MISSOURI ALLIANCE FOR DUAL DIAGNOSIS

MOADD

Missouri Alliance for Dual Diagnosis (MOADD)

Best Practices

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The MOADD Taskforce was first convened in March of 2019 with an objective to research and define best clinical practices to support people with co-occurring mental/behavioral health symptoms and a diagnosed intellectual/developmental disability. This list includes original participants who developed the contents of this document.

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Preamble

These guidelines produced by Missouri Alliance for Dual Diagnosis (MOADD) Taskforce attempt to define and describe best practice approaches for supporting individuals with co-occurring mental/behavioral health symptoms and a diagnosed intellectual/developmental disability (IDD), including Autism Spectrum Disorder (ASD). The MOADD Taskforce, which includes a diverse interdisciplinary group of professionals drawn from across the state of Missouri, was formed in recognition that individuals with co-occurring conditions face unique challenges in accessing appropriate care. Foundationally, there is an evidence base available to directly guide clinical practice in this area, but it is relatively sparse and distributed across different disciplines (medicine, behavior analysis, psychology, psychiatry). This complexity, along with discipline-specific approaches and population specialties, has led to a lack of cross-training for mental health and IDD professionals. Finally, structural barriers (within state/federal systems, and public/private insurance providers) may prevent individuals from receiving benefits that are classified under a mental health umbrella if they are already receiving IDD-associated services (and vice versa).

Given the limited mental health workforce available to begin with, we cannot further restrict care for individuals with dual diagnoses to only IDD professionals; we also cannot expect mental health and IDD professionals to break out of their historical silos without a framework for approaching care of complex and intersecting conditions. The document includes supporting literature and information to assist a clinician to make informed decisions regarding selection, implementation and monitoring of supports and interventions for individuals with dual diagnoses. Several foundational concepts also emerged that underlie an evidence-based and expert-informed approach for the assessment and intervention of mental/behavioral health challenges in individuals with IDD; these concepts are woven throughout the document, but they are explicitly described below.

Individualization

Mental and behavioral health conditions can present very differently from person to person, and treatment must always consider parameters of individual difference (including goals for treatment, cultural and family preferences, contexts in which the treatment is delivered, etc.). Individualization is especially important given the extremely wide degree of variability in presentation for underlying IDD and/or ASD, which exponentially increases the need for individualized mental/behavioral health treatment.

Safety

Mental/behavioral health conditions are very frequently associated with increased safety risks, and unfortunately this risk is often heightened in the presence of a co-occurring IDD. Everyone involved in treatment planning for an individual (including the individual themselves, whenever possible) should maintain awareness of safety risks, and play a role in monitoring and maintaining safety. Specific considerations are included for each of the described dual diagnosis combinations, and an overarching guide to safety considerations is also included.

Bio-psycho-social approach

Mental/behavioral health challenges do not occur in a vacuum. In many cases medical and physiological factors can cause/contribute to symptoms; the reverse is also true, such that mental health conditions can manifest in physical ways or lead to long term health consequences. These medical considerations exist in tandem with consideration of the social environment in which an individual lives, their learning history, and their thoughts, feelings and behaviors. Interdisciplinary collaboration/consultation is critical for the successful assessment and treatment of co-occurring mental health conditions for individuals with IDD, both to rule out underlying medical causes as well as to ensure that the whole person is attended to and supported.

Trauma-informed care

Individuals with IDD face higher rates of traumatic and other adverse experiences (both in childhood and as adults). Assessment of possible trauma history, how any adverse experiences interact with the presenting mental/behavioral health challenge, and using a trauma-informed lens in the development and delivery of treatment (and safety planning) is critical. Trauma considerations specific to each dual diagnosis combination are embedded in those chapters, with a stand-alone guide to trauma considerations also included.

Gradual improvement

Frequently drawing on approaches from the applied behavior analysis (ABA) and positive behavior support (PBS) traditions, a common element of successful intervention across the dual diagnosis combinations was a focus on achieving incremental improvement on specific, measurable targets that are identified to both alleviate suffering and improve an individual’s ability to engage in self-determination. Often that involves inclusion of incremental skill-building (e.g., functional communication training, coping skill development, etc.) as well as the incremental reduction of mental health symptoms/impairment (e.g., reduced impact of anxiety on daily living skills). Selection of treatment targets should be driven by the individual and family through a process of supported decision-making to whatever extent possible, with consideration of long-term quality of life and the use of the least restrictive approaches possible to achieve safety and gradual progress. A sample behavior plan and guidance to frequently asked questions are included to support guidance within the individual dual diagnosis chapters.

While each of the dual diagnosis chapters that follow stand alone, they also reiterate both the themes above and many other assessment and treatment approaches that transcend specific diagnostic labels. We have attempted to include targeted reviews and key citations from the scientific literature when possible, but note that this document is not intended to be a comprehensive review or detailed treatment manual; instead, we hope this document will serve as an evidence-based and expert-informed road map that *will always need tailoring for an individual situation, with consideration of the most up-to-date scientific findings*. We have included examples of how treatments with empirical support in neurotypical populations might be adapted for individuals with IDD, but emphasized that in most cases there remains a limited evidence base. Each chapter includes multiple case vignettes to demonstrate possible clinical applications of the provided guidance, but these should not be used as templates for professionals faced with similar situations.

One final note should be made regarding language and terminology, which continues to evolve in the field of mental health broadly as well as for individuals with IDD specifically. We do default throughout to the use of the abbreviation “IDD” when discussing the very large and diverse population of individuals with developmental differences, specifying in situations when we intend to refer to individuals with ASD. These conventions rely on a *person-first* framework common to medicine, psychology, and other professional disciplines. We also acknowledge that many (if not most) autistic adults prefer *identity-first* language, which is also used at times throughout the document. In practice, we urge professionals to ask the individuals they serve about what terms and conventions they prefer, and to respect those preferences.

J.N.C., M.B., & C.N.
On behalf of the MOADD Taskforce

Considerations: Universal

Part 1

General Safety Considerations

Chapter 1

1

General Safety Considerations

A safety assessment is a fundamental part of the initial comprehensive assessment conducted by the clinician. Per the Missouri Department of Mental health, a safety assessment is defined as "…an assessment by the planning team and a medical professional of an individual's physical and/or emotional status. This includes history and current conditions that might affect safe usage of any reactive strategies, and identifies those reactive strategies that should not be used with the individual due to medical or psychological issues of safety. The safety assessment should be completed annually or on the occasion of any significant change" (see 9 CSR 45-3.090 in MO Department of Mental Health, 2020; and PowerPoint overview from MO Division of Developmental Disabilities, 2020). As part of the bio-psycho-social model, it is imperative that the clinician work in collaboration with the individual and family, and with other professional team members in completion of this safety assessment.

As the safety assessment is completed, an individual safety crisis plan will be completed that outlines strategies to address dangerous behaviors when they occur and strategies to prevent imminent occurrence. This safety crisis plan should be included in the individual's coordination plan and widely available to all of those involved in the treatment and care of the individual. In accordance with the MO Department of Mental Health's Co-Occurring Protocol (2013), the following items should be included in development of the safety crisis plan for children:

- Specific risk factors and precipitators to the family and/or individual's crisis
- Both proactive and reactive action steps
- Responsibilities specific to the risk factors
- De-escalation techniques for the individual

When these techniques are unsuccessful, a hierarchy of appropriate interventions that meet the unique needs of the individual should be clearly outlined including who is responsible for each action. The safety crisis plan does not solely rely on use of law enforcement and convenient emergency placements. Additionally, a communication protocol should be outlined that denotes how Family Support Team members will be advised of the crisis and the action steps taken. All members of the team should be fully knowledgeable of the Crisis Plan and their specific responsibility (DMH, 2020).

Suicide Risk & Identification

Professionals from all disciplines working at every level of care should be mindful of the safety risks impacting the individuals they serve. Estimates for suicide risk in youth with Autism Spectrum Disorder (ASD) range from 10.9 to 50% (Segers & Rawana, 2014), and this heightened risk extends into adulthood (Kirby et al., 2019; Kõlves et al., 2021). Increased risk appears to be present for youth with and without cognitive delays (Giannini et al., 2010; Ludi et al., 2012). Both youth and adults with IDD also face higher risks for engaging in self-injurious behaviors like head-banging that pose significant safety risks, regardless of the presence/absence of suicidal intent (e.g., Oliver et al., 2017; Steenfeldt-Kristensen et al., 2020; Oliphant et al., 2020). Risk factors for suicidal ideation and attempts in youth with ASD are similar to the factors impacting neurotypical peers, with some possible additions (Cassidy et al., 2018; Cassidy et al., 2019); these include:

- Co-occurring mental health conditions (i.e., a dual diagnosis)
- Adverse experiences/victimization
- Executive functioning challenges
- Camouflaging of ASD symptoms

Clinical evaluation of suicide risk in individuals with ASD and/or IDD can be challenging. Standardized tools commonly used to assess suicide risk in neurotypical youth have been found lacking (Howe et al., 2020). The recently adapted Suicide Behaviours Questionnaire-Autism Spectrum Conditions (SBQ-ABC) for autistic adults (without co-occurring intellectual disability) holds promise (Cassidy et al., 2021). An adaptation of the Columbia Suicide Severity Rating Scale (C-SSRS) exists for pediatric and "cognitively impaired" individuals, but the validity of this adaptation is unknown (Posner et al., 2010; Interian et al., 2018).

Next Steps After Identifying Elevated Safety Risk

When any staff or support personnel suspect an individual is at risk of suicide or has unmet mental health needs impacting safety (based on direct observation or reports from others), they must take steps to ensure the individual's safety by immediately engaging appropriate mental health professionals. There should be a deliberate transfer of intervention from staff to the mental health professionals trained to assess and manage the crisis. This may include the individual's therapist, if applicable and available, or it may involve contacting a crisis line for direction.

If an individual has made a suicide attempt, and/or has expressed plans and has ready access to lethal means, staff should contact emergency services (i.e., 911). *If law enforcement are responding, ask if there is a Crisis Intervention Team (CIT) available (see below).*

If risk is elevated but imminent risk is not identified, a number of steps should be considered:

- Make contact with the individual's existing mental health professional (e.g., therapist, community behavioral health center worker), if they have one. This resource may be in the best position to provide tailored recommendations. If contact is made, staff should follow the guidance provided by the mental health professional.
- If the individual does not have a current working relationship with a mental health professional (or they are unavailable at the point of attempted contact), staff should contact alternative specialty resource(s):
    - Access Crisis Intervention (ACI) Hotline, based on the appropriate Missouri location (for a county map, see the MO Department of Mental Health ACI webpage) This hotline links callers to 24-hour crisis supports in the region that can provide assistance or appropriate intervention, and perform a mental health screening to render a clinical disposition for next steps.
    - Call 988 for the Suicide & Crisis Lifeline: A national 24-hour hotline for individuals experiencing a suicidal crisis or emotional distress. (As of July 2022, dialing 988 in Missouri replaces the previous crisis line, 1-800-273-8255).
    - Text "MOSAFE" to 741741 in order to connect with a crisis counselor from the national CrisisTextLine.Org resource.
    - Contact and access resources from the Missouri Suicide Prevention Network.
    - When consulting and planning with local law enforcement, investigate if there is a Missouri Crisis Intervention Team (CIT) available. CIT officers have additional training in safely managing behavioral health emergencies.

Safety Planning

When increased suicide risk is identified, the individual must not be left alone until contact is made with a mental health professional and guidance is received for next steps. When applicable, staff must work with family members, resource providers, and other stakeholders to develop a plan for immediate and constant supervision, as well as counseling on means restriction (blocking access to dangerous items in the environment to reduce risk of harm; for more information, see Save.Org). The discussion and plans made with the individual, caregiver and/or family to address safety issues and consultation from a mental health professional must be clearly documented within the individual's medical record. Safety planning steps generally follow a cognitive-behavioral framework (see Stanley & Brown, 2012 for an overview; for guidance on adapting this approach for individuals with IDD and/or ASD, see this webinar from Maddox et al., 2022).

For additional information regarding safety risks associated with aggression and (non-suicidal) self-injurious behaviors, see the Aggression chapter and sample behavior plan resource.

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Medication Management Primer for Dual Diagnosis

Chapter 2

Medication Management Primer for Dual Diagnosis

After having initiated first-line psychosocial interventions, consideration of psychopharmacologic intervention may be an appropriate next step in the management of mental/behavioral health challenges for individuals with Autism Spectrum Disorder (ASD) and/or other intellectual/developmental disabilities (IDD). Note that in general there is very limited research available to guide psychopharmacologic prescription practices for youth or adults with ASD/IDD (Valdovinos, 2019; Sheerin et al., 2021); while it is reasonable to consider guidance on medication selection and use for mental health conditions derived from neurotypical samples, there is ample evidence that individuals with developmental differences often show reduced benefits and face higher rates of adverse reactions (Bowers et al., 2015; Bose-Brill et al., 2017). In rare cases, specific practice guidelines do exist for certain co-occurring profiles (e.g., ADHD and ASD/IDD; Barbaresi et al., 2020), and these should be consulted directly. The approaches that follow reflect available/emerging evidence as well as clinical experience of the MOADD team, but should not be interpreted as substitute for the prescribing authority's clinical judgement in any individual case.

Medications should not be used in isolation; rather, they should be considered as a part of a comprehensive treatment plan. When reasonable efforts have been made to reduce/eliminate relevant triggers and to implement non-pharmacological interventions focused on supporting functional alternative behaviors, consideration of medication can be appropriate. Each individual being considered for possible medication treatment requires thoughtful evaluation within the context of their age, communication abilities, general health status, and the presence of any co-occurring medical conditions, concomitant medications in use, family history, and psychosocial circumstances to assess the potential risks and benefits for that person. Especially in complex cases (and when multiple medications have been trialed unsuccessfully), pharmacogenomic testing (e.g., analysis of genes involved in drug metabolism and response which can impact drug efficacy and the likelihood of adverse drugs reactions) may be considered (Hyman et al., 2020).

In almost all cases, psychopharmacologic trials for individuals with IDD follow a sequence not unlike the path followed for neurotypical individuals (e.g., 'start low and go slow'). That said, prescribing professionals are encouraged to use an intentional, single-case design approach given the complexity inherent to dual diagnosis presentations. Considerations include:

- ***Maximize benefits of psychosocial/environmental interventions and supports*.**

  As stated above, medications are often not the first line treatment of choice; feasible non-pharmacologic options should be in place, and geographic, financial and other logistical barriers that obstruct access to otherwise ideal and evidence-based supports should be closely examined. Direct telehealth service, peer-to-peer teleconsultation, single-case insurance authorization agreements, and other remedies may be possible and will likely improve the long-term outcomes for an individual patient.

- ***Identify specific targets for the medication trial.***

  In consultation with the individual (when possible), family, and interdisciplinary care team, prescribing professionals should isolate what specific mental health symptom(s) might reasonably be targeted with medication. Ideally, these targets can be subject to systematic and repeated measurement in order to evaluate the effectiveness of the trial and guide titration; options can include direct observation of specific behaviors (e.g., frequency counts of aggressive incidents in the vocational training setting) as well as standardized ratings of specific behaviors (e.g., the Irritability subscale of the Aberrant Behavior Checklist, as completed by the same caregiver every four weeks; Aman & Singh, 2017). In some cases, measurement of how much a symptom is impairing to the individual may be appropriate (e.g., the Impairment Rating Scale; Fabiano et al., 2006). It is important to note that some rating scales are intended to be idiographic (e.g., scores for an individual are only meaningful in comparison to their baseline, rather than to any normative values for a given population), and this may be the most appropriate approach given the significant phenotypic heterogeneity seen for individuals with ASD and/or IDD. Collateral reports are critical (e.g., parents, direct care staff), and multiple informants can help monitor how and when medications yield benefit. When possible, the individual should participate in symptom monitoring as well through self-report. Note that measurement tools created for neurotypical populations may not be content valid (e.g., contain items that incorrectly assume an individual uses verbal communication) for individuals with IDD.

- ***Based on the identified target(s) and the individual's age, developmental, and health status, identify medication(s) that are likely to provide symptom relief.***

  Literature review, peer consultation, and records review (especially when the individual has a history of medication use).

- ***Change one variable at a time and measure outcomes continuously.***

  Start one medication at a time, beginning at a low dose and adjusting gradually within the recommended ranges associated with factors like age, weight, co-occurring health conditions, pharmacogenetic profile, etc.

- ***Monitor for adverse effects*.**

  Whether or not therapeutic benefit is observed on the target symptom(s), an individual may experience other effects that range from the temporary/mild (e.g., transient fatigue after starting an alpha agonist; low appetite in the morning after taking a stimulant medication) to the acute/significant (e.g., extreme weight gain or extrapyramidal side effects after initiating an atypical antipsychotic). In some cases, medical evaluation (prior to, annually after, etc.) may be recommended to prevent and monitor for adverse effects. The individual and family should actively participate in the evaluation of the benefits and costs of medication use.

- ***Consider course of medication use.***

  In some cases, medication may be used for a discrete period of time and then safely discontinued; in other cases, medication may be part of an individual's long-term management of a chronic mental/behavioral health challenge. Periodic evaluation of whether a medicine continues to have a favorable cost/benefit profile is critical, especially when there may be concerns for long-term health problems associated with medication use.

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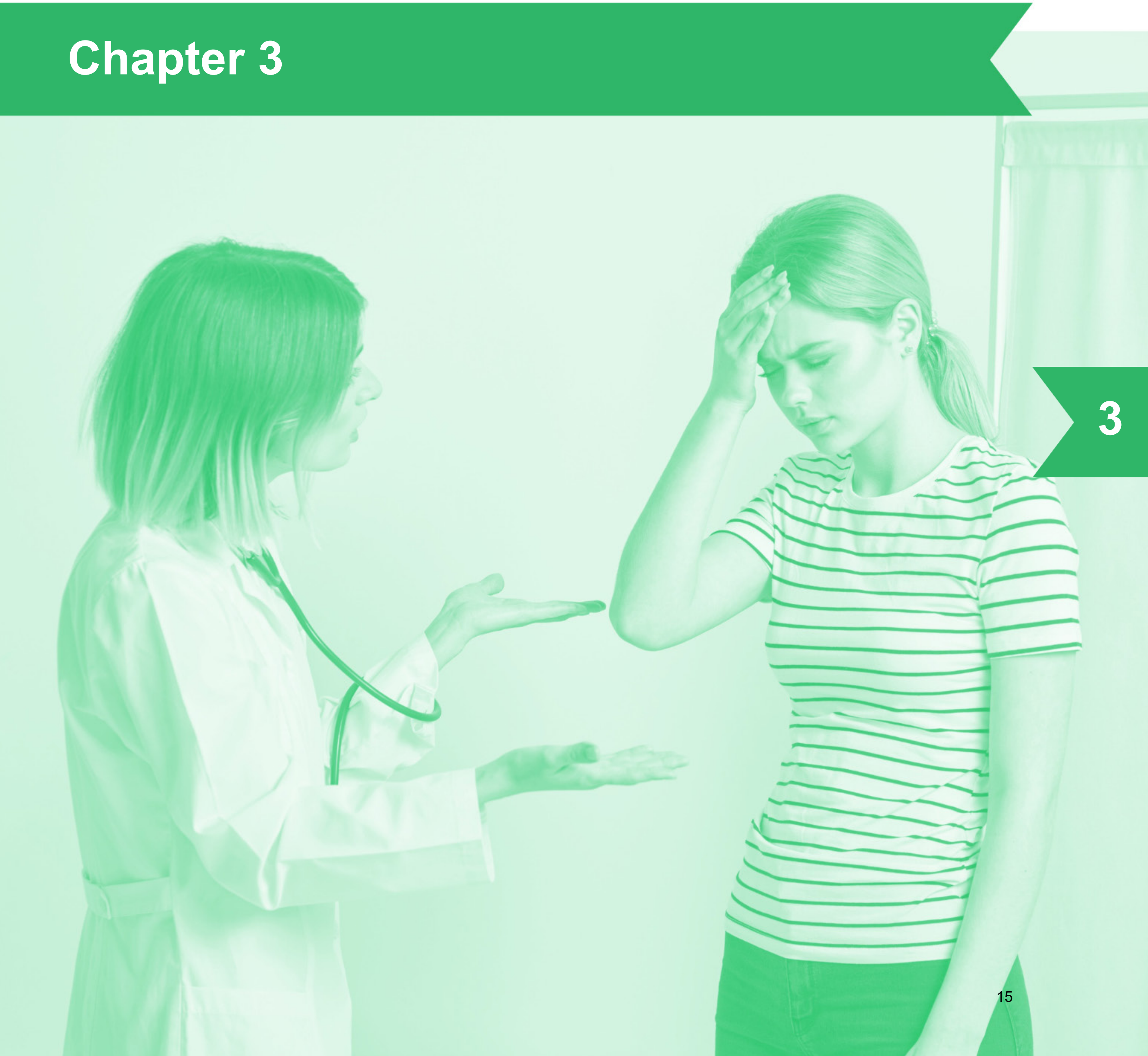
Trauma

Chapter 3



Trauma

Trauma in Individuals with Intellectual and Developmental Disabilities

The paradigm of trauma-informed care emerged based on decades of research showing strong correlations between adverse childhood experiences (ACEs; see below) and long-term health and social outcomes (Struck et al., 2021; Narayan et al., 2021). ACEs pose significant risks for later mental health conditions (including substance use and other risky/problematic behaviors); at a larger scale, generational trauma and adversities can impact parent-child attachment, bonding and parenting skills. Parental ACEs can negatively impact child development by age two in domains such as communication, problem solving and personal, social and motor skills (Folger et al., 2018).

Risk for ACEs also increases in the presence of developmental differences. Beginning in early childhood, individuals with IDD may experience significant disadvantages that trigger a cascade of adversities, altering their life trajectory and laying the foundation for observed health disparities in adulthood (Berg, et al., 2016). Youth diagnosed in infancy with a disabling physical health condition show 83% higher odds of experiencing at least 2 ACEs by age five (Reichman et al., 2018). Individuals with IDD may be up to four times more likely to experience adversity compared to neurotypical peers, and these higher rates place them at even greater risk for other negative outcomes (McNally et al., 2021; Martorell & Tsakanikos, 2008; Crosse et al., 1993). Externalizing behavior challenges, which are more common among children with IDD, increase risk of physical abuse (Gerstein, et al., 2011); internalizing behavior, communication and learning problems are also more common among children with IDD, and these challenges are associated with increased risk of sexual abuse (Turner, et al., 2011).

Youth with IDD are bullied up to twice as much compared to neurotypical peers (Van Cleave & Davis, 2006). Additionally, children with IDD are at increased risk for exposure to incidents of physical restraint and seclusion both at home and at school. Individuals with IDD are also more likely to experience both acute inpatient hospitalizations and long-term institutionalization (Schlenz et al., 2015; Jacobson & Holburn, 2002; Sullivan, 2006). Youth with IDD are up to 4 times more likely to witness family domestic violence in comparison to their peers (Sobsey et al., 1995); factors like parental separation/divorce, parental mental health problems, witnessing of violence against a parent also appear more common for youth with IDD (Vervoort-Schel, et al., 2018). In addition to emotional neglect and serious injury, experiences like out-of-home placement and disrupted (or insufficient) educational and treatment supports may also be sources of traumatic experiences for individuals with IDD.

Despite the prevalence of ACEs within the IDD population, service providers often allow IDD to overshadow the potential impact of traumatic experiences in the lives of the individuals they serve (Rich et al., 2021). Professionals from any discipline who serve individuals with co-occurring mental health and developmental conditions benefit from applying a trauma-informed perspective that can aid in diagnosis, treatment planning, and fostering resilience and protective factors for individuals and their families (Keesler, 2014).

ACEs Framework

ACEs such as abuse (physical, verbal or sexual), neglect (physical and emotional) and household dysfunction (caregiver separation/divorce, incarceration, mental illness, physical illness, substance use and witnessing domestic violence) have been studied for more than twenty years (Struck et al., 2021; Narayan et al., 2021). Exposure to trauma can change the architecture of the brain, influencing neurological, hormonal and immune development problems, and social, emotional and learning problems which can lead to the development of disease, disability, social problems and even premature death. According to the robust ACEs research, the higher the ACE score (in the absence of protective factors), the higher the likelihood that an individual could develop health conditions and social problems. Unrecognized and untreated ACEs increase risk for later depression and suicidality, tobacco, alcohol and other substance use disorders, obesity, diabetes, heart and liver disease, risky sexual activity and unplanned pregnancies, domestic violence, school absence and dropout, unemployment, and financial and legal problems (among other negative outcomes; Felitti, 1998; Narayan et al., 2021).

ACEs research has expanded to include intergenerational traumatic experiences (McDonnell & Valentino, 2016), historical traumas (Hamby et al., 2020; Bernard et al., 2021), and adverse community events (Pinderhughes & Davis, 2018). Poly-victimization and system-induced re-traumatization contributes to the complexity of how repeated trauma is experienced by vulnerable populations. This may include events and experiences such as natural disasters, home disruptions, treatment provider disruptions, community violence exposure, death or loss of a significant person, multiple hospitalizations, seclusion and restraint, bullying, foster care, racism, discrimination, and invasive medical procedures; of note, individuals with IDD face higher rates of a number of these event types (e.g., medical complexity, Croen et al., 2015; restraint/seclusion, O'Donoghue et al., 2020; bullying, Zeedyk et al., 2014). Especially of autistic individuals, "social camouflaging" (engaging in behaviors to appear neurotypical, and/or inhibiting behaviors to appear less neurodivergent) is associated with worse mental health outcomes and has been described by some as traumatic (for a review, see Cook et al., 2021).

ACEs and Dual Diagnoses: Conceptualization and Identification

Little data exists regarding the prevalence of trauma histories among individuals with co-occurring mental health conditions and IDD; however, the increased rates of ACEs among those with either mental health conditions or IDD strongly implies that individuals with dual diagnoses face even higher rates of experiencing traumatic events. Successful treatment and service delivery must recognize and address trauma histories and avoid re-traumatizing through coercive or violent interventions such as seclusion, restraint, and forced medication (Cusack et al., 2018; Muskett, 2014).

Conceptualizations of the developmental neurobiology of posttraumatic stress highlight three general areas of impact: 1) the maturation of specific brain structures at particular ages, 2) physiologic and neuroendocrinologic responses, and 3) the capacity to coordinate cognition, emotion regulation and behavior. The impact of trauma on children varies greatly depending on developmental stage. Those stages influence how a child estimates external danger and perceived threats, and their belief in their ability to protect themselves (van der Kolk, 2003). Threat perception alone can activate the brain's stress response system. Thoughts, feelings, symptoms and behaviors may be initiated, causing confusion for others who consider those threats manageable. Essentially, it is important to understand that a trauma does not have to be substantiated or proven to have a negative impact on an individual. The threat or constant fear of trauma can cause significant impairment.

In addition to collateral reports and other evidence, it may be important to interview individuals with IDD to help identify their history of adverse experiences, including maltreatment. This should only be done by qualified professional staff in coordination with relevant authorities and (if applicable) guardians for multiple reasons. First, communication and cognitive delays common to individuals with IDD may make traditional interviewing strategies difficult. Moreover, being asked to remember or discuss traumatic events can make children as well as adults become distressed, agitated, and even feel as if the traumatic event is still happening. Youth with language delays may also be more easily influenced by suggestive interviewer statements and witness coaching, and struggle to provide cohesive narratives of an event; for these and other reasons, interviewing a child only once is recommended (Wyman et al., 2019). Individuals may also struggle to report or explain how the experience continues to impact them. Reluctance to disclose maltreatment may be related to both avoidance of the distress associated with the experience as well as avoidance of consequences for disclosure. Individuals may also be hesitant to report trauma within their family system because of the bond, attachment and loyalty to family members (especially caregivers). For an extensive guide to best practices for adapting evidence-based forensic interviewing approaches, see Wyman et al. (2019). Other factors that reduce the likelihood of reporting trauma include caregiver feelings of inadequacy, grief and loss, differing opinions about parenting techniques, anticipatory anxiety related to safety of a child, stress and strain on relationships, and caregiver burnout (Ko et al, 2015). Finally, families and caregivers are also at risk for letting the presence of a known IDD or other mental health condition overshadow the presence or impact of a traumatic experience.

The diagnostic criteria for Posttraumatic Stress Disorder (PTSD) were originally derived for adult populations (e.g., combat veterans and burn victims), complicating the diagnosis of youth as well as individuals with IDD (van der Kolk, 2003). The most recent revision in DSM-5 addresses this in part by including criteria specifically for youth under age six that acknowledge the possible identification of distressing memories, dreams and re-experiencing based on affective responses and play re-enactments (rather than solely verbal reporting; APA, 2013; see Jones & Cureton, 2014). An emphasis is also placed on external behavioral manifestations (e.g., extreme tantrums, startle response, sleep disruption) as well as disrupted relationships with family, peers, and caregivers (e.g., school or therapy staff). As with anyone, the manifestation(s) of traumatic stress may change over time.

Assessment and Progress Monitoring

Several standardized tools that have been used to assess for trauma in youth are listed below; however, *there is no specific data on using most of these tools with individuals with IDD*. Clinicians should use caution when using the tools and take into the account the individual's ability to understand the questions being asked and the accuracy of their reporting of events.

- Trauma Symptom Checklist for Children (TSCC)
- Trauma Symptom Checklist for Young Children (TSCYC)
- UCLA Posttraumatic Stress Disorder Reaction Index (UCLA PTSD-RI)
- Interactive Trauma Scale (Hoover & Romero, 2019) – Web-based scale for youth with ASD

Pathways to Recovery

Individuals with dual diagnoses who are impacted by their adverse experiences can benefit substantially from intervention and supports applied using a trauma lens. Individual pathways to recovery often require a multi-pronged approach that includes trauma education, support of protective factors, resilience skills and adaptive, whole-person treatment. Least restrictive options should always be attempted first to decrease the potential for re-traumatization of children and youth with co-occurring mental health conditions and intellectual disabilities.

Trauma-Focused Cognitive Behavioral Therapy (TF-CBT) has extensive empirical support as a trauma treatment of neurotypical youth, and this approach is linked to the even broader evidence base of CBT approaches for youth and adults with mental health symptoms in the context of trauma (Fleming & Waheed, 2014; Cusack et al., 2016; Bastien et al., 2020). TF-CBT uses evidence-based application of CBT principles to reduce cognitive, affective and behavioral PTSD symptoms through psychoeducation about trauma, development of relaxation/coping and other skills (sometimes including some mindfulness and meditation components), and exposure-based techniques that gradually and systematically desensitize the individual to trauma cues in a safe and therapeutic environment. Exposure-based methods are consistently identified as an important and 'active' ingredient in treatment (see Lely et al., 2019; Lewis et al., 2020). While typically delivered individually with youth, TF-CBT also has a substantial parent/caregiver education and coaching component. There is not enough evidence available to determine the extent to which TF-CBT's efficacy holds true for individuals with IDD, but pilots show feasibility and acceptability (Byrne, 2022). Like other forms of CBT, a number of adaptations are recommended when providing TF-CBT to individuals with IDD. Strategies that have been effective include slowing down and simplifying speech, using visual supports, presenting information one item at a time, taking frequent pauses to check comprehension, using multisensory input, making specific suggestions for change, allowing time to practice new skills, avoiding assumptions that information will generalize to new situations and including multiple caregivers in various environments (for an extended review of trauma-specific CBT adaptation recommendations, see D'Amico et al., 2022 and Peterson et al., 2019).

Other Trauma-Informed Treatment Resources and Models

Two expert-informed toolkits are available that specifically address trauma treatment for individuals with IDD; both incorporate many of the elements of effective treatment described above.

- Trauma-Informed Toolkit for Providers in the Field of Intellectual & Developmental Disabilities, created by the Center for Disability Services, the HEARTS initiative, and the University at Albany's School of Social Welfare.
- The Road to Recovery: Supporting Children with IDD Who Have Experienced Trauma, created by the National Child Traumatic Stress Network.

A number of other treatment models include elements of cognitive/behavioral and mindfulness approaches, including some of the models listed below (see Mavranezouli et al., 2020). Note, however, that very limited research is available on applying the approaches below for individuals with IDD, and in some cases there is very little evidence for efficacy even with typically developing populations. A review of these interventions is beyond the scope of this document, but given the community availability of these programs we are listing them here for your reference.

- Cognitive Behavioral Intervention for Trauma in Schools (CBITS)
- Eye Movement Desensitization and Reprocessing (EMDR)
- Seeking Safety for Adolescents
- Child and Family Traumatic Stress Intervention (CFTSI)
- Sanctuary Model
- Positive Parenting Program (Triple P)
- Sensorimotor psychotherapies (e.g., Ogden, 2006)

To whatever extent possible, all treatment and supports should facilitate posttraumatic growth across a wide range of areas, including positive identity development (self-identity, self-efficacy), improving social-emotional learning skills such as self-awareness (identifying emotions, accurate self-perception, recognizing strengths), self-management (impulse control, stress management, self-discipline, self-motivation, goal setting, organizational skills), social awareness (perspective-taking, empathy, appreciating diversity, respect for others), relationship skills (communication, social engagement, relationship building, teamwork) and responsible decision-making (identifying problems, analyzing situations, solving problems, evaluating, reflecting, ethical responsibility) to promote resiliency and prevent future traumatic experiences (CASEL, 2019). Building family protective factors is also a key component of facilitating growth. This can be accomplished by providing support to families that includes asking and answering caregiver questions, providing timely information, addressing traumatic experiences of caregivers, promoting secure attachment, promoting a healing and protective environment, fostering family-informed, child-centered planning, helping families access trauma-related supports, partnering with parents to create a recovery plan and helping families navigate the challenges of systems of care (Ko, et al, 2015).

Using a Trauma-Informed Approach

A trauma-informed approach focuses on safety, trustworthiness, choice, collaboration, empowerment and cultural competence. Applying these principles when working with individuals with co-occurring disorders will foster resilience and recovery (Harris & Fallot, 2001). This type of approach expands beyond individual or group treatment models and into system changes. Trauma informed systems can improve how clients and families experience services, effectiveness of service delivery, professional training and support around issues of secondary trauma exposure and retention of quality staff.

Using trauma screening tools for children and parents/caregivers, trauma-informed assessment and re-assessments and trauma-informed treatment interventions can help improve overall outcomes. Prior to implementation of these tools, it is imperative that professionals have foundational knowledge of trauma science and symptoms. Equally critical is that providers develop skills to help manage trauma reminders and dysregulation and safety planning, as well as prevent re-traumatization and identify secondary trauma exposure that can result from addressing trauma with children and families.

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Considerations: Diagnostic Combinations

Part 2

Autism Spectrum Disorder Intellectual Disabilities and Anxiety

Chapter 4

4

Autism Spectrum Disorder Intellectual Disabilities and Anxiety

Recognition of the Dual Diagnosis

Anxiety is a normal human experience, and to a degree can be considered an adaptive response to previous experiences that allows us to avoid future threats and discomfort. In its maladaptive form, anxiety is one of the most common and problematic mental health conditions for both youth and adults. Individuals with Autism Spectrum Disorder (ASD) experience even higher rates of clinically significant anxiety than neurotypical individuals. At least 50% of youth with ASD and 20% of autistic adults qualify for a diagnosis of at least one subtype of anxiety disorder (Vasa & Mazurek, 2015; White et al., 2018; Nimmo-Smith et al., 2020). The insistence on sameness, difficulties with transition, sensory sensitivities, and other core features of ASD share overlap with typical conceptualizations of anxiety, and the earliest descriptions of autism reference this explicitly (Kanner, 1943). There are many hypothesized reasons for this longstanding connection between ASD and anxiety, from shared genetic origins (Hallett et al., 2009) to shared cognitive mechanisms (Maisel et al., 2016). Research continues to emerge regarding how best to parse anxiety disorders from ASD itself (Wood & Gadow, 2010; Kerns & Kendall, 2012), as well as how best to conceptualize and measure traditional anxiety symptoms that manifest in both neurotypical individuals and those with ASD (e.g., recurrent worry about speaking in public, along with habitual avoidance of public speaking situations) as well as unique or person-specific manifestations of anxiety that might be unique to an individual on the spectrum (e.g., recurrent worry about losing access to a restricted interest, along with habitual avoidance of situations that might result in lost access; Kerns et al., 2014).

While anxiety disorders absolutely do occur for individuals with intellectual and other developmental disabilities (IDD), the evidence is more mixed regarding whether these rates are higher than those seen in neurotypical populations (Maiano et al., 2018). There is some indication that anxiety symptoms emerge with a different trajectory for youth with IDD (Green et al., 2015). There is compelling evidence that individuals with co-occurring ASD and IDD are less likely to experience a diagnosable anxiety disorder than individuals with ASD alone (Kerns et al., 2021; Nimmo-Smith et al., 2020). While an emphasis will be placed on ASD and anxiety for the purposes of this exploration of the dual diagnosis literature, notes will be made throughout regarding unique considerations for individuals with IDD and/or limited receptive and expressive language abilities.

Functionally speaking, anxiety disorders are about avoidance (i.e., behaviors associated with reduction in thoughts and feelings of anxious distress are negatively reinforced, and therefore more likely to be repeated in the future; Dymond & Roche, 2009). This behavioral process is a common theme across DSM-based subtypes of anxiety, including Generalized Anxiety Disorder (GAD) where the internal activity of worry allows the individual to temporarily avoid more aversive thoughts, feelings and activities (e.g., Borkovec et al., 1999). Conceptually, the presence of avoidance may aid in the identification of an anxiety disorder or at least guide treatment, especially when an individual with ASD/IDD demonstrates extreme or phobia-like responses (e.g., anxious anticipation, emotional distress, etc.) to a specific stimulus (visual, auditory, olfactory, etc.) rather than a less extreme, common sensory sensitivity (Moskowitz et al., 2017a).

Verbal and written self-report are primary drivers of anxiety diagnoses in neurotypical individuals, so the application of these standardized assessments of anxiety symptoms for individuals with communication differences requires careful consideration. Reviews elsewhere evaluate the (often lacking) psychometric properties of anxiety questionnaires for use with individuals with ASD and/or IDD (e.g., Rodgers & Ofield, 2018; Moskowitz et al., 2017a; Wehry et al., 2015). Research has supported the use of the Parent- and Child-Report versions of the Screen for Child Anxiety Related Emotional Disorders (SCARED) as a valid assessment tool for youth with ASD 7-18 years of age who speak in full sentences and do not have co-occurring IDD (Stern et al., 2014). Additionally, researchers have recently developed an ASD addendum to the Anxiety Disorders Interview Schedule, a standardized clinical interview for youth (without co-occurring IDD) and parents based on DSM and empirically identified autism-specific anxiety features (Kerns et al., 2017). Another recently released tool, the Parent-Rated Anxiety Scale for Youth with ASD (PRAS-ASD; Scahill et al., 2019), holds promise for evaluating anxiety symptoms in individuals with ASD and/or IDD, including individuals with limited verbal abilities.

Finally, manifestations of anxiety can overlap substantially with other psychiatric conditions, including Aggression, Depression, and Substance Use, as well as history of adverse experiences (see separate chapters related to those conditions, including Trauma). When an individual's anxiety presentation includes significant aggression, impulsiveness, self-injury or other potentially dangerous behaviors, considerations of safety are paramount: please refer to the safety planning sections in those chapters and the General Safety Considerations chapter.

Medical Factors

The diagnosis of anxiety disorders is based on application of DSM-5 criteria in the context of a comprehensive history, in part to rule out medical causes and contributors. Obtaining information from multiple sources (parents/caregivers, school personnel, treating therapists) and the use of validated individual and caregiver questionnaires can validate and assist with classification as discussed above. Even after a diagnosis of anxiety is confirmed, medical professionals must still consider whether symptoms are being exacerbated by an underlying medical condition that may merit targeted medical intervention (Dong, et al, 2015). Left untreated these underlying conditions may worsen to further threaten the individual's health or continue to exacerbate the anxiety. There are approximately 50 different medical diagnoses which have been found to produce symptoms of anxiety disorder and although individually uncommon, collectively they are important to consider (Cosci, Fava & Sonino, 2015).

Evaluation for medical causes of anxiety requires a healthcare provider to establish the presence or absence of symptoms (via detailed medical history) or signs (based on abnormalities on physical examination) that might indicate the need for further medical testing/treatment to rule out underlying medical factors. Some medical conditions associated with anxiety can be identified by an informed medical history and physical examination. Adding screening laboratory studies can also be considered although evidence-based recommendations on this point are lacking. Because physical symptoms are included among the diagnostic criteria for GAD and Panic Disorder (PD), the simple occurrence of physical symptoms does not differentiate between the presence or absence of an underlying medical issue. Common physical symptoms and signs in GAD include trembling, muscle aches, increased sweating, nausea and diarrhea, and an exaggerated startle response. PD is more often associated with episodic rapid heart rate, and shortness of breath/hyperventilation with dizziness (APA, 2013). Consequently, it is the *type* of symptoms that are most relevant to the physician in considering the possibility of underlying illness. This discernment is not always straightforward. Additional symptoms that may be indicative of underlying medical problems include memory or other cognitive impairments, personality changes beyond depression and anxiety, progressively severe and frequent headaches, fainting or seizures, exertional chest pain, non-episodic shortness of breath, localized abdominal pain, recurrent vomiting, severe constipation or persistent diarrhea, spontaneous sweating with flushing, joint pain or swelling, rashes, and/or unexplained weight loss or weight gain. These are not expected physiologic features of anxiety and should draw the physician’s attention to the need for additional evaluation.

In addition to medical illnesses, the history can uncover factors coinciding with the onset of the anxiety symptoms that may be highly relevant. For example, if anxiety symptoms began within weeks of a new prescription for a stimulant (e.g., methylphenidate) or an SSRI medication (e.g., fluoxetine), an oral contraceptive, an anti-histamine (e.g., oral pseudoephedrine, nasal phenylephrine) or an asthma medication (e.g., theophylline, albuterol), the medication itself may be causing the symptoms. Equally, if the anxiety symptoms began following sudden discontinuation or reduced use of cannabinoids, alcohol, opioids, SSRIs or sedative medications, anxiety symptoms may be secondary to medication/substance withdrawal.

Given the physiological symptoms often associated with anxiety, it is particularly important for assessment to include a physical exam. The individual’s blood pressure, mental status (including situational awareness/orientation, memory functioning, affect and speech pattern) should be assessed in comparison to that person’s baseline. Additional assessment should include the individual’s general appearance, upper airway, dentition, thyroid and abdomen, cardiac and pulmonary auscultation, musculoskeletal and skin inspection, and neurological assessment (e.g., vision and hearing, ocular, motor, sensory, tendon reflex and gait functioning).

Historical and examination findings may each offer clues to underlying illness and indicate the need for lab testing and radiologic or other imaging tests. Even in the presence of a reassuring clinical evaluation, there are screening laboratory tests which can be useful in excluding illnesses/conditions that may not be otherwise apparent. A complete blood count (for anemia, B-12 or iron deficiency), chemistry panel (for abnormalities of glucose, sodium potassium, or calcium metabolism and chemical assessment of kidney and liver functions), a thyroid panel (for hyper or hypothyroidism), a urinalysis (for kidney function), and urine drug screen (for recent substance abuse or exposure) are easily available and, if normal, provide additional reassurance to support the absence of underlying medical illness. These medical and laboratory evaluations can often be done quickly and ensure that the treatment of the anxiety disorder (and any identified medical conditions) can proceed without undue delay.

Psychosocial Factors

In many cases, the environmental contributors to anxiety symptoms will be readily apparent (e.g., after being surprised once, a child then refuses to enter public restrooms due to auto-flush toilets). In other cases, the specific triggers may be less clear (e.g., a child refusing to go to school, but for unclear reasons). Context is critical because it will dictate how the treatment plan is developed. Not unlike many neurotypical individuals, individuals with IDD may not perceive that avoidance of their anxiety triggers is a problem. Rather, parents/caregivers, peers, partners, teachers, and others close to the individual may prompt referral for treatment services because anxious symptoms or avoidance has already (or is likely to) create ongoing or increasing psychosocial stress. A key consideration is whether continued avoidance of the specific triggers is possible or functional (e.g., whether treatment is actually appropriate). Clinical impairment may be defined in many ways, including loss of opportunity to engage in important or meaningful activities (e.g., education, work, leisure), chronic distress due to perseverative fear/worry, and disruptions to the life of the individual and/or their environment that causes substantial distress.

Especially for autistic individuals, anxiety can sometimes be the result of explicit or implicit external pressures to engage in “social camouflaging” (engaging in behaviors to appear neurotypical, and/or inhibiting behaviors to appear less neurodivergent). Camouflaging is most strongly associated with anxiety, but is also associated with worse mental health outcomes more generally (Hull et al., 2021; for a review, see Cook et al., 2021).

The history of the anxiety presentation must also be considered. In some cases, a specific experience (e.g., encounter with a dog) may lead to a phobic response. A change of setting, removal of previous supports, and/or increased performance expectations may provoke increased anxiety as well. Changes in the social environment (family, friends, teachers, co-workers, etc.) may produce anxious reactions, as can observation or awareness of the negative experiences of others (i.e., learning a loved one had a car accident). Particularly for individuals with ASD, there may not be discrete precipitants. Rather, an individual with rigid or perseverative thinking patterns may simply identify a specific troubling idea (e.g., worries that the world will end) and over time develop significant anxiety around that idea.

Anxiety symptoms may also be developed or exacerbated in response to difficulties with communication. If an individual lacks the ability to communicate effectively that they do not want to do or experience something, and absent the control to avoid the situation, anxious responses (yelling, crying, aggression, elopement/escape, etc.) may ensue. As described below, development of alternative skills (including self-calming and coping skills, but also functional communication and self-advocacy skills) can be an important component (if not prerequisite) of treatment.
Multiple professionals (medical, psychological/behavioral, etc.) may need to partner in order to establish a complete picture. The selected approach(es) should be aligned with the individual's verbal and cognitive functioning.

Functional behavioral assessment (FBA) is an umbrella term that describes behavior analytic assessment that looks for predictable patterns in behavior-environment interactions through interviews and repeated observation of natural environments (Cipani & Schock, 2010; Didden, 2007). While more commonly used to evaluate disruptive behaviors, this approach can also be used to inform treatment for behaviors associated with anxiety (including aggression and other externalizing behaviors) for individuals with IDD (Moskowitz et al., 2013). As described above, a comprehensive clinical interview with associated behavior rating scales will also help to identify possible environmental changes and antecedents, as well as to assess for levels and types of anxiety (Kerns et al., 2017). Specific questionnaires are available for self-report of anxiety symptoms and parent report on youth symptoms for individuals with IDD, although research on the psychometric properties of these measures are limited (Rodgers & Ofield, 2018; Moskowitz et al., 2017a; Wehry et al., 2015; Scahill et al., 2019).

Some features of anxiety (e.g., exaggerated startle, distress associated with specific cues/stimuli, avoidance of these triggers) are also common in both acute and chronic reactions to stress and traumatic experiences (including Post Traumatic Stress Disorder; PTSD; APA, 2013). Given that individuals with developmental disabilities are more likely to be victims of abuse over the course of their lifetimes (McNally et al., 2021; Martorell & Tsakanikos, 2008), use of trauma-informed strategies is warranted when considering a diagnosis of anxiety (see Trauma chapter). Of note, removal of anxiety-provoking cues can also unintentionally reinforce the individual's behavioral avoidance patterns; in cases when the cues (e.g., abusive individual) *must* in fact be removed from the environment, continued avoidance may be wholly appropriate. However, as described below, the most effective psychosocial interventions for reducing anxiety symptoms do involve gradual and systematic exposure to fear cues (though never actual exposure to danger) along with support to develop and implement alternative coping skills. Prolonged avoidance of anxiety-provoking experiences that would otherwise be typical, adaptive, or desired by the individual (e.g., going to school, alternating between work and leisure activities, engaging with peers) will likely exacerbate anxiety symptoms.

Psychosocial Interventions

As emphasized above, a key feature of anxiety is the avoidance of specific triggers. Across the continuum of evidence-based psychosocial treatment modalities, a common mechanism is the disruption of this negative reinforcement process along with the concurrent teaching of adaptive skills.

Implementation of supportive, skills-based interventions (e.g., teaching diaphragmatic breathing) without the systematic exposure to fear cues may still be of some benefit, but has less empirical support. Relatedly, implementation of exposure-based interventions without careful attention to the development of the treatment plan can easily result in inappropriately high (and counterproductive) levels of distress for the individual. Clinicians must attend closely to the individual's level of distress, and work with them and/or their caregivers to develop a clear sense of the unique "fear hierarchy" to avoid moving too quickly or starting exposures at too high a level.

Depending on the individual's level of language, adaptations to the psychosocial treatment format should be considered. Modifications may include (Walters et al., 2016; Blakeley-Smith et al., 2021; Bearss et al., 2018):

- Adapting written materials to use more concrete language with fewer words
- Reducing the use of figurative or metaphorical conversation and instead speak literally using plain, concrete language
- Integration of visual supports to help convey concepts or instruction
- Breaking down complex steps into smaller, simpler ones
- Clinician use of frequent practice and feedback/reinforcement (e.g., behavior skills training)
- Modifying routines to avoid difficult transitions (at least in the short-term).

For individuals with average-level verbal abilities, clinicians and researchers alike have attempted to develop "modified" protocols that adapt evidence-based treatments like cognitive-behavioral therapy (see below) for individuals with IDD, under the assumption that an individual's unique presentation will require (and benefit from) deviations from the typical treatment protocol. The most ambitious trial to date comparing "standard" vs. "adapted" CBT for youth with ASD and anxiety did find some added benefit to the adapted treatment, but individuals in the standard condition still made significant gains (Wood et al., 2020). These findings imply that clinicians trained in CBT who lack specific training in ASD can still deliver effective care.

Specific treatment approaches for addressing anxiety for individuals with IDD are listed below.

Applied Behavior Analysis (ABA): Anxiety as a construct is not always addressed in the behavior analytic literature; rather, behavioral interventions are derived to reduce specific problem behaviors (e.g., aggression, elopement, crying) and increase adaptive behaviors (e.g., compliance, functional communication, completion of daily routines). With this in mind, ABA-based approaches can readily be employed to support individuals with ASD and/or IDD whose behavioral problems are characterized as anxiety (Moskowitz et al., 2017b). As in any other ABA-based context, service begins with an FBA (as described above) to identify the specific environmental variable that results in specific behaviors associated with anxiety (e.g., aggression, elopement, yelling, crying). Strategies (documented in a Positive Behavior Support Plan) are then designed to address these variables in a systematic manner and should include replacement skills and positive environmental changes that increase the individual's ability to tolerate the triggering stimuli and/or use functional means to appropriately avoid them.

Cognitive Behavioral Therapy (trauma-focused if relevant to the precipitating factors of the condition): CBT for the treatment of anxiety in ASD has been most frequently evaluated in youth with average verbal abilities, with notable success (see White et al., 2018 for an extensive review). Randomized trials have shown efficacy for this approach in both group and individual modalities. Key components of CBT for anxiety include the development of a "fear hierarchy" (i.e., a list of least-to-most feared stimuli), gradual but systematic exposure to the feared stimuli (moving from easiest to hardest), coaching on how to self-monitor and report subjective units of distress, behavioral skills training to develop coping skills (e.g., breathing, identification of maladaptive cognitions), positive reinforcement for engaging in exposure practice and other adaptive behaviors, and social skills training (e.g., Wood et al., 2020; Reaven et al., 2012; Storch et al., 2015; White et al., 2013). There is some evidence that adapted CBT models (often integrating more traditional ABA-based approaches; e.g., visual supports, token reinforcement) can prove helpful for individuals with IDD (for a review, see Surley & Dagnan; 2019; Blakeley-Smith et al., 2021).

Mindfulness: Mindfulness as an alternative or adjunct to traditional CBT approaches has some preliminary evidence for anxiety treatment in ASD for adults (Sizoo & Kuiper, 2017; Cachia et al., 2016), and mindfulness-based strategies may be more acceptable and accessible to individuals with ASD in times of distress. Mindfulness-based treatments focus on increasing awareness of one's body and breathing, movement, surroundings, and thoughts and feelings through guided exercises and meditation.

Social skills training: Some evidence suggests that interventions designed to teach and promote social skills in adolescents and young adults with ASD result in secondary reductions in anxiety as well as depression (Schiltz et al., 2018; McVey et al., 2017). These group-based interventions use behavioral skills training approaches to model, prompt and reinforce the use of key social skills, including making appropriate conversation, choosing appropriate friends and developing friendships, and managing conflict among peers.

Medical Interventions

After having initiated psychosocial interventions, psychopharmacologic interventions are an appropriate next step. Note in general that there is limited research available to guide prescription practices for youth and adults with ASD/IDD (Valdovinos, 2019); the review that follows reflects available/emerging evidence as well as clinical experience of the MOADD team, but should not be interpreted as a substitute for the prescribing authority's clinical judgement in any individual case.

The medications most often used for treatment of the core symptoms of childhood/adolescent anxiety are selective serotonin reuptake inhibitors (SSRIs). Commonly used agents include sertraline, fluoxetine, citalopram and escitalopram. Other related medications including norepinephrine and serotonin reuptake inhibitors (SNRIs) such as duloxetine and venlafaxine are also prescribed in selected situations. At present there is very limited data on the use of these medications in the ASD/IDD population, and evidence-based treatment protocols for individuals with co-occurring ASD/IDD and anxiety disorder are not yet published; in fact, some evidence even suggests potential harm in some cases (Williams et al., 2013). Although other medications have also been used to treat specific anxiety symptoms including sleep disturbance (melatonin, clonidine, trazodone) physiologic symptoms (guanfacine, clonidine, propranolol), behavioral dysregulation/irritability (risperidone, aripiprazole) and situational anxiety (lorazepam) there is little data to endorse their use in treating core anxiety symptomatology (Vasa et al., 2016). Overall, the anxiety disorders that appear to be most responsive to treatment with SSRIs in typically developing youth are generalized anxiety disorder, separation anxiety disorder and social phobias (Vasa et al., 2016).

In the absence of high-quality data for those with IDD, there are relevant safety and efficacy studies of SSRI treatment in typically developing children and adolescents with anxiety disorders. The Child/Adolescent Anxiety Multimodal Study (CAMS) and subsequent extension (Child/Adolescent Anxiety Multimodal Extended Long-term Study; CAMELS) used rigorous, longitudinal methods to describe the safety and positive treatment responses for sertraline in children and adolescents with social anxiety disorder, generalized anxiety disorder or social phobia (Walkup et al., 2008; Ginsburg et al., 2018). In comparison studies, the treatment outcomes for the group treated with combination therapy (both CBT and sertraline) was found to be consistently superior to the control group and groups treated with CBT alone or sertraline alone (Walkup et al., 2008; Piacentini et al., 2014).

In the appropriate clinical situation, the healthcare provider with adequate training and experience in prescribing SSRIs can reasonably consider judicious prescription of these medications. The practitioner should also be mindful that FDA approvals for SSRIs and SNRIs vary by approved indication (OCD, major depressive disorder, generalized anxiety disorder) and age (from 6 and over to 12 and over for various medications) in medication selection. Consult the Medication Management chapter for additional information.

Case Vignettes

Case 1

M.L. is a 12 year-old male with ASD (without IDD; high average intellectual functioning) and a history of anxiety. He resisted the transition to middle school, and has missed >50% of school days. Parents report that anxiety symptoms worsened towards the end of elementary school, but the availability of a para and alternative classroom placements allowed M.L. to avoid places like the cafeteria and activities like interacting with non-preferred peers. However, these supports are not available in the middle school setting, and M.L. subsequently had multiple emotional outbursts the first week of school (including repeated calls to his parents at work, yelling, and eloping from the school campus to avoid going to lunch). M.L. self-reports that he worries about negative social appraisals from peers and teachers in the middle school, and has specific fears about the possibility of a school shooting (even though no elevated concerns exist). His parents both work outside the home and cannot easily pick him up during the school day; as a result they have had to proactively allow him to stay home repeatedly (with work sent home from teachers) to avoid him being listed as truant.

To support M.L., the school team first conducts an FBA to identify the full range of factors potentially contributing to his outbursts, worry, and avoidance of school. Not surprisingly, much of his behaviors are “escape-maintained,” indicating that the purpose of the behavior is to avoid, escape or delay discomforting/unwanted situations, both external (e.g., avoiding negative social appraisal and perceived dangers at school) and internal (e.g., recurrent worry actually helps him to cognitively avoid other distressing thoughts and feelings, at least in the short term). While not the primary function, the team and family note that his behaviors also produce lots of attention from those around him, including in the form of expressed concern and reassurance. The school team and family (including M.L.) develop a Behavior Intervention Plan (BIP) to add to his existing Individualized Education Plan that provides both accommodations as well as sets specific limits for what he should do when overwhelmed; the plan also coaches teachers and other staff on how to be supportive without unintentionally reinforcing his avoidance and perseverative worry. M.L. is able to identify outcomes that are valuable to him (e.g., privileges at school and home) which he can earn for practicing coping skills, following school rules, and engaging in very gradual exposure exercises with his individual therapist. The therapist monitors outcomes, engages regularly with the school team and family, and after several months of gradual progress encourages the family to consider discussing adjunctive medication supports to help M.L. continue to make gains.

Case 2

C.M. is a 25 year-old female with co-occurring ASD and IDD (minimally verbal) who lives in a group home setting. Up until recently she successfully participated in daily routines, including chores, leisure activities, and job training activities. However, following an episode in which the group home’s smoke detector was activated by a small fire from the microwave, L.M. has had increasing difficulties functioning in the group home setting. Her sleep is disrupted, she refuses to engage in previously enjoyable activities, and she appears to perseverate on the smoke detector (which cannot be removed, due to fire codes). She repeatedly says “fire,” cries, and covers her ears when staff attempt to prompt her to visit the group home’s kitchen. She hit a staff member who tried to physically guide her to sit at her normal place at the kitchen table. Since then, staff have allowed her to stay in her room, bringing her meals there and allowing her to decline typical activities. She has started to say “fire” even when invited to leave the room.

The group home and case manager request consultation from a behavior specialist who conducts an FBA of C.M.’s current challenges, and reviews data collected by group home staff from the several months in which anxiety emerged. The behavior specialist also conducts a reinforcer assessment to identify a wide range of highly motivating activities and other privileges that can be used to support intervention. The behavior specialist develops a highly structured behavior plan that involves shaping processes (akin to the exposure practices described in the previous case example)—e.g., systematic practice and reinforcement over the course of several weeks to help her first with stepping towards her bedroom door, then opening the door, and eventually with leaving her bedroom and engaging in adaptive activities for brief periods of time. The process is supported by coaching the direct care staff on how to use visuals that consistently communicate to C.M. what the expectation is and what she can earn for practicing. Progress is reviewed regularly, and the plan is modified as needed to ensure it does not move too fast (and overwhelm her). Staff are also coached on how the reasons for withholding attention and reactions when she yells “fire” unnecessarily, and ways to prompt C.M. without unintentionally triggering aggression. Over time, C.M.’s practice with leaving her bedroom is transitioned back to her previous adaptive living goals (practicing engaging in hygiene and household tasks with increasing independence). The case manager continues to monitor C.M.’s anxiety over time, and periodically when symptoms re-emerge the staff can resume regular practice to ensure she continues to succeed in her environment.

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Autism Spectrum Disorder Intellectual Disabilities and Aggression

Chapter 5

5

Autism Spectrum Disorder Intellectual Disabilities and Aggression

Recognition of the Dual Diagnosis

Aggression is frequently identified as a problem for individuals with Autism Spectrum Disorder (ASD) and other intellectual/developmental disabilities (IDD). Behaviors identified as aggressive might include physical actions that injure or potentially injure others as well as oneself. Even hostile verbal statements (e.g., threats) and agitated vocalizations may be characterized as aggressive. Prevalence rates for aggression in individuals with IDD vary widely based on a number of factors, including how aggression is defined, age groups studied, and settings such as hospitals or family homes. Estimates of occurrence within the IDD population range from 5% to 50% (Baghdadli et al., 2003; Crocker et al., 2006; Hartley et al., 2008; Kanne & Mazurek, 2011; Matson & Rivet, 2008; Schroeder et al., 1991). Autistic individuals may be more likely to engage in aggressive behaviors than other individuals with IDD, but this may be related to higher rates of other psychiatric conditions associated with ASD (Fitzpatrick et al., 2016). The most severe instances of physical aggression often result in in restrictive outcomes for the individual, including potential law enforcement involvement, displacement of home setting, hospitalization, and increased prescription of psychotropic medications (Taylor, 2020).

Medical Factors

A thorough medical evaluation followed by indicated medical treatment is a mandatory first step when addressing aggressive behavior (Reiss & Aman, 1998). Medical conditions that incur pain and may not be communicated should always be considered in the differential diagnosis when aggression emerges in patients with IDD. While not an exhaustive list, medical problems associated with increased aggression include (de Winter et al., 2011):

- gastrointestinal issues (e.g., acid reflux, constipation)
- dental problems (e.g., cavities, abscessed tooth)
- general illness (e.g., sinus infection, ear infection, urinary tract infection)
- general pain (e.g., arthritis, headache)
- seizure disorders (e.g., temporal lobe epilepsy)
- traumatic brain injury (TBI)
- hormonal changes (e.g., thyroid function, menstrual cycle)
- sleep disruption (e.g., apnea, as well as disruptions related to other medical conditions or environmental factors).

Untreated medical conditions in individuals with IDD may result in increased problem behaviors and could lead to overreliance on psychiatric medications to manage symptoms. The discomfort these conditions cause may result in an individual being less tolerant of irritating situations (including components of treatment), or cause them to lash out to make the discomfort stop (even temporarily). In the case of brain injury in the frontal cortex, the medical condition itself may lower behavioral inhibitions. Alleviating the medical or physiological conditions may reduce the probability of aggressive actions, and failing to do so may reduce the effectiveness of other interventions (May & Kennedy, 2010). Of note, aggression can also be an observed side effect of both psychotropic and non-psychotropic prescribed medications (e.g., Lamy & Erickson, 2018; Andres et al., 2017; Kawai et al., 2021). Onset of behavioral changes and initiation/dosing of medications or supplements should be reviewed.

Recurring physical discomfort (such as menstrual cycle, allergies, headache, and sleep deprivation) can also contribute to challenging behaviors by increasing the person's motivation to avoid or escape aversive or demanding tasks.

Psychosocial factors

While aggression can stem from a variety of sources (de Winter et al., 2011; Layng, 2006), examination of contributing social and environmental factors can help set the stage for treatment planning. External factors known to increase risk of aggression include a lack of high-quality social relationships, exhaustion of social support, placement in overly restrictive school or residential settings, use physical punishments, bullying and victimization, increased stress levels in caregivers, and decreased quality of life in both the affected individual and their family (Kanne & Mazurek, 2011; Fitzpatrick et al., 2016). It is important to be aware of any significant change in the individual's environment with respect to housing, caregivers, or school or family system that may be impacting the individual.

More proximal factors in the environment are also frequent triggers for aggression. From a functional behavioral perspective, aggression is commonly motivated by an individual's desire to escape or avoid external circumstances, elicit attention or other responses from others, and/or obtain tangible and other specific outcomes (Beavers et al., 2013). An often-overlooked implication for individuals with IDD engaging in aggressive behaviors is that they may lack the ability to effectively communicate these wants and needs (Matson & Adams, 2014). Aggression, in these instances, is functioning as a method of communication. As such, aggression may be strongly associated with frustration or situations that are uncomfortable or disliked by the individual and thus serves as a means to communicate these feelings.

Finally, aggression is also a potential symptom of a wide range of mental/behavioral health conditions, including: Post Traumatic Stress Disorder, Reactive Attachment Disorder, Attention Deficit Hyperactivity Disorder, Anxiety Disorders, Mood Disorders, Oppositional Defiant Disorder/Conduct Disorder, Bipolar Disorder, and Substance Use Disorders (APA, 2013). The ensuing interventions to reduce aggression described below must be pursued through a trauma-informed lens, especially given that exaggerated startle responses and hypervigilance may increase the likelihood of aggressive behaviors. For more information about trauma-informed approaches, see the Trauma chapter.

Approaches for standardized assessment and outcomes monitoring for aggression may depend on the environments in which the behaviors take place. Some form of functional behavior assessment (FBA) is recommended, such that the supportive team looks for predictable patterns in behavior-environment interactions through interviews and repeated observation of natural environments (Cipani & Schock, 2010; Didden, 2007). The goal is to identify what specific environmental outcomes (e.g., receiving attention, avoiding a specific situation) are consistently associated with the aggressive behaviors. Standardized questionnaires may be used to quantify the frequency and intensity of the aggression (e.g., the Aberrant Behavior Checklist; Aman & Singh, 2017); that said, it is important to note that these scales tend to capture a broad range of challenging behaviors rather than specific aggression targets, and normative data (if available at all) may be less important than repeated measurement of the individual in determining whether treatment is needed or has been sufficiently effective. There may even be instances where simple frequency counts (e.g., number of aggressive incidents per day) are an effective assessment strategy for monitoring the impact of psychosocial and/or medical interventions (Matson & Neal, 2009).

Psychosocial Interventions

Rather than simply eliminate or reduce the aggressive behaviors, treatments initiated because of aggression should be functional—that is, they should address the underlying reasons for the aggression in order to reduce the likelihood of recurrent problems and support the individual to engage in more adaptive behaviors. Intervention approaches must also be culturally sensitive, rely on the least restrictive means possible, and feasible to implement.

While functional interventions are being developed and initiated, a variety of prevention steps can both reduce aggression and safety risks to self/others in the short-term. Comprehensive contingency planning for intense aggression is not “treatment” in and of itself, but it may be a necessary first step in a longer plan of care that shifts to skill-building over time (Reed, DiGennaro Reed, & Luiselli, 2013). By contrast, crisis planning involves identification of strategies that are likely to resolve situations as quickly/safely as possible, while still relying on the least restrictive approaches possible. Not unlike when there are explicit concerns related to elevated suicide risk (see General Safety Considerations chapter), the prevention and de-escalation strategies must be documented in a Safety Plan along with how the strategies should be used, by whom, and under what conditions. Persons who are likely to physically intervene during an aggressive episode should receive training in behavioral de-escalation and safe physical management approaches. Note that numerous proprietary systems exist (e.g., the Mandt System, Crisis Prevention Institute training, Professional Crisis Management training, Safe Crisis Management training), with very limited empirical support available regarding efficacy or comparative effectiveness (Morrison & Love, 2003). Selection of an approach may be guided by specific organizational/regulatory requirements as well as the type of setting in question (Spears & McNeely, 2019; e.g., health care environments; see Bernstein et al., 2022). Programs should always include substantial individualization for individuals with ASD and/or IDD, as well as a continuous education and monitoring plan for those implementing the plan to ensure fidelity and safe implementation. Plans should address environmental safety hazards (e.g., table/chairs that cannot be thrown at staff, floor/wall padding to reduce injury risk in the context of repeated headbanging), as well as consider the safety of the individuals implementing the safety plan (e.g., chest pads, gloves, arm guards, face shields and other equipment, strategically selected based on the presenting challenges). The support team should communicate and collaborate with law enforcement and emergency medical supports when necessary to ensure consistent and safe responses. The support team, family, and (to whatever extent possible) the individual should be involved in crisis response planning to help ensure the safety, acceptability, and minimally restrictive selection of strategies.

Other key prevention strategies to initially reduce aggression include increasing scheduled access to enjoyable, preferred activities and social engagement (e.g., “noncontingent reinforcement,” Carr et al., 2000), limiting instructions and demands, providing meaningful choice-making opportunities, and maintaining a predictable schedule (Brosnan & Healy, 2011; Bearss et al., 2018). Clinicians should seek to identify opportunities to offer individuals choice and control over their daily activities, and work with the individual and their family to expand access to genuine and positive social experiences with peers, family, co-workers, and other community members. Actively arranging safe and nurturing environments free from any unnecessary coercion is critical to success. Over time, routines or transitions that trigger aggression may be gradually re-integrated into daily routines (with supports in place) if those activities are important for the individual’s health, safety, or long-term success; resilience to disruptions or frustrations may actually become an important skill development goal.

Especially when the individual has limited communication skills, treatment approaches/materials should be adapted along with efforts to increase communication capabilities to the greatest possible extent. Depending on the individual’s level of expressive and receptive language, adaptations to the psychosocial treatment format should be considered. Modifications may include (Walters et al., 2016; Blakeley-Smith et al., 2021; Bearss et al., 2018):

- Adapting written materials to use more concrete language with fewer words
- Reducing the use of figurative or metaphorical conversation and instead speak literally using plain, concrete language
- Integration of visual supports to help convey concepts or instruction
- Breaking down complex steps into smaller, simpler ones
- Clinician use of frequent practice and feedback/reinforcement (e.g., behavior skills training)
- Modifying routines to avoid difficult transitions (at least in the short-term).

As noted above, aggressive behaviors are often motivated by an individual's wants and needs. For example, an individual may hit people because it results in disliked people going away, or an individual may hit themselves when they have soiled clothes and hitting elicits attention and reactions from caregivers who can provide assistance. Teaching functional communication (whether it be verbal, gestural, or using pictures or other supportive devices) should be a top priority in intervention; this includes improving communication fluency so that using appropriate strategies (e.g., requesting help via sign language) are practiced enough that they do not require more focus or effort than aggressive alternatives. Functional Communication Training (FCT) has been shown to be effective for individuals with ASD and/or IDD, both alone and in combination with other approaches (Durand & Merges, 2001; Ghaemmaghami et al., 2018; Hanley et al., 2014). The body of research evidence is less strong for applying FCT with adults and for individuals with IDD but not ASD (Heath et al., 2015), but it remains a recommended practice (e.g., Gregori et al., 2021; Gerow et al., 2018). Even if FCT alone is insufficient, building an individual's communication skills may still help facilitate other intervention components, including the development of other functional skills that can eventually reduce or eliminate the occurrence of aggression.

General treatment approaches for addressing aggression for individuals with IDD/ASD are listed below. Each one likely addresses one or more of the general considerations, and care should be taken to ensure that none of the considerations above are overlooked.

Applied Behavior Analysis (ABA)/Positive Behavior Support (PBS): As already outlined above, behaviorally based treatments for aggression focus on understanding the underlying function(s) of the aggressive behavior, modifying the environment to reduce the likelihood of aggression, and supporting the individual to develop improved communication and other adaptive skills (e.g., Embregts et al., 2009; Hanley et al., 2014; Layng, 2006; Dunlap & Carr, 2007). In most cases, an FBA can identify environmental factors and motivation directly linked to the aggressive behavior (Cipani & Schock, 2007; Beavers et al., 2013). Strategies can then be systematically trialed and added to an individual's Positive Behavior Support Plan to address these variables, including prevention/antecedent-focused steps that modify the environment and promote adaptive/appropriate behaviors and reduce the likelihood that challenging behaviors like aggression (Bearss et al., 2018; Brosnan & Healy, 2011; Lang et al., 2019). As noted previously, functional communication training (FCT) should be strongly considered (Gregori et al., 2021; Gerow et al., 2018). Even though FCT and positive behavioral support (PBS) prevention and reinforcement strategies are not traditionally prioritized as elements of training in psychiatry or mental health counseling, these approaches should be considered first-line for both youth and adults with IDD and aggression. Careful consideration should be made of how the treatment strategies will be delivered both in and out of sessions. Clinicians should actively engage caregivers, staff, and other members of the treatment team to assist in behavioral practice or homework, and invite their support to help monitor the success of the intervention plan (Dawson & Bruner, 2011). Of note, caregiver-mediated approaches (sometimes referred to as behavioral parent training) should be considered whenever available, both as a stand-alone behavioral option for more mild childhood aggression and as a key component of behavioral intervention for more severe aggression across the age range (Bearss et al., 2018; Lindgren et al., 2020; see Postorino et al., 2017 for a review). These behavioral approaches can also be adapted for use in specific settings, such as hospitals (Bernstein et al., 2022) and vocational training programs (e.g., Fox et al., 2009).

Cognitive Behavioral Therapy (CBT): While there is limited to data to support CBT and other counseling-based approaches as stand-alone interventions for aggression in individuals with ASD or IDD, these approaches may be useful adjuncts. This is especially true when individuals are struggling to identify their own emotional states related to aggression, recognize events that lead to aggression, and/or understand and change their own automatic thoughts associated with the aggressive behaviors (e.g., Surley & Dagnan; 2019; Blakeley-Smith et al., 2021). Self-monitoring, relaxation techniques, goal setting, and behavioral contracting may also be effective CBT tools to integrate into a Behavioral Support Plan. If aggressive behaviors appear to be related to specific trauma triggers, elements drawn from trauma-focused CBT (TF-CBT) might be considered as well (see Stack & Lucychyn, 2019 for a conceptual review).

Mindfulness: Emerging evidence suggests that mindfulness-based strategies may be helpful additions to a traditional Positive Behavior Support Plan for reducing verbal and physical aggression (Singh et al., 2013; Singh et al., 2019). Mindfulness might also be used to support caregivers in their management of aggression and support of behavioral intervention (Hartley et al., 2019).

Medical Interventions

After having initiated psychosocial interventions, psychopharmacologic interventions are an appropriate next step. Note in general that there is limited research available to guide prescription practices for youth and adults with ASD/IDD (Valdovinos, 2019); the review that follows reflects available/emerging evidence as well as clinical experience of the MOADD team, but should not be interpreted as a substitute for the prescribing authority's clinical judgement in any individual case.

Stimulants and alpha agonists are often used as initial medication approaches for aggression, especially for individuals with IDD whose aggression may be attributable to ADHD or unspecified impulse control problems; this is particularly common in autism spectrum disorder and represents a significant opportunity for safe, effective amelioration of disruptive behaviors (Banas & Sawchuk, 2020). Anxiolytics can be considered for patients whose aggressive episodes occur in the context of anxiety, with the caveat that drugs in this class can be disinhibiting and thereby exacerbate aggression in some patients (Deb et al., 2021). Atypical antipsychotics (risperidone and aripiprazole) have the strongest evidence in reducing aggression and irritability in IDD, but adverse effects and long-term risk profiles should be continuously monitored (Im, 2021). For patients with ASD who have not responded to other antipsychotics, clozapine might be considered (Williamson et al., 2022). As the genetic origins of IDD become increasingly identified, more specified approaches to aggression are becoming possible (e.g., Fragile X; Eckert et al., 2019). While still an emerging science, consideration of pharmacogenetic testing (to understand how an individual metabolizes enzymes relevant to specific types of medications) may be helpful in prescribing for individuals with ASD/IDD (Hyman et al., 2020). Consult the Medication Management chapter for additional information.

Case Vignettes

Case 1

J.O. is a 13-year-old male with ASD, mild language impairment, and ADHD. His parents report that since starting middle school there has been a significant increase in his aggressive outbursts. They are concerned that starting a new school has possibly triggered the latest outburst in aggression, as these behaviors were not present in elementary school. They reported that J.O. has an individualized education plan (IEP) at school, but it has never included anything related to aggression. In addition, they reported that aggression issues have begun to arise at home, with increased explosiveness surrounding his morning and after-school routines. Aggression is reportedly mostly verbal at school, but becoming physical in nature at home. J.O's parents are concerned that due to J.O's size, and his lack of insight into his behaviors, that he could end up hurting someone.

J.O.'s family works with his case manager/treatment team to help create a safety plan related to his aggression. J.O.'s parent requests to reconvene the IEP team in order to have an FBA that can identify triggers to aggression and then create a behavior intervention plan (BIP) to address those behaviors. The parents place J.O. on the waiting list for in-home "ABA therapy," and in the interim are participating in a telehealth parent coaching program where they are learning to conduct informal functional assessments in the home setting and initiate behavioral interventions themselves. This includes a functional communication plan to prompt J.O. to use a specific phrase (e.g., "break please") when he is overwhelmed, rather than hitting a parent to signal he needs to pause the routine. This same approach is added to the IEP at school, where he can request to leave the classroom for brief breaks in the nearby sensory room and he can earn privileges for appropriately returning to class once he has calmed. If issues persist following these interventions, J.O. would benefit from a consultation with a physician specialist (e.g., child psychiatrist or developmental pediatrician) to determine if pharmacological intervention would be beneficial in reducing aggression at home and at school.

Case 2

C.D. is a 26-year-old female with Trisomy 21 (Down syndrome) and moderate cognitive delay. She has a history of aggressive outbursts and is on a variety of medications to help control her aggression. She is currently prescribed clonazepam, venlafaxine, lamotrigine, ziprasidone, and diazepam. Recently at her group home, C.D. became aggressive towards staff following dinner. Following that incident, she reportedly engaged in self-directed aggression by biting and scratching at her hands and arms. Similar incidents have occurred in public places, resulting in calls to law enforcement. The director of the group home requested a consult with the treatment team for C.D. to support her safety, ability to remain in the placement, and opportunities to visit community settings.

The treatment team will engage a behavioral specialist to conduct an FBA, identify triggers to both aggression towards others and self-directed aggression. The FBA identifies escape as a possible motivator, but aggression also seems to occur when C.D. is engaging in preferred activities; after further data collection, the team identifies that the majority of C.D.'s aggression occurs following meals, so the team has requested a full medical workup to determine if there is something in CD's diet that could be related to her outbursts. C.D. was later diagnosed with Celiac disease and changes to her diet have led to a significant reduction in her outbursts. The treatment team has provided psychoeducation to C.D. regarding Celiac disease and the need for dietary changes. In addition, a consult with a psychiatrist was recommended and CD was able to have several of her medications reduced or removed. Positive behavioral supports remain in place to help C.D. learn to identify foods that are problematic, as well as develop other adaptive and self-help skills that reduce the likelihood of aggression in the long-term. Finally, the team consulted with the local Crisis Intervention Team (CIT) regarding aggression toward self and others in community settings, and identified an appropriate point-person at the local station who can serve as an ongoing resource (see General Safety Considerations chapter).

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Autism Spectrum Disorder Intellectual Disabilities and Depression

Chapter 6

Autism Spectrum Disorder Intellectual Disabilities and Depression

Recognition of the Dual Diagnosis

Depression is the episodic experience of low mood and associated behavioral and cognitive symptoms. While often responsive to treatment, relapse and/or recurrent symptoms is also quite common. Autistic adults are almost four times more likely to experience depression in their lifetimes (compared to neurotypical adults), with almost 50% reporting depressive symptoms and 25% reporting that they are currently depressed (Hudson et al., 2019). Prevalence estimates based on standardized assessments of depression yield somewhat lower estimates (e.g., lifetime and current estimates of 37% and 23%, respectively; Hollocks et al., 2019) but these discrepancies may be due in part to diagnostic overshadowing (Rosen et al., 2018). Based on parent report, about 25% of youth on the spectrum have experienced significant symptoms of depression (DeFilippis, 2018). Estimates vary widely for youth and adults with intellectual and developmental disabilities (IDD), but reported prevalence rates of at least 7% (across the range of intellectual disability severity) still exceed the typically developing population (Walton & Kerr, 2016; Cooper et al., 2018). Similar diagnostic overshadowing concerns exist for individuals with even mild intellectual disability or borderline intellectual functioning, with multi-method assessment approaches yielding rates of depression at least as high as 13.7% (Scheirs et al., 2022). The chronic nature of the condition requires a bio-psycho-social approach to support improvement and quality of life.

A key principle of recognition for depression is a change in mental state, mood, and/or behavior (APA, 2013). For individuals with IDD and/or Autism Spectrum Disorder (ASD), depression may be most often recognized through externally observed changes in level of function (including regressive loss of previously-acquired skills), motivation to engage in typical activities of daily life, enjoyment in (and motivation to obtain) previously enjoyed activities, and/or overt changes in behavior that are maladaptive (e.g., agitation/aggression, withdrawal/psychomotor retardation, increased absorption in stereotypic behavior, disorganization, self-injurious behavior; Magnuson & Constantino, 2011). For individuals with severe to profound intellectual delays, challenging behaviors like aggression and self-injury, irritability, sleep disturbance, reduced appetite, and fatigue may also be indicative of depression (for an extensive review, see Eaton et al., 2021).

Given that verbal and written self-reports are primary drivers of depression diagnoses in neurotypical individuals, use of these standardized assessments of depression symptoms for individuals with communication differences requires careful consideration. Even among individuals considered verbally fluent, commonly used self-report tools perform inconsistently (Gotham et al., 2015a; Cassidy et al., 2018). More recent evidence provides some support for using tools such as the Beck Depression Inventory to assess depression in verbally fluent autistic adults (Williams et al., 2021), but more research is needed. Collateral report tools for parents, caregivers, teachers, and direct care staff are an option for youth as well as individuals with limited communication abilities (e.g., 'Withdrawn' scale of the Aberrant Behavior Checklist; Aman & Singh, 2017), but tools developed initially for neurotypical individuals may not be appropriate (e.g., Gotham et al., 2015b).

Finally, manifestations of depression can overlap substantially with other psychiatric conditions, including Aggression, Anxiety, and Substance Use, and adverse experiences (see chapters on these conditions, including Trauma). When an individual's depression presentation includes significant aggression, impulsiveness, self-injury or other potentially dangerous behaviors, considerations of safety are paramount. Irrespective of the cause of the change in mental state, depression itself is associated with elevated suicide risk, so a complete appraisal of safety is a necessary first step whenever a diagnosis of co-occurring depression is considered. Safety measures should be maintained throughout treatment at minimum (for an extensive review of safety planning, see the General Safety Considerations chapter). Especially in the context of depression, it is important to ascertain whether there is a family history of attempted or completed suicide, since suicidality is heritable (runs in families) in a manner that is independent from depression itself (which also runs in families). Not unlike assessment of depression itself, standardized evaluation of suicide risk in individuals with ASD and/or IDD can be challenging; commonly used tools to assess suicide risk in neurotypical youth have been found lacking (Howe et al., 2020), although the recently adapted Suicide Behaviours Questionnaire-Autism Spectrum Conditions (SBQ-ABC) for autistic adults (without co-occurring intellectual disability) holds promise (Cassidy et al., 2021).

Medical Factors

There are many conditions that can manifest depressive symptoms in individuals with IDD. The most serious conditions to differentiate from depression are drug interactions or medication adverse effects, thyroid abnormalities (incurred by medication treatment or the developmental disability itself), and catatonia. Other psychiatric considerations include Adjustment disorders (e.g., acute symptoms that are brief in duration and often related to external changes) as well as Bipolar disorders (which include periodic manic episodes; APA, 2013). Confirmation of depression requires a review of recent medication changes (including look-up of potential adverse drug interactions for clients on two or more medications), thyroid function studies (typically serum free thyroid hormone (T4) and serum thyroid stimulating hormone (TSH) levels), physical examination of the client for overt signs of catatonia (i.e. if primary manifestation of mental status change is psychomotor retardation), and an exhaustive review of environmental/situational factors that may have precipitated either an adjustment disorder or major depression (see Psychosocial factors), including Substance Use Disorders.

Psychosocial Factors

Psychosocial assessment should include an appraisal of environmental/situational factors that are particularly influential in the development of depressive symptoms. For instance, loss of a close loved one is one of the most influential causes of depressive syndromes in all people; note that loss of caregivers, friends, or acquaintances can be as salient as the death of a relative for some individuals. Social, communication and cognitive differences can amplify the perceived salience or importance of relationships, and may also result in misinterpretations of natural life events affecting a relationship (e.g., a move, a rebuke, a schedule change; Magnuson & Constantino, 2011). In this context, “loss” includes any extent to which disruption of a relied-upon source of interpersonal connection or a sudden increase in social marginalization has resulted in a greater degree of disconnection from the family, community, society, or social group. If this is the driving force of depression symptoms, the treatment approach should reflect what would be invoked for complicated bereavement (a specific type of Adjustment disorder) and should consider opportunities for developing new, alternative social connections (i.e., to succeed the individual who was lost).

Some individuals with IDD may communicate that depression symptoms are related to existential concerns, which can emerge as early as middle childhood in neurotypical individuals and are associated with depressed mood (Weems et al., 2016). The themes of existential crises tend to revolve around concerns pertaining to mortality (e.g., fear of death), meaninglessness (concern that limitations of one’s ability severely jeopardize meaning or purpose), isolation, dread of choice/change (e.g., increasing opportunity to make major decisions may be experienced as overwhelming), and perceptions that agency or capacity to direct one’s own course has been violated (e.g., feeling controlled or “managed” as if a puppet). Such conditions can lead to “learned helplessness,” the phenomenon of no longer trying to escape or change undesirable conditions because of previous unsuccessful attempts and no apparent avenues for exerting control (Gacek et al., 2017). Here again, the intervention approach must include addressing the existential concern being experienced by the individual, rather than assuming that they are incapable of formulating or struggling with such concerns (for more information, see Baumel & Constantino, 2020).

Individuals with IDD face higher risk for experiencing sedentary lifestyles, which (in addition to increasing risk for obesity and other negative health outcomes) may be a physical and psychosocial risk factor for depression as well as a barrier to recovery (St. John et al., 2020). Restricted/repetitive behaviors (including perseveration) common to ASD may inadvertently contribute to social isolation and depressive symptoms; conversely, the inability to access or engage in pursuits that are part of an individual's core preferences might also lead to depressive symptoms. Notably, "social camouflaging" (engaging in behaviors to appear neurotypical, and/or inhibiting behaviors to appear less neurodivergent) is associated with worse mental health outcomes (for a review, see Cook et al., 2021). Finally, chronic deficits in motivation to engage in adaptive behaviors sometimes seen for individuals with IDD may be compounded by anhedonia (loss of pleasure), resulting in a vicious cycle of increased withdrawal from routines and social contexts that can further intensify depressive symptoms. Note that there is some evidence that higher verbal/cognitive abilities can be associated with lower self-perceived social competence and subsequently higher rates of depression for individuals with IDD (Rai et al., 2018).

Traumatic experiences (recent, chronic, or past) can have sustained effects on mood and behavior, so evaluation and treatment of depression symptoms must include a trauma-informed approach (see Trauma chapter). Whether or not experiences might be perceived by others as traumatic, the focus on the experience and reaction of the individual should be the focus. As noted elsewhere, individuals with IDD have higher rates of victimization and other traumatic experiences (McNally et al., 2021; Martorell & Tsakanikos, 2008). Bullying and negative peer interactions may be another relevant component to the intersection of traumatic experiences and depression symptoms, given how peers and the environment fundamentally shape an individual's self-perception and day-to-day life experience (in adolescence, as well as adulthood; Zeedyk et al., 2014; Martinez-Cao et al., 2021). Interpersonal conflict with family members has also been associated with depression symptoms (e.g., Greenlee et al., 2020).

Psychosocial Interventions

Management of depression for individuals with IDD must consider the full range of possible precipitating factors outlined above, with the approach tailored to the individual's communication and cognitive abilities as well as their interests and strengths. Regardless of verbal/cognitive ability, treatment will likely include a combination of efforts to bolster environmental supports as well as encourage productive and prosocial activities (including opportunities to increase independence and contribute meaningfully in the community). For all individuals, a combination of standardized assessments (when possible, as discussed above) coupled with behavioral observations should be identified to monitor progress. Especially when aggression and other problem behaviors are part of the presentation, functional behavioral assessment (FBA) approaches should be engaged identify predictable patterns in behavior-environment interactions (Cipani & Schock, 2010; Didden, 2007). Safety planning for suicidal ideation/risk and other self-injurious behaviors, as well as active intervention for aggression towards self and others, must also be a part of the treatment plan (see chapters on General Safety Considerations and Aggression for additional details). When developing psychosocial treatments for depression (including associated disruptive/aggressive behaviors, approaches should be tailored to the individual's level of language and learning style. Modifications may include (Walters et al., 2016; Blakeley-Smith et al., 2021; Bearss et al., 2018):

- Adapting written materials to use more concrete language with fewer words
- Reducing the use of figurative or metaphorical conversation and instead speak literally using plain, concrete language
- Integration of visual supports to help convey concepts or instruction

- Breaking down complex steps into smaller, simpler ones
- Clinician use of frequent practice and feedback/reinforcement (e.g., behavior skills training)
- Modifying routines to avoid difficult transitions (at least in the short-term).

Specific treatment approaches for addressing depression for individuals with IDD are listed below. Each one likely addresses one or more of the general considerations, and care should be taken to ensure that none of the general considerations are overlooked.

Positive Behavior Support Planning draws on the principles of applied behavior analysis to reduce/resolve depressive symptoms by increasing social contact and activities with others and building preferred/motivating activities into daily schedule. This involves the development of a structured behavior intervention plan that includes measurable goals, a reinforcement plan to incentivize incremental success with achieving the goals, and a teaching/prompting plan to increase the likelihood that the individual will experience success.

Applied Behavior Analysis (ABA) / Positive Behavioral Support (PBS): Depression as a construct is not always addressed in the behavior analytic literature; rather, behavioral interventions are derived to reduce specific problem behaviors (e.g., aggression, elopement, crying) and increase adaptive behaviors (e.g., compliance, functional communication, completion of daily routines). With this in mind, ABA-based approaches can readily be employed to support individuals with ASD and/or IDD whose behavioral problems are characterized as depression (e.g., Ross, 2017). As in any other ABA-based context, service begins with an FBA to identify the specific environmental variable that results in specific behaviors associated with specific behaviors of concern (e.g., aggression, avoidance of adaptive routines). Strategies (documented in a Positive Behavior Support Plan) are then designed to address these variables in a systematic manner and should include replacement skills and positive environmental changes that increase the individual's participation in functional activities. Behavioral approaches to prompt and teach new (or previously used) skills for leisure, social interaction, vocational participation, and activities meaningful to the individual function as a form of *behavioral activation*, a key mechanism of depression treatment for many individuals with and without IDD (see Bal et al., 2022; Kerns et al., 2016; and Hillier et al., 2011).

Cognitive Behavioral Therapy: Cognitive Behavioral Therapy (CBT) incorporates the behavioral approaches already described, integrating additional attention to the interrelationships between thoughts, feelings and behaviors for individuals (tailored as needed to the verbal abilities of the individual; White et al., 2018; Bal et al., 2022; Kerns et al., 2016). CBT can be trauma-focused if relevant to the precipitating factors of the condition (see Romney & Garcia, 2021). CBT goals should include components of behavioral activation, as noted above (scheduling pleasurable activities, social interaction, and/or achievable adaptive activities on a daily basis), cultivation of positive appraisal of self, others, and life circumstances; redirection of self-defeating assumptions and perceptions; management of intrusive negative thoughts; targeting of any and all elements of learned helplessness. There is some evidence that adapted CBT models integrating more traditional ABA-based approaches (e.g., visual supports, token reinforcement) can prove helpful for individuals with IDD (for a review, see Surley & Dagnan; 2019; Blakeley-Smith et al., 2021).

Of note, in-home therapeutic supports to extend clinic-based ABA and/or CBT programs can help integrate into daily life (at home, in school, etc.). Completion of homework (e.g., behavioral activation, self-monitoring, etc.) is critical, but understandably difficult for individuals experiencing depression and their caregivers. Clinicians should give special attention to coordinating the goals of intervention with caregivers and support personnel, who are critical in reinforcing goals, completing assigned homework, monitoring success, and adjusting the intervention to ensure opportunities for practice and generalization (Kerns et al., 2016). Strategies such as motivational interviewing, goal setting, in-session rehearsal of homework, and social reinforcement of caregivers for supporting the intervention plan can support adherence and coordination.

Other forms of supportive counseling/psychotherapy may be helpful for individuals with IDD and depression with substantial existential concerns (e.g., Baumel & Constantino; 2020); relatedly, cognitive strategies to help decrease distress around certain thoughts as well as identify maladaptive thinking patterns is also a core component of CBT (Kerns et al., 2016).

Social Skills Training: Emerging evidence suggests that interventions focused on enhancing social interaction success can also reduce depression symptoms, as well as suicidal ideation (Hillier et al., 2011; Schiltz et al., 2018). Even facilitation of unstructured social contacts might serve as a form of behavioral activation (see above).

Vocational Rehabilitation: For adults with IDD and depression symptoms related to social marginalization, a sense of meaninglessness of daily routines (an existential concern), and/or absence of sense of contribution to the community, vocational rehabilitation may be a key element of recovery (Hillier et al., 2011; Menzes et al., 2020). Similarly, when depression symptoms are precipitated by failure to sustain a role or level of function in a work setting, vocational experiences be critical for improving self-efficacy (and function as effective scheduled activities for behavioral activation; see above). Youth and adults with ASD and/or IDD face substantial risks for unemployment/under-employment, which can in turn exacerbate social disconnectedness and poor physical health outcomes that are also associated with depression risk (for a review of vocational interventions, see Weld-Blundell et al., 2021).

Mindfulness: Mindfulness as an alternative or adjunct to traditional CBT approaches has some evidence for depression treatment in individuals with ASD (Menezes et al., 2020; Cachia et al., 2016; Sizoo & Kuiper, 2017). Mindfulness-based treatments focus on increasing awareness of one's body and breathing, movement, surroundings, and thoughts and feelings through guided exercises and meditation.

Medical Interventions

After having initiated psychosocial interventions, psychopharmacologic interventions are an appropriate next step. Note in general that there is limited research available to guide prescription practices for youth and adults with ASD/IDD (Valdovinos, 2019); the review that follows reflects available/emerging evidence as well as clinical experience of the MOADD team, but should not be interpreted as a substitute for the prescribing authority's clinical judgement in any individual case.

Psychopharmacology of depression for individuals with IDD is not different from that implemented for major depression in neurotypical individuals, except for dose-adjustments for conditions associated with abnormal drug metabolism or sensitivity to adverse effects. Studies of the efficacy of the various classes of antidepressant medications for individuals with ASD and/or IDD are limited, but extrapolation of published effects is reasonable and potentially lifesaving when psychosocial approaches are not sufficiently successful in reducing depression symptoms (Menzes et al., 2020). Consult the Medication Management chapter for additional information.

Medication classes for treatment of depression include the major classes of antidepressants listed below.

- Selective-Serotonin Reuptake Inhibitors (SSRIs)
- Serotonin-Norepinephrine Reuptake Inhibitors (SNRIs)
- Bupropion
- Tricyclic Antidepressants (TCAs)
- Monoamine Oxidase Inhibitors (MAOIs)

It is common for one or more of these important classes of medication to be overlooked among patients with IDD and treatment-resistant forms of depression. Note that the SSRIs and SNRIs confer advantage in simultaneously reducing anxiety as well as depression symptoms.

Each of these biological therapies has been associated with transient increases in suicidal ideation in some patients, and therefore patients and caregivers should be educated about the management of this risk when initiating these therapies (see Kafali et al., 2018). Long-term, the benefit of these agents in preventing suicidal behavior outweighs the transient risk of aggravation of suicidal thinking early in the course of treatment. In individuals with cycling mood disorders, the use of antidepressant medication without co-administration of a mood stabilizing agent (see below) can result in the precipitation of mania.

Adjunct therapies for treatment-resistant depression are listed below; note that in most cases there is limited or no available research on these approaches for treatment-resistant depression for individuals with ASD and/or IDD.

- Supplementation with exogenous thyroid hormone (irrespective of thyroid hormone level but this should be checked and followed when exogenous thyroid hormone is prescribed)
- Co-administration of a mood stabilizing agent (i.e., in the context of Bipolar Disorder or Cyclothymia), including:
    - Lithium
    - Neuroleptic (Antipsychotic) Mood Stabilizers
    - Anticonvulsant Mood Stabilizers
- Non-pharmacologic biological therapies, including:
    - Transcranial Magnetic Stimulation
    - Electroconvulsive Therapy
    - Vagal Nerve Stimulation

When catatonia is part of the depression presentation (a common cause of deterioration in functioning in young adults with Down Syndrome), treatment options may include Benzodiazepenes (particularly Lorazepam), Electroconvulsive Therapy, and neuroleptic medication (Palumbo & McDougle, 2018).

Case Vignettes

Case 1

H.O. is a 22-year-old female who was diagnosed with ASD and ADHD late in middle school when social and behavioral challenges started to interfere with her success at school. She lives with her parents, but she is enrolled in college and participates with no academic supports. She reports to her provider that she feels deeply sad, and she has started having recurrent thoughts about how she needs to "tough it out" and finish college despite feelings of misery and loneliness. She reports she no longer has a clear sense of how completion of degree will contribute to a life path that she finds meaningful. She has had intermittent compulsions to harm herself in the context of stress and rumination, has been distracted from doing her best academic work, and has only partial insight into the extent to which the recent loss of her long-term boyfriend has precipitated a grief reaction that is extending to numerous facets of her life. She has infrequent social contacts outside of her family, and she has become withdrawn from them. Her grades fell last semester and she is distressed that the situation will only get worse over the next 6-12 months.

Following formal screening for self-harm risk indicating the individual does not require crisis interventions; however, safety planning is still completed (e.g., identification of who she can talk to if she is in crisis, agreement to invite her parent into the conversation at the end of the visit to discuss safety and support at home). H.O. is referred to a local counselor with experience serving young adults on the spectrum to provide cognitive-behavioral supports (e.g., coaching on how to reconnect with previously enjoyed activities, re-connect with social supports, relaxation and mindfulness strategies for managing feelings of sadness and recurrent thoughts) as well as some initial vocational counseling to help her evaluate her educational and career options. H.O. and her provider also agree that she initiate pharmacotherapy with an SSRI (escitalopram). Her symptoms continue to be monitored regularly by the mental health providers to ensure safety and gradual reductions in depression symptoms.

Case 2

D.K. is a 28-year-old non-verbal adult with intellectual disability living in a group home setting. He has been in that placement for about 2 years, during which he was an active participant in daily routines and community living activities. However, direct care staff identify that for about 6 months he has gradually withdrawn from his previous participation in recreational activities; his self-care has decreased, he is now irritated easily, and even escalated to mild aggression toward a housemate recently. Behavioral consultation reveals that a regular member of his care team left the agency around the time his symptoms emerged; this staff member was D.K.'s primary attendant for over a year, and they had a very positive relationship. D.K. resists getting out of bed, naps often, and has started gaining weight.

In addition to developing a behavior support plan to address aggression, the team also begins a series of behavioral preference assessments with D.K. to help identify what leisure activities, household routines, housemates, staff, and outings are most motivating to him. This information informs changes in his schedule and programming, and several of the activities are integrated into his functional communication training program so that he has the ability to initiate requests (via an iPad speech program) to access them at appropriate times. Regular morning walks with his favorite staff member and housemate are scheduled to help him transition out of bed in the morning and begin the day with exercise. As his mood improves, D.K. is enrolled in a vocational skills program to help him gain access to broader communities and fulfilling activities over time.

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Autism Spectrum Disorder Intellectual Disabilities and Substance Use Problematic and Risky Behaviors

Chapter 7

Autism Spectrum Disorder
Intellectual Disabilities and Substance Use
Problematic and Risky Behaviors

Recognition of the Dual Diagnosis

Individuals with Intellectual and Developmental Disabilities (IDD), including Autism Spectrum Disorder (ASD), face higher rates of a wide range of mental/behavioral health challenges compared to neurotypical peers (Pinals et al., 2022). As such, it should not be surprising that Substance Use Disorders (SUD), along with other problematic/risky activities associated with poor impulse control, also occur at higher rates within the population of individuals with IDD. Limited research is available regarding the prevalence of these challenges. Most studies of SUD in adults with ASD are too small to provide meaningful prevalence estimates (e.g., Arnevik & Helverschou, 2016); however, much of the recent evidence suggests that individuals with ASD have higher rates of SUD generally (as well as alcohol use and illicit drug use specifically) compared to the neurotypical population, in addition to higher associated mortality risk (Huang et al., 2021; Haasbroek & Morojele, 2021; Roux et al., 2021). Not all recent estimates are in alignment, perhaps due to different clinical/community sampling approaches in different countries and cultures (e.g., Weir et al., 2021). High (but variable) estimates of SUD for individuals with other IDDs are also reported, in addition to concerns that this population is less likely to receive treatment (Chapman & Wu, 2013). Some risk factors for SUD appear similar to neurotypical individuals, including family history of SUD and co-occurring externalizing disorders; other risk factors appear to be specific to ASD, including limited sense of social belonging and low social support (Ressel et al., 2020). Certain risk factors are specific to alcohol use (anxiety sensitivity, impulsivity, sensation-seeking) and the severity of substance use (negative thinking patterns, sensation-seeking (Poelen et al., 2017). The literature is especially scant on SUD in autistic adolescents (Adhia et al., 2020); while some estimates suggest there may be lower rates of alcohol use compared to neurotypical adolescents and young adults (Kaltenegger et al., 2021), some experts have called for increased SUD screening and prevention efforts for adolescents on the spectrum given lack of awareness (Anderson & Catallozzi, 2021).

The limited available evidence also raises significant concerns about the risk for individuals with IDD to engage in risky or otherwise problematic activities associated with poor impulse control. These problematic activities include excessive electronics use (sometimes referred to as addiction to the internet, screens, gaming etc.; Jang et al., 2021). Youth with ASD are anecdotally more likely to engage in problematic video game use, but how this is defined (and/or distinguished from restricted interests) is unclear (Coutelle et al., 2021). Risk for problematic internet use (and likely other problematic/risky behaviors) increases with increased access to the medium as well as co-occurring depression and externalizing symptoms (Normand et al., 2021). Anecdotal reports of specific types of problematic internet use (e.g., pornography or shopping addictions) associated with IDDs (and ASD in particular) have not yet led to systematic definitions for these conditions, and in fact the broader literature on problematic internet use suggests caution in considering these phenomena to be "addictions" akin to SUDs (see Kuss et al., 2017; van Rooij et al., 2018; Williams et al., 2020). A review of this area is beyond the scope of this document, but SUD and these problematic/risky behaviors will be grouped for the purposes of this review due to the significant overlap in psychosocial approaches to treatment (see below).

Medical Factors

In terms of psychiatric classification, diagnosis of a SUD related alcohol, nicotine, and other drugs will depend on whether use is problematic due to statutory reasons (e.g., drinking under age 21; marijuana use in a locale without legalization), risk may be conferred due to associated impairment (e.g., inability to keep one's self safe), impact on other life activities (e.g., reduced social connections, poor school/work performance), and risks taken to obtain/maintain access to the substance (e.g., stealing to pay for access or to obtain the substance). Rather than extensively review debates over how to define addiction (e.g., based on physiological or psychological dependence, tolerance, etc.; Heinz et al., 2020), the key focus for establishing a dual diagnosis of IDD and SUD should be on the behavioral criteria outlined in the DSM-5 (APA, 2013); this includes difficulty stopping use even when desired, taking the drug in larger quantities (and/or more frequently), spending substantial time in pursuit of/use of the drug, cravings, the problematic impact that substance use has on other life areas (relationships, work, recreation, etc.), and repeated use despite associated risk/danger. There is clear overlap among these criteria with the reasons that internet/gaming use and other behaviors might be considered clinically problematic; for instance, video game play that persists despite substantial detriment to relationships and educational/vocational, excessive spending to maintain/gain access to electronics and media on the internet, and repeatedly accessing content via illegal means (stealing, hacking, etc.) and/or accessing content that is in and of itself illegal (e.g., child pornography). In lieu of widely accepted diagnostic categories, either Specified or Unspecified Disruptive, Impulse-Control and Conduct Disorder codes may be of relevance (APA, 2013). In cases where risk is in part due to age, property destruction, aggression and/or theft, Conduct Disorder may be appropriate consideration (APA, 2013; see the chapters on Aggression and General Safety Considerations for additional information). Careful consideration should be paid to how core features of ASD and/or IDD (e.g., rigid thinking, repetitive behaviors, difficulties with social cognition, etc.) may overlap with or exacerbate problematic substance use and other risky behaviors; while it is important to avoid pathologizing behaviors that are not leading to functional impairments (e.g., an individual who engages in uninterrupted online gaming for 10 hours per day in the context of maintaining other healthy habits, a job, and relationships with others via the internet), it is also critical to avoid diagnostic overshadowing that may limit access to treatment (e.g., conceptualizing chronic alcohol use to numb sensory sensitivities as 'just part of ASD' despite significant health deterioration).

In the case of possible SUDs, urine/blood drug screens can help determine what substance(s) have been used and the level of current/recent use. This information will assist in the monitoring for withdrawal symptoms and other side effects, as well as inform decisions regarding immediate safety needs (e.g., restricting access to medicine cabinet contents because of pill use, restricting access to phone/computer to prevent communication with a dealer, etc.). Depending on the substance and course of use, monitoring of vital signs and immediate medical intervention may be needed. Note that withdrawal symptoms can vary in intensity for some substances depending on the previous level/frequency of use; for instance, alcohol withdrawal can include mood and cognitive effects (e.g., increased anxiety/depression, agitation, confusion, hallucinations) as well as physiological effects (e.g., rapid heart rate, headache, nausea, insomnia, fever, seizures). Excessive substance use is also associated with a wide variety of long-term health risks which should be monitored as well.

Numerous medical and psychiatric conditions may need to be ruled out in the evaluation of possible SUD, including anxiety and depression (see separate chapters), Bipolar conditions, ADHD, and even schizophrenia. Impulse control problems are also associated with mental health conditions that disrupt adaptive coping strategies (including all of the above, as well as histories of adverse experiences; see Trauma chapter). Some medical conditions are also associated with impaired impulse control (e.g., Parkinsons; Weintraub & Claassen, 2017), and reduced inhibitions are a known adverse effect of some medications (Scavone et al., 2019; Wolfschlag & Håkansson, 2021). Additionally, intoxication and/or impairment related to interactions between substances (including both prescription and over-the-counter medications), as well as individual differences in metabolism (in some cases narrowing the therapeutic window of prescribed medications).

Psychosocial Factors

When potential patterns of misuse occur, it is important to consider and identify any risk/vulnerability factors, including peer-pressure or exploitation, negatives social influence, and offending history. It is also important to ask questions related to harmful use, who the use is harmful to (e.g., client using substance or caregiver, agency provider), and cultural norms of both the client/family, caregiver, agency, etc. Furthermore, it is important to consider frequency of use, degree of impairment, and current medications when determining level of harmful use. For instance, a 25-year-old individual with mild intellectual disability who drinks several beers with his/her friends during course of a 4-hour baseball game (without disruptive behaviors, risk of driving while intoxicated, etc.) may only be ‘problematic’ if this access is not approved by the individual’s guardian and permitted by any other supervising authorities (e.g., group home policies), or if the individual’s prescription medications interact in unsafe ways with alcohol. Alternatively, a much different assessment and response plan might be required for a 16-year-old with ASD who repeatedly steals prescription medications from neighboring houses. Context, history and safety matter for both the assessment and treatment planning of SUDs and other problematic behaviors. To that end, it is also important to note that individuals with IDD have higher rates of victimization and other traumatic experiences (McNally et al., 2021; Martorell & Tsakanikos, 2008), and these experiences are well known to increase risk for SUD (Simmons & Suárez, 2016); both the assessment and subsequent intervention for SUD and problematic/risky behaviors should therefore be trauma-informed (see Trauma chapter, and Luteijn et al., 2020).

In the case of problematic/risky behaviors, assessment of the current frequency/intensity of use (and subsequent impact on other life activities) is critical. This may be accomplished through a combination of interviews and review of gaming/browser histories, examination of financial records, search of room/possessions, access of attendance records, collateral contacts, etc. Determining how and when the individual engages in the problematic behavior will inform efforts in treatment to manage, eliminate and/or monitor access. When problematic behaviors are identified and initially blocked, safety considerations should be included in the assessment plan (e.g., strategies to prevent and safely respond to aggression; see General Safety Considerations and Aggression chapters).

When possible, assessment of substance use and problematic/risky activities should proceed in partnership with the individual using a non-judgmental and empathetic approach (see VanDerNagel et al., 2013 for a detailed framework). This process will require tailoring to the individual, and it may benefit from the use of visual aids and other communication supports. Consideration of the individual’s self-determination (e.g., the Arc’s Self Determination Scale; Wehmeyer & Kelchner, 1995), decision-making, and adaptive functioning may help inform this process as well. Treatment progress should be monitored continuously given the chronic nature of SUD and long-reinforced problematic/risky behaviors, ensuring that intervention elements can be gradually reduced after established success as well as reinstated in the event of increased risk/relapse (see McLellan et al., 2005).

Psychosocial Interventions

For substance use problems, the framework of harm-reduction (reduction of use to decrease both acute and long-term physical and other negative outcomes) has emerged as a best practice approach (see Charlet & Heinz, 2017; Logan & Marlatt, 2010). While complete abstinence may be a potential goal, individuals are supported through this framework to focus on improving their health outcomes through use minimization (Mann et al., 2017; Vearrier, 2019). While research remains limited, this framework has been applied for individuals with ASD, grounded in adapted cognitive behavioral therapy (CBT) techniques (e.g., Helverschou et al., 2019; Rengit et al., 2016; see below). While evidence is limited, the same approach is conceptually appropriate for a wide range of other risky/problematic behaviors as well (e.g., Tanner et al., 2017). When employing harm-reduction strategies, consider targeting frequency of use, quantity (or amount of time engaged in activity) of use, duration of time between use, or other dimensions related to substance use/activity engagement. Similarly, service providers should consider cross-training staff/caregivers on risks and vulnerabilities of individuals with IDD and/or ASD, including peer pressure and exploitation, deficits in self-determination and aspects of autonomy and decision making, etc. Special consideration should be given to the factors discussed above (legal, social/cultural, etc.) that may dictate what the specific goals of treatment are for an individual. Modalities for treatment are discussed below.

Individual Psychotherapy: Individual therapy guided by harm reduction principles have been subject to very limited study for individuals with ASD and/or IDD and substance/activity use problems, but CBT is supported for neurotypical populations and may inform adaptations for individuals with IDD. CBT-based interventions support individuals to identify and change the thoughts, feelings and behaviors contributing to their substance use and/or risky behaviors, including through the development of self-monitoring and adaptive/coping skills (e.g., Ray et al., 2020). The CBT umbrella of intervention also includes approaches such as *motivational interviewing* (techniques that help increase an individual's motivation to change their behaviors and engage in treatment; Lundhal & Burke, 2009) and *mindfulness* (techniques that help an individual to increase awareness and reduce judgment of their thoughts, feelings, and body experience from moment to moment; Li et al., 2017). Modified CBT (including the incorporation of motivational interviewing and/or mindfulness) shows promising effects on decreasing and/or preventing various problematic behaviors for individuals with IDD for SUD broadly (Helverschou et al., 2019; van Duijvenbode et al., 2015; McGillicuddy & Blane, 1999). Specifically, promising effects have also been observed for individuals with IDD and alcohol use (Kouimtsidis et al., 2017), nicotine use (Singh et al., 2013), and gambling (Guercio, Johnson, & Dixon, 2012). Evidence from applications with neurotypical populations also include excessive/problematic use of the internet, video games and pornography use (Wölfling et al., 2019; Crosby & Twohig, 2016). CBT-oriented approaches employ a variety of active formats (e.g., psychoeducation, role-plays), and should include modifications/accommodations tailored to the individual participants' needs, including (Walters et al., 2016; Blakeley-Smith et al., 2021; Bearss et al., 2018):

- Adapting written materials to use more concrete language with fewer words
- Reducing the use of figurative or metaphorical conversation and instead speak literally using plain, concrete language
- Integration of visual supports to help convey concepts or instruction
- Breaking down complex steps into smaller, simpler ones
- Clinician use of frequent practice and feedback/reinforcement (e.g., behavior skills training).

Even when delivered in an individual therapy format, CBT-based interventions almost always involve family/staff and explicitly create environmental contingencies to encourage appropriate coping/skill development, while preventing and discouraging problematic/risky behaviors based on the behavioral intervention literature (see following section).

Applied Behavior Analysis (ABA) and Positive Behavior Support (PBS): ABA/PBS elements are critical components of SUD and problematic behavior treatment, including use of functional behavior assessments (FBAs) and skills-based training to improve an individual's ability to engage in appropriate alternative behaviors (e.g., obsessive/compulsive behaviors, Vause et al., 2020; media use, Pluhar et al., 2019; nicotine ingestion, Piazza et al., 1996; inappropriate sexual behavior, Pritchard et al., 2016). Some problem-specific tools are available to aid in the functional assessment (e.g., the Video Game Functional Assessment-Revised; Buono et al., 2016). Treatment planning for some individuals with IDD may include functional communication training (e.g., Durand & Merges, 2001), especially when aggressive behaviors are part of the clinical presentation (see Aggression chapter for additional details). Interventions also commonly include environmental changes to restrict, limit or monitor access to the substance/activity, as well as establishing scheduled and/or contingently delivered incentives (often referred to as "contingency management" in the SUD literature; see McPherson et al., 2018). In cases where substance use or other risky behaviors are occurring in the context of trauma, some guidance (but limited empirical evidence, at this point) is available regarding how to integrate trauma-informed approaches into treatment for individuals with IDD (Luteijn et al., 2020).

Community-based therapeutic support: As noted above, family, support staff, and other social networks of the individual should be supportive of the goals to reduce and/or eliminate problematic substance/activity use; one key facet of this support is providing a reinforcing environment for the individual to interact with while going through possible periods of withdrawal (e.g., emotional 'mood' swings, irritability, depression/anxiety symptoms), as well as during periods of stable reduced use. Caregivers, friends, and other social networks should also be considerate of engaging in similar substance/activity use around the individual, particularly in the beginning of treatment. Wrap-around implementation of the behavioral support plan.

Group Therapy / Social Skills Training: Group-based versions of the individualized approaches described above have not been studied for individuals with IDD; however, group-based social skills training may be helpful more generally in improving an individual's social connectedness and positive peer connections (reducing risk factors for relapse/continued use). Specific skill targets for consideration could also include skill-building to improve safety and self-help (e.g., to prevent exploitation), recognition of bullying and negative social influences, and appropriate assertiveness training. Traditional, peer-led "12 step" programs and support groups for substance use have not been evaluated for individuals with IDD, but they may be considered based on an individual's presentation, needs and available supports (e.g., Kelly et al., 2020). Note that mandated participation in group sessions may provoke anxiety or anger among individuals with IDD, leading to dropout, rejection by other group members, and induced feelings of failure and exclusion (Arnevik & Helverschou, 2016).

Vocational Rehabilitation: In keeping with a harm reduction framework (but without direct research evidence), treatment planning will likely include careful consideration of establishing/enhancing prosocial forces to help an individual maintain success in the long-term; for many individuals, this may include expanding engagement in vocational pursuits. Keep in mind that working conditions should be dissimilar from environments and social circles previously associated with problematic substance use and/or risky behaviors, especially early in treatment (e.g., it would be inadvisable for an individual to return to work at a convenience store if that had been a primary source of alcohol for abuse).

Case Vignettes

Case 1

BL is a 32-year-old male who currently smokes cannabis and has mild intellectual disabilities. BL resides in an individual supported living (ISL) environment. BL had been arrested at his previous ISL provider for possession of cannabis, after a staff member called law enforcement when they observed BL smoking. His previous placement gave a 30-day notice on BL due to his cannabis use. BL is working full-time at a sheltered workshop. Under the current circumstances, we will work with BL on his cannabis use with the goal to abstain from use over time. A four-week harm reduction program is initiated which includes individual CBT along with positive behavior support planning to assist with identifying internal and external stimuli that trigger urges to use, and identification of alternative/replacement behaviors (e.g., social skills; tolerance and acceptance of triggering events, etc.). BL is engaged in self-monitoring to track his own use; residential staff support monitoring, and the administration of a contingency management plan (i.e., reward system) in which BL can access privileges contingent upon compliance with facility rules. Weekly goals are set that gradually increase expectations over time. Staff at the sheltered workshop are coached to praise and incentivize compliance with facility rules and other key target behaviors.

Case 2

MS is a 25-year-old female with moderate intellectual disabilities, unspecified mood disorder, and post-traumatic stress disorder. She lives with her parents, but she repeatedly elopes from her home (sometimes for days at a time) to access and use alcohol and other street drugs. On three recent occasions she has tested positive for methamphetamines, requiring brief hospitalization. MS also reports engaging in risky sex acts to obtain money and access to substances.

Treatment planning includes development of a home Positive Behavior Support plan to increase monitoring and prevent elopement when possible, as well as to incentivize following rules at home with access to privileges (e.g., community outings with a parent or other responsible adult). Regular testing for substances and sexually transmitted diseases is initiated. Social and vocational skills training is initiated in order to increase her prosocial contacts and activities; additionally, an adapted sexual health program is initiated to help educate MS on safety, healthy relationships, and setting boundaries.

Case 3

PR is a 45-year-old male with mild intellectual disabilities, cerebral palsy, and alcohol use disorder. Recently, PR has started to access cannabis cigarettes, and often smokes them after binge-drinking. Alcohol use has gradually increased, and staff at the vocational program report smelling alcohol on his breath at work on several occasions. His physician reports unhealthy weight gain over the last 2 years, with some impact on cardiac function. PR has a history of attempting to touch others in inappropriate body areas and making inappropriate sexual comments, and these behaviors have increased in frequency with his substance use.

Treatment planning includes individual CBT as well as regular testing for drugs (with intermittent breath alcohol testing at the vocational program). Additional Positive Behavior Support elements are negotiated, including incentives for negative drug tests, participation in social skills group practice, and appropriate behaviors toward coworkers at his vocational program. PR also participates in an adapted drug/health education program which includes coaching on development of personal health goals, exercise, etc. In-home supports help him to engage in brief daily exercise that he selects, and they provide opportunities to sample a variety of leisure activities to foster appropriate hobbies. His physician continues to monitor weight and cardiovascular functioning, which may require medical management as well.

Case 4

BC is a 16-year-old girl with ASD and ADHD who participates in general education programming at her public school. Her parents and school counselor are concerned because of her increasing preoccupation with very specific YouTube videos. She has been caught watching them repeatedly on school devices, and has skipped classes multiple times in order to watch videos on devices she borrows from others or brings from home. She spends hours each evening at home in her room watching the videos, and she has stopped completing homework. BC's parents report severe tantrum behaviors (yelling criticism at parents, property destruction, etc.) when they try to interrupt her media use. She has made multiple self-harm threats when her parents bring up disconnecting the internet or blocking her access to YouTube.

Safety planning is immediately initiated, which includes means restriction (e.g., removal of sharps, medication access, ligature risks, etc.) and increased monitoring in both the home and school settings. One iPad from home is designated as her platform for watching videos, and access is blocked on all other devices; BC's therapist helps the parents negotiate a schedule for noncontingent daily access during leisure times as well as opportunities to earn additional access for meeting daily goals (e.g., attending class, no safety violations). The therapist also coaches BC's parents on conflict prevention strategies, including how to decrease verbal prompting that appears to be a frequent trigger for arguments and escalation. BC's physician and family collaborate on trialing medication supports to decrease irritability/rigidness. Over time, BC's Behavior Support Plan is expanded to include incentives for engaging in other prosocial/therapeutic activities (e.g., participation in a club at school of her choosing, participation in individual CBT for mood management and executive functioning difficulties).

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