medications in this population—namely, the risk of undertreating an actual, comorbid psychiatric disorder versus inappropriately medicating a behavioral issue.

CONCLUSIONS

Large intermediate care facilities and long-term wards of state psychiatric hospitals are no longer the mainstay of services for persons with IDD. The ability of individuals with IDD to thrive in a wide range of community integration opportunities depends on their optimal behavioral and somatic health, and clinicians must understand and use the available approaches for treating them. Individuals with IDD in the mental health system have unique needs, and attention to their co-occurring psychiatric and IDD conditions is critical. The mental health system presents many challenges in working effectively with persons with IDD, but with increased attention to this population’s varied and individualized needs, clinical treatment approaches can be improved in provider organizations and across care systems.

AUTHOR AND ARTICLE INFORMATION

Department of Psychiatry, University of Michigan, Ann Arbor (Pinals, Anacker); Maryland Developmental Disabilities Administration, Annapolis (Hovermale); Massachusetts Association for Mental Health, Boston (Mauch). Send correspondence to Dr. Pinals (dpinals@med.umich.edu).

This work was presented at the annual meeting of the American Psychiatric Association, New York City, May 5–9, 2018. Development of this work was partially supported by a contract from the Substance Abuse and Mental Health Services Administration (SAMHSA) to the National Association of State Mental Health Program Directors.

The views, opinions, and content expressed do not necessarily reflect the views, opinions, or policies of the Center for Mental Health Services, SAMHSA, the U.S. Department of Health and Human Services, or any state or other institutions with which the authors are affiliated.

The authors report no financial relationships with commercial interests.

Received October 11, 2019; revisions received November 4, 2020, and March 12 and April 11, 2021; accepted April 22, 2021; published online August 4, 2021.

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