University of New Hampshire
Institute on Disability

Integrated Mental Health Treatment Guidelines for Prescribers in Intellectual and Developmental Disabilities

Second Edition

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Table of Contents

Introduction

How to Use the Guidelines

Andrea Caoili, MSW, LCSW, EdD, Chief Editor

Background

Despite advances in mental health care, many people with intellectual and developmental disabilities (IDD) and autism spectrum disorders (ASD) face significant barriers in accessing integrated, evidence-based mental health treatment. Traditional guidelines often lack relevance for people with IDD and mental health conditions, neglecting the intersection of medical and psychiatric care.

The *IDD-MH Prescriber Guidelines* were developed to address these gaps. Designed for prescribers—including psychiatrists, primary care clinicians, nurse practitioners, and interdisciplinary teams—this guide offers pragmatic, evidence-informed strategies for mental health assessment and treatment tailored to people with IDD/ASD.

Our approach combines input from diverse community partners, including people with lived experience of IDD and mental health conditions, family members, clinicians, and prescribers, with a comprehensive international literature review. This dual lens of lived experience and empirical evidence ensures the content is both practical and grounded in best practices in the literature.

Structure and Navigation

The guide is organized into five sections:

- Health Promotion for People with Intellectual and Developmental Disabilities
- Optimizing the Treatment Environment: Working with Patients and Supporters
- Assessment of Medical and Psychiatric Conditions
- Best Practices in Mental Health Diagnosis and Treatment
- Appendix

Each section has a series of chapters and tools, enhanced with real-world vignettes, followed by actionable recommendations, and curated resources to support deeper learning and implementation.

Acknowledgements

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Looking ahead, the editors remain committed to building this foundation, with plans for periodic updates that reflect emerging evidence and evolving clinical practice. We welcome and value your ongoing feedback as these guidelines continue to grow and improve.

Disclaimer

This guide is intended for informational and educational purposes only and does not replace clinical judgment or individualized medical assessment. Medications discussed herein should be prescribed with caution and are not intended as first-line treatments. *The IDD-MH Prescriber Guidelines* is not a diagnostic instrument or comprehensive textbook; instead, it offers general guidance grounded in evidence-based prescribing practices.

Use of the content in this guide is at the professional's discretion. It is essential to evaluate each patient's unique clinical context and to consult current prescribing information or other primary resources as needed.

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Health Promotion for People with Intellectual and Developmental Disabilities

The Importance of Hope as an Essential Part of Patient Care

Dan Tomasulo, PhD, MAPP, MFA

Many patients with intellectual and developmental disabilities and mental health needs (IDD/MH) have a history of being treated as if their presentation is "hopeless." It is often assumed that these patients lack resilience and character to work with the clinician to address clinical needs. This often leads to poor treatment approaches and outcomes because shared hope between the patient and the clinician is key. The cultivation of hope has been linked to psychological and physical well-being.[1] From the very beginning, pioneers in mental health have seen hope as an essential ingredient that helps people feel better. During the treatment process, Freud himself thought his patients' "expectations, colored by hope and faith" mostly explained its success or failure. Karl Menninger viewed hope as the essential ingredient of healing and encouraged psychology practitioners to study it. More recently, Irvin Yalom, the celebrated existential and group therapist, identified the instillation of hope as a crucial factor in the therapeutic process. Today, Martin Seligman, the "father of positive psychology," and Chris Peterson[1] have elevated hope as one of the 24 core character strengths that make human beings flourish. Additionally, Steven Maier and Martin Seligman[2] offer specific research which suggests that hope happens when there is an expectation that future bad events will be temporary, specific, and manageable.

Other researchers, like Snyder,[3,4,5] Cheavens,[6] and Lopez[7] suggest that hope involves having a pathway to achieve goals and the agency, or motivation, to reach these goals. Other researchers, like Barbara Fredrickson[8], understand hope as an exception, because unlike other positive emotions, it comes into play only when our circumstances are difficult or at least uncertain. And medical researchers such as Kaye Herth[9] have found that hope and healing happen when there is sufficient support.

What emerges from the plethora of research is an understanding that hope plays an essential role in reducing risk for distress while facilitating both physical and mental well-being. To consider implementing a treatment plan without addressing the hope factor is to limit its potential. To illustrate hope's central role in patient care and its relationship to well-being, consider the following 2020 study on hope and aging.

In the first-of-its-kind study, researchers affiliated with the Human Flourishing Program at Harvard University's Institute for Quantitative Social Science investigated the link between hope and aging.[10] They found older adults (average age 66) with higher degrees of hope were more likely to have better physical, psychological, and social well-being. Those with greater hope had reduced risks of cancer, chronic conditions, sleep problems, chronic pain, and dying. They also reported increased positivity, higher life satisfaction, a greater sense of purpose, less psychological distress, and better social well-being. On the other hand, those with lower levels of hope or hopelessness had an elevated risk of anxiety, depression, and posttraumatic stress disorder (PTSD). Having hope may be the best protection against a more difficult tomorrow.

Below is a partial list of findings suggesting hope and its correlates are associated with improved outcomes:

- Lower levels of perceived stress
- Lower use of avoidance coping strategies
- Fewer depressive symptoms
- Less anxiety
- Improve functioning in borderline personality disorder
- Reduced post-traumatic stress disorder symptoms
- Improved adaptive coping strategies
- Reduced rumination
- Less catastrophizing about pain
- Diminished neuroticism
- Improved executive function
- Decreased impulsivity
- Increased emotional stability
- Improved adaptive coping strategies
- Reduced rumination
- Less catastrophizing about pain
- Enriched interpersonal relationships
- Better cardiovascular health
- Lower risk of Alzheimer's disease
- Higher levels of well-being
  - More positive emotions
  - Greater resilience and coping skills during difficult times
- Greater productivity
- More compassion
- Greater kindness
- Fewer negative thoughts
- Better sleep
- Improved psychological adjustment
- Better academic performance and achievement
- Increased athletic performance
- Greater coping skills for illness and loss
- Improved social-emotional problem-solving
- A longer, happier life

Beyond these findings is an applied aspect showing hope can be taught, facilitated, and cultivated.[10] The power of hope to prevent illness and distress, enhance recovery from mental and physical illness, and promote longevity and well-being is well-established. Introducing strategies to cultivate hope are essential to enhance the effectiveness of any interventions designed to enhance well-being while reducing suffering. This includes the mental health treatment of people with intellectual and developmental disabilities.

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Health Promotion for People with Intellectual and Developmental Disabilities

I Leslie Rubin MD

Joshua Berezin MD, MS contributed to the research and background for this chapter

> Every person with intellectual and developmental disabilities (IDD) should have access to health care that is compassionate, coordinated, competent, and comprehensive, supporting their fullest health, autonomy, and quality of life throughout the lifespan.

The World Health Organization (WHO) originally defined health as a state of physical, emotional, and social wellbeing, and subsequently added the concept of health promotion as a process of enabling people to increase control over their own health and quality of life.[1–3] For people with IDD and mental health conditions, health promotion is a critical element in the treatment and management of mental health symptoms.[4]

Fundamental Components in Primary Health Promotion

Nutrition

Adequate nutrition[5,6] with a well-balanced diet, meals at regular, predictable intervals and assurance of adequate hydration, particularly in the hot summer months, is critical to physical health and mental wellbeing. It is important to consider the method of eating for everyone, because, while some may be able to feed themselves independently, others may require different levels of assistance or may require dietary modifications. Those who cannot eat and swallow safely and effectively may require alternative feeding strategies, for example by a gastrostomy tube.

Physical Activity

Physical activity is critical to health and wellbeing[7] and should be factored into the daily routine for every person. While some people with IDD may be independently mobile and should have routine walks or other physical activities as desired, for those with limited mobility, physical activity should be tailored to their abilities and preferences. For some, structured physical activity in the form of physical therapy, adaptive physical education, or other activities like aquatic therapy may be necessary.

Sleep Hygiene

Good quality sleep is not only essential for good physical health, but also critically important to mental health and wellbeing. A regular sleep routine in a comfortable bed, in a quiet environment, can make a difference between a good mood or a bad mood in the morning and throughout the day which can significantly affect behavior patterns and social interactions.[8,9]

Predictability and Routine

Predictability and routines that include times for meals, physical and social activities, and all forms of preferred community participation are essential to reduce anxiety and promote mental health through emotional and social stability, and personal growth. Routines are also essential for bowel movements and the prevention of constipation.

Relationships and Belonging

Natural (unpaid) supportive relationships with family, friends, and others should be encouraged through both one-on-one interactions and in group settings to promote inclusion within broader community networks.

Sensory Integration Activities

Many people with IDD have sensory processing difficulties, particularly those with autism, and require more intensive or more frequent physical activities or participation in expressive activities such as music or art. Some prefer to be outdoors and may enjoy and benefit from actively gardening.[10]

In keeping with the understanding of health as a dynamic interaction between the individual and the environment, primary health promotion also requires a holistic, integrative approach that also nurtures physical, emotional, and social wellbeing (Figure 1).

Figure 1: **Social Determinants of Health**[11]

Clinical Care

People with IDD and mental health needs represent a heterogeneous group of people with a wide range of abilities and associated medical and adaptive characteristics, each within a cultural context. It therefore behooves the clinician to get to know and understand as much as possible about the person, their social background, language preference and communication abilities, preferences, and anxieties, as well as the past and present medical history. This population also has a greater likelihood of chronic medical conditions,[12,13] may consult with several medical specialty providers and may be on multiple medications. A comprehensive review of all medical records is essential in the evaluation process and critically important in formulating a diagnosis and prescribing treatments for both chronic and acute conditions.

Elements Required to Obtain a Useful and Valuable Clinical History

- It is critical to provide as comfortable a setting as possible, in a quiet location with minimal distractions. It is important to speak softly, move slowly, and provide a reasonable amount of time for the person with IDD to adapt to the environment and the people in it. Furthermore, when conducting a physical examination, it is important to say what you are going to do before you do it, to give the person time to prepare, comply, and cooperate.
- Be aware of the person's communication style and mannerisms that help in gathering important historical information, and in conducting the physical examination to provide additional information for the diagnostic assessment.
- Examine and explore the person's patterns relating to daily health and routine. This includes eating habits, sleeping habits, bowel and bladder routines, exercise routines, work routines, social routines, as well as habits such as smoking or drinking alcohol or other emotional outlets.
- Inquire about any changes that may have taken place in any of the daily routines, as well as changes in the person's weight and vital signs. It is also strongly advisable to obtain a history of living circumstances, past and present, with attention to any changes that may have taken place in the recent past.
- Review past medical history which includes all past physical health related episodes, previous diagnoses, notes from specialty health care providers, previous emergency room visits, hospitalizations or surgeries, history of allergies, past medications, medication responses and reactions, current medications (including the duration of the regimen, with exploration of possible drug interactions), and past history of behavioral responses to medical, social, and environmental experiences.

Application of these principles in clinical approach will help to create a comprehensive multidimensional picture of the patient and the complex interplay between physiological, psychological, social, emotional, and environmental factors. It also helps guide an assessment of the current clinical challenge to determine whether further evaluations or referrals are necessary, and assure a more accurate diagnosis, more appropriate treatment and therapeutic recommendations, and more favorable outcomes.

Other Assessment and Treatment Considerations

For any provider of mental health services for people with IDD, be it a primary care provider or specialty provider, it is important to be aware of the physical health conditions that may manifest as mental health or behavior disorders. There are many conditions that are not obvious on physical examination that should be considered, most commonly, gastrointestinal disorders of GERD and constipation. The following should be considered:

- It is critically important to take as good a history as possible from the patient, as well as from family members, and other care providers because the more perspectives that are considered, the easier it is to make a diagnosis.
- Assistance with the clinical interview by someone who knows how to elicit accurate responses from the patient is highly desirable.
- Ask informants to describe as accurately as possible what they saw and heard, rather than offering opinions, hypotheses, or even diagnoses.
- It is also helpful to inquire about a timeline that begins from baseline wellness to changes in presentation (medication changes, altered eating, drinking, sleeping, weight, etc.) to understand potential contributing factors might be helpful in clinical assessment.
- A review of medical and psychiatric histories as well as environmental and social history is essential.
- Be aware of the medical conditions that may be present with behavior changes or challenges, most notably, constipation.
- Conduct a broader based physical examination than would be usual for patients, looking specifically for common causes of irritability and aggression.
- Obtain laboratory tests and X-Rays where appropriate and consult with specialty providers, as necessary.
- Be aware that other practitioners may also have minimal historical information that can result in misdiagnosis.
- There are common side effects of medications, particularly psychotropic medications that can explain some of the presenting symptoms or findings.
- People with IDD have atypical nervous system functions, responses, and reactions that may result in unusual presentations of physical or psychological conditions, as well as other organic system anomalies that place them at elevated risk for a variety of health problems and potential adverse drug events.

Conclusion

People with IDD experience higher rates of health problems than the general population—often with unique presentations, chronicity, and complex interactions between physical and mental health. These problems may go unrecognized, misdiagnosed, or undertreated, due to communication challenges, diagnostic overshadowing, and systemic barriers. It is therefore incumbent upon health care providers and prescribers to employ an integrated health approach and consider all factors that may impact the effectiveness of a mental health diagnosis and treatment formulation for a person with IDD. The treatment plan should incorporate appropriate health promotion strategies to be optimally effective.

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Fundamentals of Psychopharmacology

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Before addressing the other topic areas in the IDD-MH Prescribers Guidelines, a basic overview of important diagnostic and treatment considerations is necessary. There are four basic concepts, or fundamentals, for prescribers of psychotropic mediations to consider:

Concept 1

The prescriber should be a qualified, credentialed clinician who has a solid understanding of basic psychopharmacology and experience in the assessment and treatment of behavioral and psychiatric disorders in people with Intellectual and Developmental Disabilities (IDD).

The prescriber requires a working knowledge of psychopharmacological literature, especially evidenced-based, best practice parameters. These practice parameters include knowledge of:

- Basic pharmacology of medications
- Side effect profiles
- Pharmacogenetics of drug-drug interactions
- Toxicity and adverse effects and how they mimic challenging presentations or psychopathology
- Sensitivity to the consequences of long-term use

In addition to basic pharmacology, the prescriber should be familiar with the biopsychosocial aspects of a comprehensive assessment and how to apply these findings to nonpharmacological supports and psychotherapies. Embedded in this process is the capacity to monitor treatment efficacy. There are many strategies to monitor positive and negative responses, but it is up to the treatment team to modify the treatment to match the data.

Monitoring System Requirements

- Monitor new medical/neurological changes that affect behavior
- Monitor behavioral or other systems of measuring symptom response
- Review side effect profiles of all medications and how they might affect behavioral health: track dosing schedules, serum drug levels (when appropriate), and lab studies to maintain the general health of the patient
- Create timelines to track psychosocial, ecological, and medical/pharmacological data

Concept 2

Many prescribing decisions are contingent on an accurate diagnosis.

The brain changes and adapts throughout our life cycle. Behavior, cognition, and complex brain functions are vulnerable to many physiological, genetic/metabolic, and medical/neurological disorders as well as many forms of environmental toxicity. Those emerging during gestation and early childhood tend to be more severe, and many are associated with severe/profound IDD. Later in life, many early-onset conditions can also predispose individual vulnerability to behavioral and psychiatric disorders.

Pain, constipation, dental abnormalities, and medication side effects frequently contribute to the emergence of new challenging behaviors, escalation of long-standing challenges (baseline exaggeration), or the emergence of new challenging behaviors that are misattributed to primary psychiatric disorders. Recognizing the link and correcting the underlying conditions can help resolve these problems and diminish the likelihood of misdiagnoses and inappropriate treatments.

This should remind us that behavioral and psychiatric disorders can arise from many sources. As a result, making categorical statements about causality (genes or environment, functional or organic) is less helpful than taking a systematic view of multiple contributing factors. It is necessary to use a biopsychosocial approach that incorporates predisposing factors, precipitating events or circumstances (adverse childhood events), and perpetuating and preventative factors (resilience and strengths). This approach also helps the prescriber avoid many diagnostic and treatment pitfalls such as an overzealous reliance on psychotropic medications.

Concept 3

The decision to use psychotropic drugs is the product of a team process, and as such, is only one piece of a systemic, ecological, and trauma-informed treatment approach.

It is essential to have thorough family and medical history, physical-neurological examination, psychological evaluations, appropriate diagnostic testing and psychiatric assessment, careful review of interpersonal, familial, cultural, and other ecological factors, and a re-assessment of previous diagnoses and treatment protocols.

The goal in this process is to view the person in a larger context and not fall into the trap of assuming that any single therapeutic intervention can resolve the issues recognized in this collaborative process. Psychotropic medications are adjunctive tools, not definitive answers. They are one part of a larger intervention. If the decision goes forward to use psychotropics then several conditions should apply:

- Before prescribing, it is the team's responsibility to set up a program to monitor both positive and negative treatment responses. The decisions to change medication or dosing schedules, add to or replace existing medications, and taper or discontinue ineffective medications should be data-driven and systematic.
- The process of introducing psychotropic medications involves matching existing assessment data and diagnosis, with an evidence-based decision about specific medications. Once the team decision is made, medications should be started at low doses and only increased when the data suggests an incomplete response. The titration process should be a methodical, data-informed process designed to define the individual's therapeutic dosages.
- A critical step in this process involves differentiating regression secondary to drug toxicity or adverse events from symptomatic worsening, emergence of a new condition, or relapse. The decision to taper or discontinue the drug should follow a reverse strategy of slow incremental reductions of 10% or so of the original dose. This is especially true for challenging behaviors that are not associated with a specific psychiatric disorder. Patience and reliance on the effectiveness of ecological interventions to stabilize regression during withdrawal are essential.
- Some people with recurring mood disorders or chronic psychoses such as schizophrenia are susceptible to relapse when off psychotropic drugs. Relapse is generally a gradual process. A sudden escalation in symptoms may suggest a withdrawal phenomenon. It is useful to remember that repeated withdrawals of psychotropic medications can contribute to treatment resistance.

Concept 4

Always remember that psychotropic drugs are adjuncts to an existing treatment plan, they are not the definitive treatment of any psychiatric disorder.

Assessment and treatment are cooperative ventures that culminate an extensive team effort. The collaboration draws strength from multiple professional disciplines, direct care providers, mental and medical health practitioners, and perhaps most of all, the individuals, their families, and community resources. It is essential to encourage reporting of observations, listening to these reports, and making changes when needed, as well as educating the person, caregivers, and other team members about potential problems.

Optimizing the Treatment Environment: Working with Patients and Supporters

Engaging with Patients, Family Members, & Supporters

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Revision (2025): Melanie Hecker, BA; Karen Weigle, PhD; Diane M. Jacobstein, PhD; Micah Peace Urquilla, BA

Bringing voices shaped by real-world journeys into care, this chapter explores how patients, their family members, and supporters, through their lived experience, become vital partners in designing and shaping their healthcare.[1]

Communication

Speak directly to the patient, regardless of whether they have spoken to you.

> **Why it matters:** People with disabilities often report that providers talk to a family member or caregiver, without including them in conversation. They experience this as demeaning and hurtful.

Speak to every adolescent and adult as an adult.

> **Why it matters:** Providers sometimes slip into a patronizing or paternalistic tone when talking with people who have disabilities. This is experienced by many as demeaning and disrupts provider-patient rapport.

Active listening includes "listening" and attending closely to nonverbal communication. Take the time to ensure you understand what a person is communicating, especially if their communication modality is different than your own.

> **Why it matters:** It is easy to underestimate the importance of what patients have to say or to misunderstand them. Patient insights can have important implications for treatment decisions and should not be discounted.

It is of paramount importance that providers work to earn a patient's trust. With trust comes greater insight and disclosure.

> **Why it matters:** Patients with disabilities have often had poor experiences with medical providers. As a result, many come in with difficult experiences from their past, discomfort, and wariness or reluctance to share.

Familiarize yourself with alternative forms of communication (e.g., sign language, adaptive/augmentative communication devices, picture boards)

> **Why it matters:** Providers often assume that if the person is not speaking, they do not have anything to say. This is both disrespectful and ineffective.

Ensure that plain language resources, translation, and interpretation services are readily available.

> **Why it matters:** These are important to foster understanding, respect, and patients' ability to follow the treatment plan. Plain language is federally mandated in all instances involving health and safety information for the public.

Take the time to get to know the patient and their concerns by asking many exploratory questions.

> **Why it matters:** Simply asking, "What brings you here today?" may not be enough to yield vital information.

Remain open to or ask for feedback from your patients.

> **Why it matters:** Humility goes a long way toward understanding patients' concerns and needs.

Practice patience and kindness when a patient is in crisis—this goes for the patient and their family members or caregivers- they may be in crisis too! It can be hard to remember even the simplest details when you are stressed.

> **Why it matters:** It is common for providers and staff to become upset or irritated with a patient or family member if they seem unable to provide the relevant history needed to provide treatment.

Address any hesitation your patient may have with the medical system. Validate their concerns.

> **Why it matters:** It is important to remember sensitivities resulting from negative past experiences. It is also important to clarify any potential misunderstanding while responding attentively to a patient's current discomfort.

Engaging with Supporters and Community Partners

Engage the patient’s family member or caregiver that they choose to invite into the appointment. They can be one of the best resources you have!

> **Why it matters:** Providers sometimes hesitate to engage the patient’s family member or caregiver in the discussion. At the same time, take care not to exclude the patient.

Invite people with lived experience to come to a grand rounds or professional development session. Engage your local disability advocacy group and develop relationships with community agencies.

> **Why it matters:** Partnering with community resources and learning from people with lived experience can help you best support people with disabilities within your practice.

History-Taking and Diagnostic Formulation

Seek to understand what a patient’s disability means to them and how it uniquely affects them.

> **Why it matters:** A common error is to assume that everyone with a particular disability has the same needs. There is tremendous heterogeneity within IDD diagnoses. People with a given diagnosis may have dramatically unique needs, ability profiles, social support, and experiences.

Explore medical and behavioral phenotypes associated with a patient’s genetic syndrome.

> **Why it matters:** A common error is to make a diagnosis without fully understanding a patient’s biopsychosocial vulnerabilities. There is a great deal of updated information available on behavioral phenotypes, diagnoses, and genetic syndromes. The DM-ID2 is a great resource for familiarizing yourself with these phenotypes and can inform the diagnostic process considering biological, psychological, and social vulnerabilities.

Seek to understand how a patient’s health and mental health have been treated in the past and how this may affect current presentation. Many people with IDD have had very negative experiences in medical offices, including if they were hospitalized as children or institutionalized in the past.

> **Why it matters:** Patients with IDD may be mislabeled as “difficult” or “challenging” when they are highly anxious, to the detriment of their treatment. Do not overlook past treatment experiences or the discomfort behind the behavior. Understanding these experiences in the wider context of their lives may give helpful hints for promoting trust and comfort before treatment interventions.

Take the patient's entire life into consideration: Where do they live? Where do they work? School? Family? Cultural background? LGBTQ+ status? Skills/interests?

> **Why it matters:** The context of patients' lives may give greater insight into contributing factors and vulnerabilities, as well as helpful hints for treatment interventions.

Utilize patient feedback assessments including Patient-Reported Outcome Measures (PROMs) and Patient-Reported Experience Measures (PREMs) to assess patient experiences related to mental health treatment and needs.

> **Why it matters:** A lot of valuable information is missed when providers rely solely on proxy and informant feedback.

Explore what opportunities a patient may have to be meaningfully engaged in each week. Encourage patients and caregivers to find recreational and social opportunities in the area.

> **Why it matters:** Boredom, inactivity or lack of meaningful engagement can play a vital role in the patient's presenting problems.

Medication and Other Treatment Approaches[2]

Prioritize a patient's medication history and especially consider if any other providers prescribe medication.

> **Why it matters:** Polypharmacy is a serious problem among people with IDD, especially when multiple prescribers are involved and not communicating with each other.

Explain why you are recommending medication, treatment, etc. in a way the patient can understand and then check to make sure they have understood.

> **Why it matters:** Many patients do not understand medical jargon or concepts until they are explained in a plain and personally relevant manner.

Listen to your patient when they say medication side effects are impacting their life.

> **Why it matters:** Providers may dismiss reports of side effects as "common" and therefore acceptable. Acceptability is up to the discretion of the patient.

Effective treatment of the presenting symptoms may include medication but may also require collaboration and support to address the larger contributing context in a patient's life.

> **Why it matters:** Meaningful activities, supportive relationships, and self-determination can often improve outcomes.

Seek to understand how a patient takes medication. Do they have someone to help them? Do they often skip/forget doses? Do they take it in the morning, afternoon, or night? Make a plan to promote adherence and consistency.

> **Why it matters:** These measures are likely to improve the chances that the medication will be taken as directed.

Explore how a patient typically responds to pain, needles, or shots.

> **Why it matters:** It is helpful to understand this well in advance to allay fears and make the experience comfortable.

Ask: "What might be hard about my recommendations?"

> **Why it matters:** Patients may not bring up concerns independently.

Conclusion

By centering lived experience, communicating with respect and clarity, engaging patients and supporters thoughtfully, and approaching diagnosis and treatment with humility and context, prescribers can help foster therapeutic relationships built on trust, understanding, and genuine collaboration. In doing so, we move toward a healthcare experience that honors each person's voice and experiences.

Considerations for Waiting Rooms[3]

This section was developed by people with IDD and mental health service experiences and offers important guidance about the treatment environment. Waiting room conditions may be upsetting for people with IDD. Doctor's offices can set the tone for how these and future appointments will go, so planning to reduce discomfort can be highly effective. The waiting room should be as accommodating as possible and avoid common triggers. To ensure your patients' well-being and maximize successful outcomes, the following recommendations should be considered:

- Make a commitment to provide training to your office staff to ensure that your waiting room and office staff know basic information about how to communicate with people with autism and IDD, especially those who use alternative means of communication. Staff should be instructed to talk directly to the patient, rather than the family member or caregiver as a proxy. For further information on augmentative and alternative communication (AAC) and communication best practices, see the following resources:
- The AAC Institute's 10 Rules of Commitment
- Communication FIRST: Listen (short film)
- International Society for AAC: Communication Access
- ASAN: Best Practices for Inclusion of AAC users
- A medical office may be an anxiety-inducing environment for many people with IDD, and some people respond by moving around and making noise. These are not behaviors to be concerned about; they may in fact be self-regulating for the person. Instruct your waiting room staff not to get angry at or reprimand patients with IDD in your waiting room, as this may escalate the patient's anxiety.
- Have calming tools such as squeeze balls and fidget cubes available in your waiting room. Every purchase from the following fidget shops benefits Autistic people:
  - » shop.autisticinnovator.com
  - » allthingssensoryshop.com
  - » weightedwildlife.com
- Institute a practice-wide policy of no strong fragrances. Share this new policy in your newsletters, email communications, and new patient paperwork.
- Fluorescent lighting can be difficult for people who have visual sensory issues. Consider using light filters for fluorescents and/or more ambient lighting options such as floor lamps.

- Pale blue or pastel walls can help create a calming atmosphere.
- If you have a TV in your waiting room, make sure there is an easy way to quickly lower the volume or turn it off.
- If possible, set aside a quiet seating space or “calm room” (not a treatment room) in case your waiting room becomes overstimulating for people with sensory issues. This is especially important for large, busy hospital waiting rooms or those that include people of all ages or noise tolerance.
- Consider instituting a policy about requesting patients to use headphones with cell phones or tablets.
- Delays are an inevitability, and some people may have difficulty waiting. Others may be using pre-arranged transportation to get to the office. Consider delayed announcements, a visual display of estimated wait times, or prioritizing appointment times for patients who do not do well with waiting (dislike crowds, difficulty waiting prolonged periods, or may have other sensory challenges).
- Regarding appointment delays, consider procedures to text a patient who may be outside or in the car when you are ready for the appointment.
- Give people a realistic timeframe for when to expect to be seen after moving them to the exam room. Try to avoid leaving people alone in the exam room for extended periods.

Conclusion

In conclusion, the thoughtful design of the waiting room and broader clinical environment can make a significant difference in the comfort and engagement of patients with IDD. Because this guidance was developed by people with lived experience of IDD and mental health needs, it reflects real needs and practical solutions. Small changes, such as training staff in respectful communication, reducing sensory triggers, providing calming tools, managing lighting and noise, and offering a quiet space, can help reduce anxiety, build trust, and set a positive tone for every visit.

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The Person Experiences Interview Survey for Adults with Intellectual and Developmental Disabilities[1]

Micah Peace-Urquilla; Joan B. Beasley, PhD

The Person Experiences Interview Survey[1] (PEIS) for adults with IDD is a patient reported experience measure for improving the quality of mental health care experiences.

Measuring mental health care experiences helps to improve quality, and the use of a patient reported experience measures (PREM) is recommended. The Person Experiences Interview Survey was developed for adults with IDD to gather information about their mental health service experiences.

The PEIS does not require a proxy or informant and is accessible for adults with limited verbal ability. It was created and evaluated through direct collaboration with people with the lived experiences of IDD and mental health concerns.

Guidelines for using the PEIS in mental health treatment:

- The PEIS is to be completed as a structured interview, in conversation with the service recipient
- Some recipients' access, attention, and cognitive needs may require that the interview is broken up and completed over several conversations
- The PEIS can be conducted multiple times – first to establish a baseline, and follow-ups to assess the impact of changes to one's care
- The PEIS has practical tools and videos to allow clinicians to implement.

Website: https://iod.unh.edu/evaluation-telehealth-services-mental-health-outcomes-people-intellectual-disabilities

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Sensory Considerations for Medical Providers[1]

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Sensory processing is how a person detects and responds to stimuli in their environment and body. All people detect and manage sensory input in different ways, which shape people's actions and behaviors in their environments. Patterns of sensory behaviors, such as hyperresponsiveness (e.g., sensitivity) or avoidance, can lead to problems with physical exams and the ability to interact with health care providers. These sensory patterns do not merely cause annoyance or discomfort, but can overwhelm a person, be painful, and make the person with IDD unable to function and/or follow requests. If a sensory trigger is present, a person with an IDD may not be able to focus on anything else like the words you say, your face, gestures, or other things in the environment. In some cases, exposure to sensory triggers can cause dysregulation, a sure sign that the person is in extreme distress.

It is especially important for prescribers and other office staff to explain or show (on someone else) each piece of equipment used and what it is going to do (blood pressure cuffs, thermometers, etc.) While these may seem like everyday items to some, they can cause increased stress and sensory arousal for a person with IDD.

Sensory triggers are unique to everyone, and different patients may have different combinations of triggers. One patient may be triggered by strong scents and flickering lights, while another may be triggered by high pitch sounds and scratchy clothes.

It is important to ask new patients what their sensory triggers are and how to avoid or mitigate them. Behavioral reactions to sensory stimuli are a manifestation of a person's sensory patterns and needs and should not be understood or treated as a behavior that is extinguishable with medication, behavior plans, or exposure. If sensory triggers are causing significant interference with people's daily lives and well-being, a referral and evaluation by a licensed occupational therapist can provide information the team can use to support successful engagement in health exams and other daily activities.

The following is a discussion of some common sensory triggers and how to accommodate them. Please note that a patient may have a sensory trigger that is not discussed here.

Visual

The most common visual sensory triggers involve lighting. Flickering, fluorescent, and strobing lights are all common visual triggers. Most fluorescent lights that bother a person with overreactive visual senses are not seen as bothersome to others (although the flickering is very subtle and recognizable to them). Bright, contrasting colors can also cause visual overstimulation.

> **Considerations:** It is important to avoid fluorescent or strobe lighting in your practice and to quickly change any flickering light bulbs. The use of lamps or natural lighting is usually preferred. Using pastel or pale colors as opposed to bright colors to decorate your office can also help prevent visual triggers. Sometimes a lot of items in the room can cause visual sensory overload; fewer items and wall hangings are more calming. It is also suggested during medical checkups not to approach the person straight on from the front, which may cause much more anxiety and a fight or flight response. Approach from the side (e.g., for tongue depressor, light in nostril, palpate the neck, or listen to heart).

Audio

Loud or unexpected noises are the most common sound triggers. High-pitch, low-pitch, or repetitive noises can also be triggering. However, some sound triggers are unique to the person.

> **Considerations:** It is important to quickly be able to turn off or turn down any music or television you may have playing in your practice. Remember that fluorescent lights also create a low humming noise that can be distracting for many people. Have a quiet, low sensory space in your practice set aside for patients who may need to leave an area due to the presence of a sound trigger. You may want to have a few pairs of noise-cancelling headphones (made of material that can be disinfected frequently) that patients may use while in the office. Also, if a procedure is going to produce a sound (even as common as a blood pressure cuff inflating/deflating), make sure to let the person know.

Tactile

There are many common tactile triggers. For many people with IDD, another person touching them is one such trigger. Other common tactile triggers involve clothing, ranging from scratchy or tight clothes to clothes with seams in them. The feeling of a certain object or material on a person's hands or skin can also be a tactile trigger (latex, cotton swabs/balls, clay, or chalk). Food and medication textures can also be tactile triggers.

> **Considerations:** To accommodate tactile triggers surrounding clothing, have hospital gowns and slippers on-hand that are not scratchy and do not have seams. You may also need to allow the person to leave their clothes on or wear only underclothes without a gown if hospital clothing cannot be tolerated. Also, have non-latex gloves available.

Sensory triggers involving being touched by another person can be difficult to address in a medical setting. Firm touch is usually tolerated better than light touch. Avoid touching a patient with IDD as much as possible and never touch the person without letting them know. Surprise can result in a startle response.

> **Considerations:** In instances where touch cannot be avoided, a prescriber can briefly distract a patient by talking to them about their interests. "Priming" techniques can also be used to help the person better tolerate touch. An example is rubbing the arms or legs to "wake up" the sensory system and decrease the startle response to further touch. It is best if the provider directs the patient or their parent/support person (if present) to give themselves 5 firm self-hugs or squeeze clasped hands together 10 times. It is also helpful to tell the patient what you are doing and what to expect, so they are not surprised by any procedures and are better prepared for what is to come. Always let the person know you are going to touch them ("I'm going to touch your wrist to count your pulse." or "I'm going to press around a little on your neck because I need to feel what is there.").

Taste/Texture

Strong, bitter, sour, and salty tastes can all be sensory triggers. This can pose a problem for prescribers, as medication often has a strong bitter taste. Textures of foods, medications, and even liquids can be disturbing to some people, which again must be considered in the delivery method of prescription medications. Many people have strong gag reflexes to certain textures, which will keep them from being able to swallow.

> **Considerations:** There are a few methods that prescribers can use to help mitigate taste triggers in medication. One approach is to fill the medication with a flavor coating. A prescriber can also recommend taking the medication with a flavored beverage such as fruit juice.

Taste and texture triggers may also prevent a person with IDD from eating certain foods, which may lead to nutritional issues. If nutrition becomes a problem for a patient with sensory triggers, it is important to work with them on a diet plan that allows them to obtain the nutrients they need while also avoiding foods that trigger them.

> **Considerations:** The prescriber may make a referral to an occupational therapist, dietician, or nutritionist in the event of nutritional issues. One strategy these providers often use is called priming of the face/oral area. Massaging the masseter (chewing muscle) on the jaw area of the face and firmly clamping teeth together 10 times will often decrease an overreactive gag.

Interoception

Interoceptive sensory triggers are internal signals related to bodily sensation like hunger, thirst, temperature, or heart rate. For some people with IDD, interpreting and responding to these internal cues can be difficult or even distressing and can present some challenges in communicating internal states and sensations. People with IDD may be hyper- or hypo-responsive to pain or changes in temperature. The sensation of hunger may go unnoticed or may be experienced as nausea. Some may be sensitive to the sensation of thirst and prefer to always have a drink on hand. Office policies regarding food and drink should accommodate these needs. Like tactile triggers, people with IDD may be sensitive to sensations like the pressure of a blood pressure cuff, the cool touch of a stethoscope, or the sensation of having blood drawn or receiving an injection. The use of these tools and what a person might feel during use should be discussed thoroughly with the patient beforehand.

> **Considerations:** Accommodating sensory differences in interoception requires thoughtful office policy and frequent, open conversation with patients regarding their internal experience. Office policies regarding food and drink should include reasonable accommodations for those who may be especially sensitive to these internal triggers, allowing them to keep food or drink on hand while waiting and attending appointments.

Prescribers should discuss a patient's baseline for these and other important internal cues like pain and note and discuss potential signs of departure from that baseline like irritability, body position, or facial expressions (i.e., hunching over, strained expressions.) Nearby restrooms should be clearly marked, well-maintained, and easily accessible. Prescribers should take care to discuss all potential side effects – not only common side effects – of medications with the patient and their caregiver (if present,) and carefully, continually assess a patient's response to medications. Similarly, prescribers and other office staff such as nurses and assistants should carefully discuss their use of medical instruments like stethoscopes and blood pressure cuffs and prepare the patient for any sensations that may cause discomfort.

Proprioception

Proprioceptive sensory triggers impact a person's sense of body position and movement, and can result in dizziness, disorientation, discomfort, and even anxiety in people with IDD. People with IDD may need more time or modeling for how to carry out certain movements, such as rolling over on an exam table or turning their head, to prevent dizziness or disorientation. It is important to tell a patient if you will be approaching or touching them to move a part of their body, such as positioning an arm for a blood draw or manipulating another part of it. Busy patterns on wallpaper or flooring, or hectic waiting rooms with a lot of movement can trigger proprioceptive responses for hypersensitive people with IDD.

Considerations: In instances where movement is required, provide more time and clear instruction or modeling for people with IDD to execute movement or motor-related activities. Ask and describe what you will do before moving or manipulating a part of someone's body. Keep waiting and office areas as clean and spacious as possible; do not pack furniture or wall art closely together and avoid stripes or other busy patterns that may be triggering to some people. Include clear signage for where to go to check in, check out, and restrooms, as well as arrows or other signs that can help patients navigate office hallways.

Conclusion

Understanding sensory processing, and how it varies greatly among people, especially those with IDD, is fundamental to providing respectful and effective care. Sensory triggers can disrupt communication, overwhelm people, and fundamentally interfere with clinical care. By asking about a patient's triggers, adapting the environment, explaining procedures in advance, and collaborating with occupational therapists when needed, providers can reduce distress and support meaningful participation. Adopting these strategies fosters a clinical setting in which patients with IDD can be heard, respected, and engaged rather than sidelined by sensory barriers.

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Transition from Youth to Adult Mental Health Services for People with IDD

Braeden Friedman; Katharine Stratigos, MD; Debra Rosenblum, MD

Editors' Note: This chapter focuses on young adults engaged with multiple service systems. However, many prescribing considerations apply to the transitional needs of anyone with IDD as they move into adult to children's mental health services regardless of their global service needs.

Overview

This chapter focuses on supporting youth with IDD who are actively engaged in children's mental health and related services in and outside of the school setting, as they transition to adult services. It is crucial for prescribers to understand these support systems, especially when there is a lack of social workers or additional resources to guide patients and families. Prescribers must extend their role beyond medication management to actively support patients and their families in developing a comprehensive biopsychosocial treatment plan.

For youth with IDD and their families, the transition to young adulthood is complex and creates a major re-alignment in expectations, roles, and responsibilities.[1] This transition can be the point at which the patient's path most deviates from same age peers and involves many potential changes including engagement with IDD services, educational settings, medical care, social relationships, living circumstances, and daytime programming.[1,2]

Impact on Mental Health

For transitional youth, there is an increased risk of poor mental health due to the loss of routine, diminished social support, and increased social isolation, which can contribute to anxiety, depression, and feelings of grief for patients.[1,3] Families often experience stress, grief, isolation, and uncertainty during this transition.[4]

As discussed elsewhere in these guidelines, there is a greater prevalence of some psychiatric illnesses as well as an increased incidence of physical, sexual, and emotional trauma for people with IDD when compared to the general population. The transition from pediatric to adult medical and behavioral health providers can create a care gap that can lead to emergency room visits and possibly unnecessary inpatient psychiatric admissions due to lack of access to appropriate services and care.

Role of the Prescriber

Prescribers play an important role in supporting patients and their families during this transition by addressing mental health needs, facilitating planning, and advocating for person- and family-centered care. While some barriers to transition are structural—such as limited availability of adult IDD programs or nonequivalent adult services—there are also critical psychological factors that mental health providers can actively address. Assumptions and biases about people with disabilities often interfere with effective planning. For example, wrongly assuming limitations in cognitive or communication abilities, leading people to underestimate a person's capacity to participate meaningfully in their own transition process. Prescribers can educate other providers and prescribers, promote inclusive practices, and align treatment plans with the person's goals, strengths, and developmental needs. Table 1 details key considerations for transitional youth with IDD including categories/domains, the prescriber's role, and clinical implications.

Table 1: Considerations for the Transition from Youth to Adult Services for People with IDD

Category	Consideration	Prescriber's Role	Clinical Implications
Transition Planning Timeline	Initiate transition planning early (e.g., by 14-16)	Encourage starting this process early	Enhances service continuity, prevents possible service gaps
Cognitive and Communication Profile	Up to date cognitive profile, adaptive functioning, and communication needs	Tailor communication approach, utilize plain language and visual aids when needed	Informs consent process and shared decision making; having up to date evaluation ensures having necessary documentation for eligibility at developmental agencies
Developmental Agencies	Each state has developmental agencies that provide supports and services	Know which developmental agencies to refer patients based on where they live.	Provides or contracts to provide individualized supports and services for people with IDD.
Coordination of Medical or Psychiatric Care	Identify new adult providers (psychiatry, PCP, therapy, case management, etc.)	Facilitate handoffs, send summaries, and history. Ensure accurate updated diagnoses are documented and reconcile medications.	Minimize disruptions in medical or psychiatric care.
Capacity and Consent	Assess decision making capacity and guardianship status	Determine capacity for informed consent; involve legal guardians when needed	Ensure ethical and legal care is provided.
Behavioral and Functional Needs	Evaluate current behavioral supports and functional independence	Coordinate with other providers (e.g., behaviorists, occupational therapists, physical therapists, and support staff)	Promote independence and stability
Social Determinants of Health	Consider housing, employment, education, financial and social support	Screen for social needs; refer to appropriate community resources	Addresses whole-person care
Self-advocacy and Autonomy	Foster patient involvement in care decisions and advocacy skill building	Encourage patient voice in treatment plans; provide opportunities for independent health management	Builds long term self-efficacy, improves adherence and outcomes
Crisis Planning	Prepare for potential psychiatric or behavioral crisis	Create Crisis plans, teach coping skills to patients and family; If START is in your state, consider a referral to START services.	Reduce emergency department and inpatient psychiatric admissions.
Insurance	Ensure continuity of insurance (e.g., Medicaid, SSI, waiver programs)	Educate families about different options; connect them to a social worker or care manager	Prevents loss of access to medical and psychiatric care

Begin Transition Planning Early

An early, ongoing transition plan is essential for a successful adjustment and should begin by age 14. Thoughtful, coordinated planning requires communication, strong advocacy, and a person-centered approach—recognizing that one size does not fit all. A school-based transition model is critical to effectively prepare for adulthood and should be revisited at regular intervals throughout the school years to ensure it remains responsive to the student's evolving needs.

Include the Person with IDD

Having the person with IDD involved in their own transition planning has been found to improve outcomes.[3,5] Many people with IDD are able to express their preferences when given the right communication support. People with IDD want their opinions to be respected and to be involved in making choices about their lives.[3] Many young adults with IDD yearn for the same self-determination as their neurotypical peers-such as pursuing work or college, enjoying unsupervised recreation, dating, having a place of their own, and possibly starting a family.

Support Families in the Transition Process

Families may struggle to accept the transition to adulthood for their child and the right to make their own choices, as they may see them as a "dependent" child and not as a young adult who may have differing opinions about next steps.[6] This tension often becomes clear as youth learn to self-advocate and express their own goals and aspirations[2]. This underscores the importance of truly understanding what the person really wants. Families may be focused on keeping the person "safe and busy" sometimes at the expense of pursuing what would be meaningful for that specific person.

Additional Resources Regarding Transition to Adulthood

- Got Transition: National Resource on Health Transition: www.gottransition.org
- Family Voices: Supporting Families of Children with Special Health Care Needs: https://familyvoices.org/
- The Arc: Advocacy and Services for People with IDD: https://www.thearc.org/
- The Center for Parent Information Resources: Transition planning hub: www.parentcenterhub.org

- Self-Advocacy Resource and Technical Assistance Center: https://selfadvocacyinfo.org/
- RespectAbility: Advancing Inclusion and has resources on sexual education: https://www.respectability.org
- Supported Decision-Making Center: The National Resource Center on Supported Decision Making: https://supporteddecisionmaking.org/
- The Arc's Center for Future Planning: https://futureplanning.thearc.org/
- The IDD Toolkit: Many resources on this site in regards to caring for people with IDD in a healthcare setting: https://iddtoolkit.vkcsites.org/
- HealthCare: More information on health care for people with IDD: www.healthcare.gov

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Delivering Telehealth Mental Healthcare for People with Intellectual and Developmental Disabilities

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> Because some patients have had negative experiences with telehealth, they may be reluctant to engage with prescribers virtually. It's therefore essential to acknowledge and address those concerns up front to help ensure successful telehealth interactions.

Overview

Telehealth is defined as any services provided using telecommunication platforms, such as a computer, tablet, or phone.[1] There are several factors to consider in the telehealth decision-making process including patient and family preferences, communication styles, and access to devices and the internet.[1-4]

Framework for Telehealth-Based Service Activation[5]

There are three primary stages to address when providing telehealth services. They are Prepare, Engage, and Assess.

Prepare: Prepare yourself, the patient, and their caregivers to maximize their telehealth service experiences.

Engage: Use strategies that build rapport, provide accommodation, promote trust, and encourage participation.

Assess: Continual assessment of effectiveness to refine telehealth services to meet the needs of each person and family.

These principles build the foundation for effective mental health services provided via telehealth.

PREPARE

To help patients and caregivers prepare for telehealth sessions, and communicate their needs ahead of time, encourage them to watch the video “How to Make Telehealth Work for You” and complete the accompanying worksheet. These tools are available for free access here.[6]

Professional Comfort with Telehealth

It is important to be familiar with navigating the telehealth platform(s) your clinic uses to minimize disruptions during sessions. This includes knowing how to use common features such as unmuting your microphone, turning on your camera, and enabling closed captioning. Confidence in navigating the platform(s) allows you to support patients and caregivers so they can be actively engaged during their visit.

Providers should be familiar with the user’s interface. For example, providers should understand how users navigate their electronic health system to access the link, or what control options are available during the meeting.

Scheduling

As with in-person services, meetings should be scheduled at a time that works best for the patient and caregiver. For some with limited internet bandwidth or devices, scheduling must accommodate the needs and responsibilities of other members of the household (e.g., family members’ work schedules, siblings’ school, or homework schedules).

Supporting Patients’ Use of Telehealth Technology

Practice & Support: Confirm that the patient knows how to join their upcoming session, whether it be via an e-mailed meeting link or by joining a secure portal/website. Patients may need guidance on multi-step processes for joining via secure portals or websites to ensure they understand how to navigate to the appropriate appointment link. Clinic staff should provide all new users with a supported opportunity to practice accessing, as well as step-by-step instructions that include screen shots.

Patient Comfort and Privacy

Reduce Distractions: Telehealth sessions are most effective in a quiet, private environment. Using headphones can reduce background noise and distractions. You can encourage the patient to set phone, email, and text notifications to “do not disturb” or silent during the appointment.

Create a Comfortable, Safe Space: Ideally, the patient should identify a private or semi-private space for telehealth appointments. A designated space for the patient’s telehealth equipment and materials creates a familiar, consistent setting to promote full engagement. Having materials readily available, like fidget devices or a blanket fosters comfort. If privacy is limited, invite the patient to use headphones or chat (if your telehealth platform allows for this feature.

Identify a Trusted Supporter: Preparing for telehealth may include identifying someone who can assist with technology if needed. Having a trusted supporter to call on can reduce anxiety and help the patient remain resilient and engaged if technology or other challenges arise.

ENGAGE

This section provides strategies to promote engagement through telehealth by building rapport, encouraging communication, and implementing accommodations. These strategies create a comfortable and supportive environment for the patient.

Build Rapport

Active Listening: Demonstrating active listening over telehealth involves the use of open, friendly, and engaged body language. Non-verbal cues that demonstrate you are present and engaged include smiling, nodding, and looking/leaning into the camera as much as possible.

Follow-up: Implement strategies for action items identified during sessions such as contacting other providers, tests, or starting a new prescription. If you use a note taking system that patients can also access through medical portals, clearly label action steps and who should do them by what date for clarity for the patient and their caregivers.

Positive Engagement: Strength spotting is a positive psychology method to identify patient characteristics and is an effective way to build rapport, promote engagement, decrease tension, and improve self-esteem. The goal is to foster an environment where strengths are activated. For more information on using strengths-based approach, visit the VIA Center for Character Strengths[7] and Proof Positive Autism Wellbeing Alliance.[8]

Use of Cameras: Medical telehealth platforms may have different control options when it comes to camera use. Some may allow users to turn cameras on and off, while others may always require cameras on. Be aware that patients may be distracted by or may not like to see themselves on screen and may decide to turn their camera off. Prescribers can gradually encourage the patient to turn the camera on for brief periods of time until they are comfortable keeping it on the entire time.

Accommodations

As with in-person services, accommodation should always be considered when planning telehealth sessions. For services to be accessible, providers must work with the patient and their caregiver if present, to ensure appropriate accommodation is provided.

Some accommodations, such as language interpretation services, may require additional preparation for effective implementation. Familiarizing yourself with how to enable telehealth platform features is an easy way to make telehealth services more accessible. To provide quality telehealth-based services, you need a clear understanding of the expressive and receptive communication abilities and preferences of the patient and their caregiver(s). Additional accommodations for services over telehealth are outlined in Table 1.

Table 1: Recommended Accommodations for Telehealth Accessibility for Patients with IDD

Area	Accommodation Principle	Examples
Motor	• Support movement • Modify tasks that require movement of the hands or whole-body movement	• A supporter who is present can offer hands-on assistance with paperwork, notetaking, or other activities • Set up keyboard shortcuts for those who are unable to operate a mouse • Adapt poses or postures for certain physical examinations to be done while seated instead of standing or laying down
Sensory	• Provide enhanced sensory input • Reduce uncomfortable sensory input	• Help the patient identify a meeting space they feel comfortable in (noise, light, texture) • Invite the patient to get up and move as needed during the session (stand, stretch, use fidgets, bounce on an exercise ball)
Cognitive	• Reduce the amount of input or information provided at one time • Provide information in multiple formats to enhance understanding	• Provide predictability in session routines to reduce cognitive load. • Reduce the number of "clicks" required to engage in tasks
Attention	• Reduce the amount of time needed for each task • Enhance motivation and enjoyment • Reduce the amount of information or input at one time	• Plan for shorter sessions or short breaks for the patient as needed • Instruct the patient on how to turn off camera self-view if it is distracting • Ensure that your background is not cluttered or distracting or use a virtual background
Visual	• Enlarge text and images • Provide information in non-visual formats	• Provide short, visual descriptions ("I'm a white woman with blonde hair wearing glasses and a green sweater. I am sitting in my office.") and introduce others in the room with you • Use materials that are compatible with screen readers and ensure all images include screen reader-friendly descriptions, such as alt-text • Screenshare is not accessible for those using screen readers, so provide materials as email attachments or links
Hearing	• Enhance auditory information • Provide information in non-auditory formats	• Provide ASL Interpretation if needed. Spotlight the interpreter so they are always visible on screen • Automatic captioning may not be sufficient as they can be inaccurate. CART captioning or other live transcription is recommended. • Check in occasionally to ensure everyone understands and has had a chance to contribute • Do not speak more loudly on telehealth than one would in-person
Communication	• Promote exchange of information • Enhance understanding and cognition • Support rapport-building	• Address the patient directly and include them in conversation even if a caregiver is the primary informant or communication support. • Learn about the patient's expressive and receptive communication preferences and needs ahead of time and allow them to communicate in ways that work best for them (chat features, writing, drawing) • Schedule language interpretation services as needed. • Use closed captioning features on the patient's preferred telehealth platform

ASSESS

A necessary part of mental health service delivery and medication management is the assessment of well-being. Conducting a mental health assessment via telehealth can be effective. However, there are unique considerations and challenges when using telehealth outlined below.

Use of Assessment Instruments via Telehealth

The structure of a mental health assessment largely remains the same whether done in-person or virtually. The key elements of the assessment typically include an exploration of the presenting problem, assessment of mental status, psychosocial and medical history, and cultural considerations.

Adapting Questionnaires for Telehealth

Prescribers may use checklists or questionnaires to monitor symptoms and medication side effects. These may be administered on paper or tablet during in-person visits. For telehealth, administration procedures may need to be adjusted:

- Paper documents can be emailed or mailed to patients, depending on their preference.
- Secure medical systems may also deliver documents electronically.
- When delivered electronically, ensure that patients and caregivers know how to respond.
- Prescribers can also choose to administer the questionnaire verbally during the session.
- People with IDD may need more time to process and respond to questions. They may also benefit from both reading/seeing each question while it is asked aloud.
- If tools are completed before the session, inquire who provided the responses to the questions. Caregivers or other supporters may have good intentions, but they may inaccurately answer on behalf of the patient.

Navigating the “Screening Out” Effect

The “screening out” effect is the phenomenon in which the patient or caregiver only shares pieces of the full situation which directly impacts the provider’s ability to conduct a comprehensive assessment. This is often unintentional but can have a significant impact on accurate information gathering and service planning. Effective strategies to complete comprehensive observation and assessment via telehealth include:

- Ask the person targeted questions to gain a better understanding of their environment (ex: "What is your favorite room in your home?")
- Invite the person to provide a "tour" of their environment with their tablet or smart phone
- Speak to caregivers/family members to gather their observations that may be difficult to gather via telehealth
- Attend to interpersonal interactions between family members for patterns or interaction approaches that may contribute to dysregulation

Monitor for Engagement, Dysregulation, and Risk

A person may become dysregulated for many reasons, some of which may be the direct result of meeting over telehealth. Stress may begin to increase due to overstimulation, frustration with technology, or distractions. Common signs that may indicate increased stress while employing telehealth are:

- Turning off the camera: Be mindful of any sudden changes in camera usage and what that might mean for the person. For example, someone may abruptly turn their camera off if they become upset during a session or someone who typically has their camera on has not had it on recently
- Pacing or walking away from the screen
- Changes in facial expression: Grimacing, lack of eye contact, or looking off into the distance
- Changes in tone of voice, speech volume, or length/pace of response: One or two-word answers, appearing withdrawn from conversation, decreased eye contact, speaking faster/louder
- Stating that they need a break
- Be aware of both common and person-specific signs of stress. Communicate with a trusted supporter onsite to help monitor non-verbal and other signs that may be difficult to observe on telehealth.

Conclusion

Telehealth holds promise for improving access to mental health services, but only if thoughtfully designed around the needs of patients with IDD and their families. By preparing all participants, engaging with accommodations and rapport-building, and continually assessing effectiveness and stress, providers can deliver telehealth care that is accessible and responsive. When telehealth is implemented with intention, it can become a meaningful channel to stronger therapeutic relationships and better outcomes.

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Cultural Competency in Mental Healthcare

Tawara D. Goode, MA

All mental health conditions are influenced by culture.[1] Understanding and responding to the role of culture in mental health requires an expansive view, one that is not confined only to patients and their families.[2] Applying a cultural lens or framework in mental health encompasses but is not limited to:

- The training and practices of all clinicians.
- Ongoing professional consensus on the classification of psychiatric diagnoses based on clinical expertise and research over time.
- Beliefs and practices about mental illness, mental health, and emotional well-being among the racial, ethnic, cultural, and other identity groups that reside in states, territories, and tribal nations.
- The lived experience of diverse populations in states, territories, and tribal nations and the socio-cultural and economic contexts in which they live.[3]

For over a half a century, the need to be responsive to the cultures, cultural identities, and languages of persons in need of health and mental health care are well documented in the literature. The first ever Surgeon General's report on mental health issued in 1999 emphasized the importance of culture for both patients and providers.

> "The cultures that patients come from shape their mental health and affect the types of mental health services they use. Likewise, the cultures of the clinician and the service system affect diagnosis, treatment, and the organization and financing of services."[4]

Culture and language are inextricably linked. Culture is encoded in language through forms of expression, communication preferences, and the way words are used. It is through language that a person can express thoughts, feelings, preferences, and comprehend others. Cultural and linguistic competence are essential areas of knowledge and skills for all mental health care practitioners. In caring for persons who have intellectual and developmental disabilities (IDD) and their families, clinicians must seek to understand:

- The unique cultural beliefs and practices about mental illness among individuals with IDD and their families
- People with IDD and their families' conceptualizations of what causes mental illness or mental health conditions
- What constitutes well-being for individuals with IDD and their families
- What language and terms are used by individuals with IDD and their families to describe these conditions
- What interventions and treatment are culturally acceptable for treatment for individuals with IDD and their families

It also means understanding cultural differences that may exist between the diversity of people with IDD, their families, and the mental health professionals that provide treatment and care.

Cultural competence and linguistic competence are widely recognized by policy makers, researchers, health and mental healthcare practitioners, and educators as fundamental aspects of quality.[2] Cultural and linguistic competence are viewed as essential approaches to reduce health and mental health disparities and promote equity by improving access, treatment and care, utilization, and outcomes.[5, 6, 7] While the evidence supports the efficacy of these approaches, many health and mental health professionals continue to struggle to fully integrate knowledge and skills of cultural and linguistic competence in practice, including in their prescribing of medications for mental health conditions. While there is a substantial body of literature on cultural and linguistic competence in provision of mental health care, evidence-based practices specifically for persons with IDD across diverse racial, ethnic, cultural, and linguistic groups are still emerging.[8, 9] This section of the guide will define cultural competence and linguistic competence and offer examples for mental health professionals to enhance the practice of prescribing psychiatric medications for this patient population.[10]

Definitions of Cultural Competence and Linguistic Competence

Cultural competence and linguistic competence, while closely related, are defined differently in literature and by statute, regulations, and guidelines. This guide will use the nationally and internationally recognized definitions of cultural competence adapted by Georgetown University National Center for Cultural Competence (NCCC) from the seminal work of Cross et al., *Towards a Culturally Competent System of Care*,[11] and linguistic competence developed by National Center for Cultural Competence (NCCC) faculty as described in Figure 1.

Figure 1: **Cultural and Linguistic Competence Definitions**[7]

Cultural competence requires that organizations establish a defined set of values and principles and demonstrate behaviors, attitudes, policies, and structures that enable them to work effectively cross-culturally. Culturally competent organizations have the capacity to (1) value diversity, (2) conduct self-assessment, (3) manage the dynamics of difference, (4) acquire and integrate cultural knowledge, and (5) adapt to the diversity and cultural contexts of the populations and communities served. Cultural competence in a developmental process evolves over an extended time period. Both individuals and organizations are at various levels of awareness, knowledge, and skill along this continuum.

Linguistic competence is the capacity of an organization and its personnel to communicate effectively and convey information in a manner that is easily understood by diverse groups including persons of limited English proficiency, those who have low literacy skill or are not literate, individuals with disabilities, and those who are deaf or hard of hearing. Linguistic competence requires organizational and provider capacity to respond effectively to the health and mental health literacy needs of populations served. The organization must have policy, structures, procedures, and dedicated resources to support this capacity.

Currently available data do not provide the exact number of persons with IDD in the U.S. It can be deduced that persons with IDD are clearly representative within the demographic groups in Figure 2.[12–15] It is impossible to know the cultures and languages of every person with IDD and their families that present for care in any given mental care setting. It is possible to use best and promising practices that demonstrate competencies in understanding and responding to culture and language to improve diagnostic accuracy, treatment planning, and ultimately the desired outcomes of treatment. Cultural competence and linguistic competence exist at both individual and organizational levels.

Figure 2: **Cultural Competence Conceptual Framework**[16]

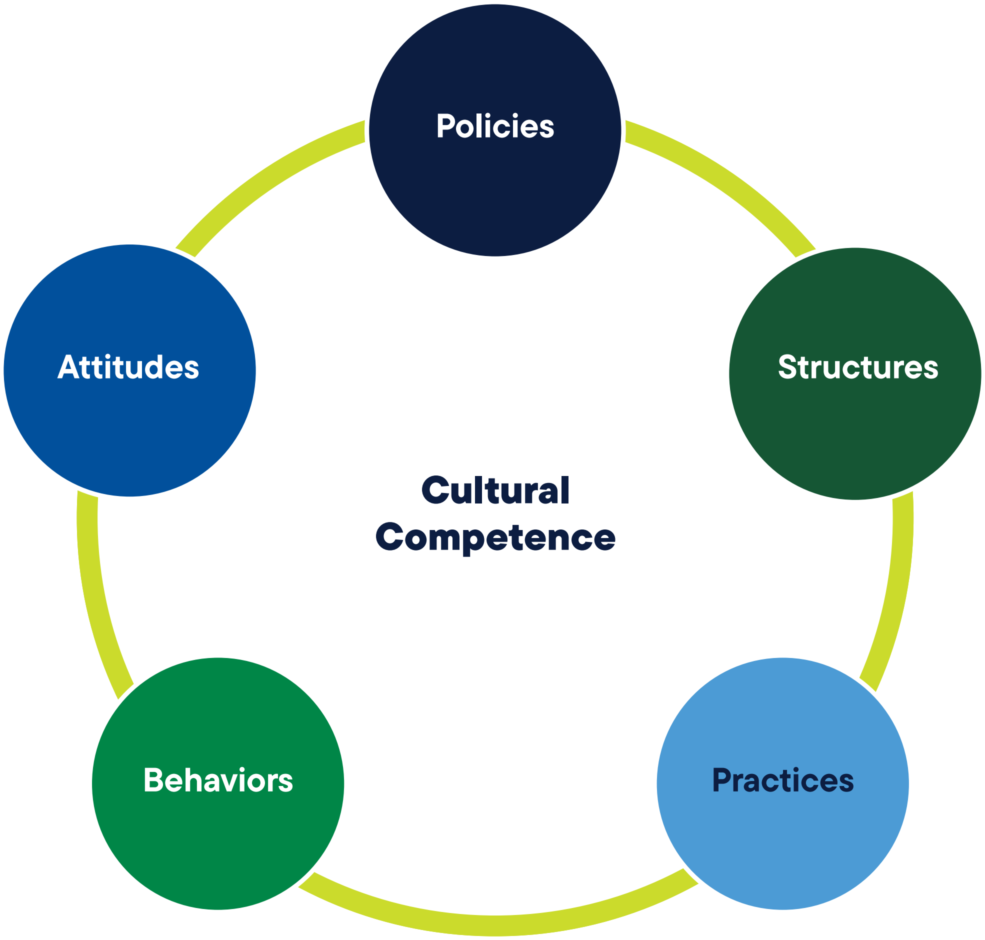
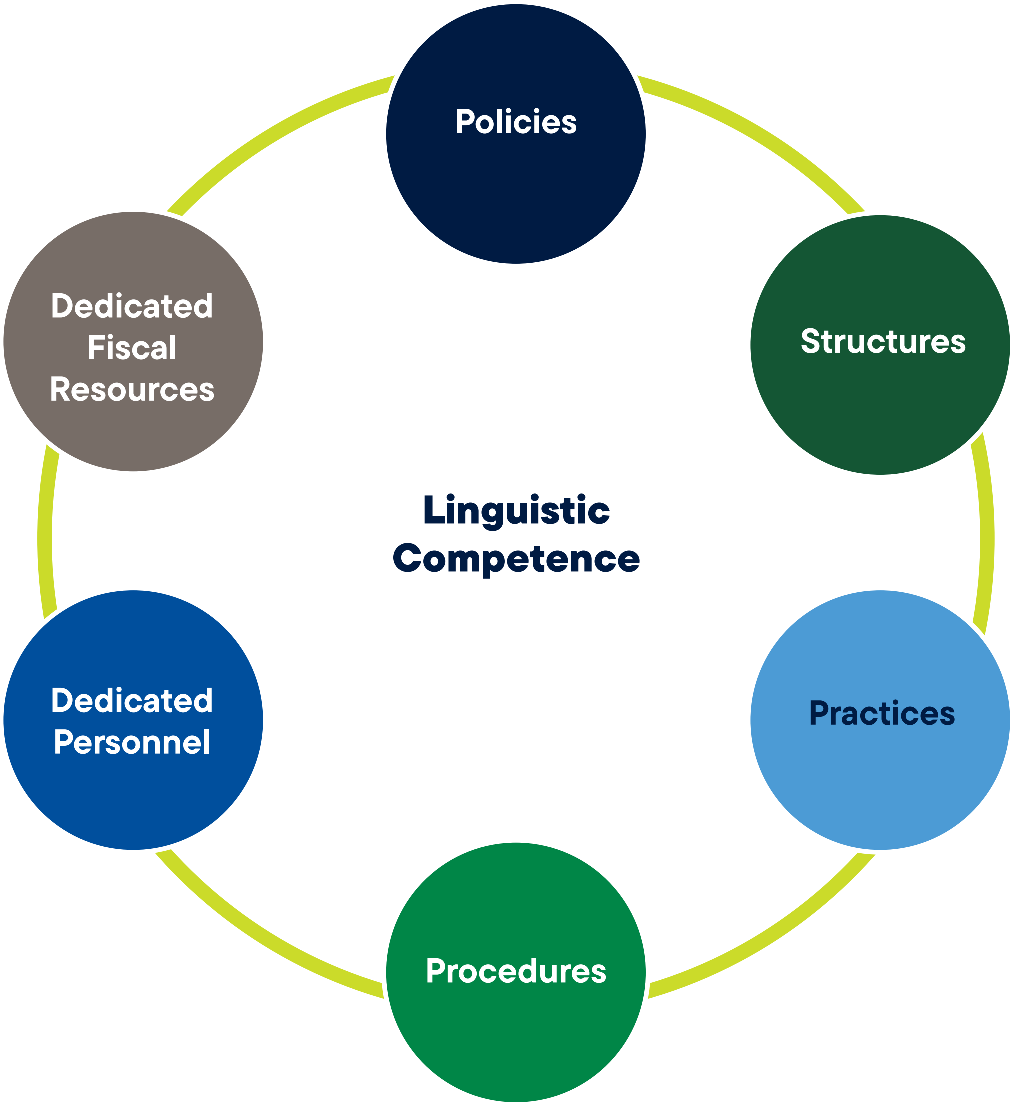


Table 1: **Five Elements of Individual Cultural Competence Adapted for IDD-MH Practitioners**[16]

Element	Description
Acknowledge Cultural Differences	• I recognize and accept differences in cultural beliefs and practices about IDD and mental health. Respect other disability belief systems or explanatory models even if they differ from my own.
Understand Your Own Culture	• I acknowledge and accept that the discipline or profession of psychiatry/mental health is not culturally neutral. • I reflect on whether and how my cultural belief system affects interactions and communication with people with IDD.
Engage in Self-assessment	• I reflect upon how my perceptions about people with IDD affect my clinical decision-making. • I ask colleagues, with whom I work closely, to complete an assessment of what they perceive as strengths and areas for growth in culturally competent care and compare them with my own assessment of diverse patients with IDD that I treat.
Acquire Cultural Knowledge and Skills	• I actively seek to enhance knowledge of cultural belief systems and practices about mental health at the intersection of IDD from the academic literature, and from the perspectives of the patients and their families that I treat.
View Behavior Within a Cultural Context	• I accept that some racial, ethnic, and other cultural groups have historical and present-day experiences of bias, stereotyping, discrimination, and disparate treatment, and as a consequence, lack trust in mental health professionals and systems.

Consistent with the definition of linguistic competence presented in this guide, in addition to translation and interpretation services, providing treatment to persons with IDD requires other accommodations. This may include and is not limited to: ASL and other sign languages; information in plain language such as oral, written, graphic, pictorial, and easy-to-read formats; augmentative and alternative communication (AAC); braille and low vision technologies; and computer-assisted technologies. Linguistic competence also requires consideration of mental health literacy, numeracy literacy, computer literacy, and financial literacy as routine aspects of your practice.

Figure 3: **Linguistic Competence Framework**[17]



Selected Excerpts from NCCC's Cultural and Linguistic Competence Checklist Series

I provide all information about the patient's mental health in a manner that is easy to understand and takes literacy and mental health literacy into consideration:

- During face-to-face verbal interactions.
- When using video or telehealth platforms.
- In the electronic health record.
- In written documents.
- I use language that acknowledges and respects the person's experience of disability.
- I routinely use bilingual or certified interpreters to ensure quality assessment and treatment.
- I adhere to language access requirements as mandated by statute, standards, and practices within the context of my role and responsibilities as a mental health care provider (See additional resources links for laws and guidelines on language assess)
- I always keep in mind when interacting with family members or caretakers who have limited English proficiency that:
- Limitations in English proficiency are in no way a reflection of their cognitive functioning.
- Limited ability to speak the language of the dominant culture has no bearing on their ability to communicate effectively in their first language.
- They may or may not be literate in their language of origin or in English.

Reflection Questions

1. Culture influences every aspect of life and defines identity as humans. In what ways does this affect people with IDD?
2. To what extent do I consider intersectionality in diagnosis and treatment?
3. How would you define cultural competence? How does this definition affect the way you provide treatment to people with IDD?
4. How will you apply the five elements of cultural competence in your mental health practice?
    - How do you consider the definition of linguistic competence, as presented in this guide, in assessment, diagnosis, and treatment?

5. How will current and projected demographic changes affect the mental health care you provide to people with IDD?

6. To what extent do you participate in ongoing education on mental health disparities affecting people with IDD and effective strategies to address them at the individual and organizational levels?

Additional Resources

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- Title VI, Section 601, Civil Rights Act of 1964 (P.L. 88-352)
- National Standards for Culturally and Linguistically Appropriate Service in Health and Health Care
- CLAS Behavioral Health Implementation Guide, Report, and Toolkit

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Culturally Competent Prescribing Resources

Roberto Blanco, MD

All psychiatric conditions are based on culturally accepted norms of behavior in a patient population. How much a symptom cluster deviates from these norms typically determines pathology. As with any other patient population, these cultural factors are present and important considerations in the care of people with Intellectual and Developmental Disabilities (IDD), and it is important to understand how patients and families view themselves and their goals within their communities. In fact, due to the increased effect of environment on symptom clusters in IDD, cultural factors may play an outweighed role. Knowledge of culture and cultural competency provides a critical role in assessing and optimizing care for individuals with IDD. Best practices include utilizing tools such as the Cultural Formulation Interview, having individuals and families explain how their experiences would be explained to others, and any concerns they have with individuals from different cultures understanding symptomatology and diagnosis. While it's impossible to understand every culture and sub-culture, a humble, caring, and curious approach to understanding family and individual beliefs about behaviors, diagnoses, and routines will likely yield improved information gathering. This also leads to improved diagnostic accuracy, treatment planning, and ultimately desired outcomes of treatment such as treatment fidelity, improvement in pathologic behaviors, and improved well-being.

The following resources are provided to the public at no cost and were curated by the editors of this guide.

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Assessment of Medical and Psychiatric Conditions in People with Intellectual and Developmental Disabilities

Medical Assessment Considerations for Patients with Intellectual and Developmental Disabilities

I. Leslie Rubin, MD and Lauren R. Charlot, PhD, LICSW

Editors' Note: Some content in this chapter is intentionally repeated from the early chapter on Health Promotion because it is critically important to the mental healthcare of people with Intellectual and Developmental Disabilities (IDD). Accurate and comprehensive assessment for people with IDD requires attention to communication, setting, and the thorough gathering of medical and behavioral history. Reiterating these elements emphasizes their central role in ensuring high-quality care and accurate diagnostic and treatment formulation.

Overview

For the mental health provider who cares for the behavioral and mental health needs of people with intellectual and developmental disabilities (IDD), the challenges are manifold.[1]

- Clinicians may not have the training or tools to engage people with IDD in reporting their symptoms and experiences. While resources are somewhat available, adaptive strategies are not typically included in clinician training.
- People with IDD may have difficulty with expressive language and have difficulty describing their symptoms using traditional communication methods, which makes it difficult to explore the important medical, emotional, social, or environmental history, which are the cornerstones of a clinical diagnosis.
- For the people who are unable to articulate symptoms of discomfort or pain, behavioral expressions of the symptoms may not necessarily reflect the actual cause of discomfort or pain. For example, some people who are on the autism spectrum may have dramatic emotional reactions that are out of proportion to symptomatology, or, even in the presence of significant pain, there may be minimal expression of the symptoms.
- People with IDD may present to the healthcare provider accompanied by a family member or a familiar supporter, or, in some instances, they may be accompanied by an escort with limited or no prior experience with the patient. If the third party is a family member or familiar supporter, then interpretations of symptomatology and the provision of a reasonable history will help to

make a diagnosis; however, if the third party is an unfamiliar escort, then the history is minimal or non-existent, making the assessment and diagnosis of the condition more challenging. It is important to note that even family members may not necessarily serve as accurate proxies on behalf of the person with IDD.

- To complicate the challenge of the assessment, the person with IDD may be fearful of the clinician and uncooperative for the physical examination, or become defensive and aggressive, making it more difficult to confirm clinical suspicions or explore physical conditions that may be causing the symptoms.

With these considerations in mind, it is critically important for the healthcare provider to be aware of the limitations in making a diagnosis based on history and behavior.[1] **It is important for the clinician who is evaluating concerns about discomfort or pain through behavioral manifestations to consider a differential diagnosis that includes medical conditions, possible mental health considerations, as well as social and environmental factors.**

There are additional elements required in obtaining a useful clinical history:[1]

- It is critical to provide as comfortable a setting as possible, in a quiet location with minimal distractions. It is also important to speak softly, move slowly, and provide a reasonable amount of time for the person with IDD to adapt to the environment and the people in it. When conducting a physical examination, it is important to say what you are going to do before you do it, to give the person time to prepare, comply, and cooperate.
- Be aware of the person's communication style and mannerisms that help in gathering important historical information, and in conducting the physical examination to provide additional information for the diagnostic assessment.
- Examine and explore the person's patterns of behavior relating to daily health and routine. This includes eating habits, sleeping habits, bowel and bladder routines, exercise routines, work routines, social routines, as well as habits such as smoking or drinking alcohol or other emotional outlets.
- Inquire about any changes that may have taken place in any of the daily routines, as well as changes in the person's weight and vital signs. It is also strongly advisable to obtain a history of living circumstances, past and present, with attention to any changes that may have taken place in the recent past.

- Review past medical history which includes all past physical health related episodes, previous diagnoses, notes from specialty health care providers, as well as histories of previous emergency room visits, hospitalizations or surgeries; history of allergies; past medications; medication responses and reactions; current medications, including the duration of the regimen, with exploration of possible drug interactions; and past history of behavioral responses to medical, social and environmental experiences.

Answers to these questions help to create a comprehensive multidimensional picture of the individual and the complex interplay between the physical, physiological, psychological, social, emotional, and environmental factors. It also helps guide an assessment of the current clinical challenge to determine whether further evaluations or referrals are necessary, and ensures a more accurate diagnosis, more appropriate treatment and therapeutic recommendations, and favorable outcomes.

Etiological Considerations[1,2]

Important to the clinical assessment of a person with IDD is the etiology of the condition. Different etiologies that include prenatal, perinatal, and postnatal causes, as well as genotype and phenotype, will explain physical characteristics, behavioral patterns, and in some cases, associated organ system disorders. An etiological framework of developmental disabilities from neuromotor, neurocognitive, and neurobehavioral perspectives can help the clinician conceptualize the underlying central nervous system disorder. Varied etiologies can determine the clinical manifestations and shape understanding, diagnosis, and management.

Figure 1: **Developmental Disabilities Causes and Consequences**

Causes

Prenatal

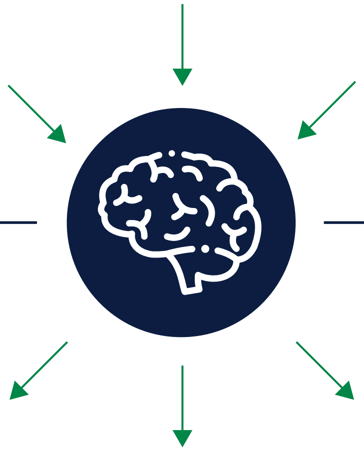
- Genetic
- Chromosomal
- Non-chromosomal syndrome
- Congenital anomalies
- Chemical insults
- Intrauterine infections
- Placental insufficiency
- Maternal illness
- Poor antenatal care

Perinatal

- Prematurity
- Low birth weight
- Hypoxic-ischemic injury
- Cerebral hemorrhage
- Jaundice
- Infections

Postnatal

- Medical illnesses
- Inadequate intervention
- Environmental toxins
- Poverty
- Adverse childhood experiences



Consequences

	Motor	**Cognitive**	**Social**
Mild	Dyscoordination	Learning disabilities	ADHD
Severe	Cerebral palsy	Intellectual disabilities	Autism

Knowledge of the etiological diagnosis is an invaluable aspect in the clinical assessment of a person with IDD. Three illustrative examples will be offered: people on the autism spectrum who tend to have less obvious physical or medical co-morbidities; people with predominantly motor disabilities such as cerebral palsy, who are likely to have more complex physical and medical co-morbidities; and people with an underlying congenital chromosomal or non-chromosomal syndromes, such as Down syndrome, which each have their own unique physical characteristics, underlying organ system disorders, and at times, patterns of behavior. It is important to note that within each of these categories there are variations and variabilities as well as commonalities. In each, the level of cognitive ability and ability to communicate vary, and there may be overlapping diagnoses. So, a person with cerebral palsy or Down syndrome may also have an autism spectrum disorder. Similarly, the underlying central nervous system disorder often plays out with similar physical and mental health concerns as are experienced by the general population but with greater likelihood and often to a greater degree. **Thus, each person with IDD should be seen as a unique individual with some likely physical and behavioral patterns that help to establish an accurate physical or mental health diagnosis.**

Autism Spectrum Disorders

People with autism spectrum disorders (ASD) have underlying difficulties with communication, interaction, and socialization, and can become easily frustrated in being unable to express themselves or make a request. This can lead to distress which may manifest in a fright, flight, or fight response with profound consequences. They are also more likely to have exaggerated reactions to sensory stimuli that may not bother anyone else. Their overreactions in these two examples may be interpreted in terms of behavioral pathology or a mental health disorder, so careful attention needs to be paid to the circumstances of any dramatic presentation.[3]

People with ASD are also more likely to have repetitive mannerisms and behaviors, tic disorders, and even Tourette's syndrome and seizure disorders. Therefore, unusual patterns of action or movement need to be analyzed for more accurate characterization and thus inform the approach to management. People with ASD also have psychiatric comorbidities such as sleep disorders, ADHD, anxiety, OCD, depression, bipolar disorder, episodic dyscontrol syndrome, and psychoses. These need to be factored into the diagnostic consideration and managed accordingly.

Because people with ASD have limited communication skills, a tendency for unusual (over or under) sensitivity to sensory stimuli and may have possible significant emotional overreactions, and their physical symptoms are more likely to manifest in behavioral reactions. This is best known and documented with gastrointestinal disorders such as gastroesophageal reflux (GERD) and constipation.[4] Because people with ASD and/or IDD may be unable to describe their symptoms accurately, discomfort or pain may be expressed with a variety of behavioral symptoms such as withdrawal (especially with constipation), or frustration manifesting in emotional or behavioral challenges.

Both medical conditions can be easily missed because the symptoms may be in the form of non-specific emotional or behavioral presentations without any clinically observable physical or medical signs or symptoms. The challenge to the clinician with these underlying medical conditions, is that it may be difficult to get a complete or comprehensive history or even perform a thorough examination to determine the diagnosis, and even so, it may be difficult to diagnose clinically because there may be no obvious findings. In these situations, it becomes imperative to develop an approach that is systematic in exploring changes in the environment and in reviewing the possible non-visible conditions that might explain physical pain or discomfort that may be present, such as headache, dental pain, or abdominal pain. It is therefore critical to explore the possible physical conditions before attributing the behaviors to a psychological or psychiatric cause.

Cerebral Palsy[5-8]

Cerebral palsy (CP) is defined as a disorder of movement and posture as a result of a fixed insult to the developing brain that occurred before, during, or soon after birth. The diagnosis of CP is based on the presence of motor characteristics with significant functional implications; however, the reality is that the central nervous system (CNS) insults are often diffused and involve other functional elements. The CDC reports that for people with CP, more than 40% have intellectual disability, 35% have epilepsy, and more than 15% have vision impairment.[1] The association between ASD and CP has been well documented.

Overall, the prevalence of associated mental health disorders in people with CP is higher than the general population, especially as people age. When evaluating a person with CP, it is important to be aware of emotional and social factors in the person's life as these may result in frustration, anger, anxiety, or depression. Furthermore, care providers who are family members may also be stressed because of the physical demands of supporting a person with physical limitations in activities of daily living as well as other related stresses that may be emotional, social, and financial difficulty.

People with CP are more likely to have complex medical problems too. There is obvious musculoskeletal involvement with limitations in movement and changes in posture, associated with changes in muscle tone, especially spasticity, which may involve muscle spasms or tremors and clonus. They are also more likely to have seizures which may be expressed in a variety of different forms and can be confused with behavior disorders. Seizure medication prescribed to manage seizures may have a variety of different side effects ranging from gastrointestinal disorders, metabolic and hematological disorders, and often changes in behavior. They can also cause things like headaches and dizziness that can manifest in behavior challenges (due to functional communication limitations). People with CP are also more likely to have other organ system disorders and ailments that do occur in the general population, but with greater frequency and intensity, most notably gastrointestinal disorders, such as GERD, and constipation.

It is critical for the health care provider to be aware of common conditions; to make specific inquiries of the patient, family members, and caregivers; and if there is an index of suspicion, refer the patient for an x-ray of the abdomen to rule out constipation, or to a gastroenterologist for further evaluation. It is quite clinically acceptable to prescribe laxatives if constipation is suspected and monitor the outcome, or to prescribe an anti-reflux mediation or antacid if GERD is suspected. These 'first aid' measures will hopefully provide some relief to the patient with a reduction in symptoms with consequent improvement in presentation and assist the clinician in making a more accurate diagnosis while waiting for consultations with a gastroenterologist, or other specialty providers.

Diagnostic Syndromes

People who have a chromosomal anomaly (genotype) or a non-chromosomal syndrome are likely to have distinctive physical characteristics (physical phenotype), characteristic organ system involvement, and often a behavioral phenotype. For reviews of a compendium of genotypes and phenotypes it is helpful to consult the latest edition of *Smith's Recognizable Patterns of Human Malformation*,[9] first published in 1969 and now in its 8th edition. This book offers a compilation of chromosomal and non-chromosomal disorders along with physical descriptions and associated organ system complications and medical comorbidities. In addition, the reader is referred to the text *Health Care for People with Intellectual and Developmental Disabilities Across the Lifespan*.[2] This text contains in-depth information on a select group of common conditions with more detail on the medical complications of each of the syndromes discussed. It also has a comprehensive review of all physical and mental health related considerations as well as addressing familial, educational, and social aspects of health and health care, and systems of health care delivery.

Down syndrome[9,10] is the most common and well-known genotype associated with IDD and has a variety of associated organ system conditions that may manifest at birth. Examples include congenital anomalies such as congenital heart lesions, and gastrointestinal anomalies such as duodenal stenosis or Hirschsprung's. Although congenital lesions are dramatic and require urgent care including surgery, other more common conditions associated with Down syndrome pose clinical challenges to primary care and mental health care providers.

In these situations, the clinician should become familiar with the range and variety of medical conditions. Visual and hearing impairments and obstructive sleep apnea are common, so it is important to be aware of these possibilities and refer them for evaluation when suspected. Like other causes of IDD, a person with Down syndrome may have GERD and constipation which need evaluation. In addition, hormonal disorders, most notably hypothyroidism, may manifest as loss of energy or lethargy. For this reason, regular screening for hypothyroidism is recommended. Musculoskeletal disorders are also more common in people with Down syndrome, including hypotonia with ligamentous laxity and tendency for dislocations and subluxations. Of particular concern is the tendency for atlanto-axial subluxation – that is cervical vertebrae C1 on C2, which may manifest in an inability to walk which may be misinterpreted as willfulness (or less strengths-based, as non-compliance). People with Down syndrome are more likely to have ADHD and ASD than the general population, so it is important that the clinician is aware of these conditions and looks beyond the Down syndrome diagnosis for assessment of challenging behaviors. Like everyone else, people with Down syndrome may have mental health conditions or have adverse life experiences that shape their presentation.[11] For the clinician, it is important to be aware that people with Down syndrome are more likely to develop Alzheimer's dementia at an earlier age than the general population.

Medication Adverse Effects

An important and serious consideration for the clinician is that people with IDD are more likely to have associated neurological and medical conditions that require medication management, and that all medications have potential side effects. These side effects may have metabolic, hematological, organ system disturbances, or CNS disturbances that manifest in neuromotor, neurobehavioral, or neuropsychiatric concerns particularly if taken long term. Therefore, medication should be thoroughly reviewed on a regular basis and, when assessing a person for changes in behavior, it is important to determine the onset of the symptoms in relation to changes in medication administration. It is critically important to be sure that the person is indeed taking their medication as prescribed, that is, knowing that it is given and that it is swallowed. One further consideration about medication is that there may be a difference in effect between the brand medication and different generic forms which should be discussed with the pharmacy if suspected.

Conclusion

For any clinician who provides physical or mental health services for people with IDD, be it a primary care provider or specialty provider, it is important to be aware of the physical health conditions that may manifest as mental health or behavior disorders. This chapter provides an overview for the reader to become familiar with the common conditions that are often missed because people with IDD may not be able to describe their symptoms accurately or clinicians do not know how to elicit important and relevant clinical information. There are many conditions that are not obvious on physical examination that should be considered, most commonly, the gastrointestinal disorders of GERD and constipation.

The important message for the clinician is to:

- Take as good a history as possible from the patient, as well as from family members, and other care providers because the more perspectives, the easier it is to make a diagnosis.
- Get assistance with the clinical interview by someone who knows how to elicit accurate responses from the patient.
- Ask informants to describe as accurately as possible what they saw and heard, rather than offer opinions, hypotheses or even diagnoses. It is also helpful to enquire about a timeline that begins from baseline wellness to changes in presentation (medication changes, altered eating, drinking, sleeping, weight, etc.) to understand potential contributing factors might be helpful.
- Review the medical and psychiatric history as well as the environmental and social history
- Be aware of the medical conditions that may present with behavior changes or challenges.
- Conduct a broader based examination than would be usual for patients looking specifically for common causes of irritability and aggression.
- Obtain laboratory tests where appropriate and consult with specialty providers if necessary.
- Be aware that other practitioners may also have minimal historical information that can result in misdiagnosis.

- There are common psychotropic side effects that can often be missed. People with IDD have atypical nervous system functions, responses, and reactions, as well as other organic system anomalies and are at an elevated risk for a variety of health problems, but also for adverse drug events.

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General Considerations for Medical Problems

I. Leslie Rubin, MD, Robert Baldor, MD, & Lauren R. Charlot, PhD, LICSW

Important Issues	Why This Is Critical	What to Consider
Before psychotropics are started, there is a need for a comprehensive medical assessment.	Patients with IDD may not report medical symptoms comprehensively. Even well-meaning family members and supporters might underestimate or miss medical causes of challenging behaviors.	Conduct a broader based examination than might be usual for patients without IDD. This means testing for common causes of irritability and aggression. Unexplained outbursts may be due to missed or under treated medical conditions.
It is the prescriber's responsibility to elicit information directly from the patient rather than relying solely on informants.	While informant reports can be valuable, especially when a patient cannot articulate their symptoms or history, they should not replace their voice. Research has demonstrated that informant reports often disagree with the patients' own reports of what is troubling when the patient cannot explain themselves accurately.	Informants tend to focus on observable, externalizing behaviors and may underreport changes in internal states or subjective complaints, sometimes concluding that the patient has no complaints simply because symptoms are not clearly voiced.
Insist on medical records and make sure caregivers know that it is the only way you can provide safe, effective care.	Absent accurate patient self-report, this is another tool to clarify common errors informants may make describing the patient's medical concerns.	Be aware that other practitioners also often receive minimal historical information at times, so people with IDD may be misdiagnosed while physical discomfort is missed and is the actual cause of altered mood and behavior.
People with IDD experience challenges in processing verbal communication and benefit from receiving information in multiple ways.	Be careful not to overestimate the patient's expressive and receptive communication abilities.	Even if supporters do not think that the etiology of challenging behavior is related to medical issues, a more thorough exam is needed. This might reveal a medically modifiable source of emotional and behavioral challenges.
People with IDD are commonly referred for a mental health evaluation secondary to externalizing behaviors (yelling, hitting, self-injury, running, wanting to go to the hospital). **Problems like feeling miserable, anxious, and unwell are missed, even by caring people.**	This means it is critical to interview the patient and informants in a way that will ensure the physician obtains accurate data.	Ask informants to describe what they saw and heard, rather than providing their own hypotheses. For example, motor restlessness might be termed "mania" when it may be caused by a wide array of underlying problems. Teach informants that externalizing behaviors and negative moods are the final common pathways for distress in people who have few ways to demonstrate this.

General Considerations for Medical Problems, continued

Important Issues	Why This Is Critical	What to Consider
Supporters may view externalizing behaviors (e.g., irritability) as willful attempts to gain attention, or a means of "escaping" unwanted demands.	It is critical to establish why a person shows an increase in trying to get caregiver's attention. It may be due to feeling unwell (dizzy, excessively tired, etc.)	People may try to escape tasks/events when they are ill but lack cognitive means to explain why. This is not an act of "noncompliance," rather than one of not feeling well.
Clarifying when, where, and under what conditions challenging behavior, dysphoric mood, sleep disruptions, and alterations in food and fluid intake occur help inform more effective care.	The physician needs tactics to ensure underlying medical irritants are found and not improperly addressed as behavioral or psychiatric in nature. By the time medical irritants are identified, patients can develop a myriad of complications, often from ineffective psychotropics.	Along with asking for clear, observational descriptions, the prescriber might request a timeline that begins from baseline wellness to changes in presentation (medication changes, altered eating, drinking, sleeping, weight, etc.) to understand potential contributing factors.
Many people with IDD who have mental health needs are treated with psychotropics, and many with polypharmacy. Recent studies show an extreme increase in reliance on psychotropics to manage mood and behavior that should be treated in other, lower risk ways.	A combination of psychotropic use may be effective if the person responds well to these interventions (decrease distress, improve activity level and mood, and treats a specific syndrome such as depression, anxiety). However, many times psychotropics are added and retained when not helping without the patient being part.	There are common psychotropic side effects that can often be missed. These are outlined in the ADE table. **People with IDD have atypical nervous systems and other anomalies and have been found to be at an elevated risk for health problems but also for adverse drug events.** At times, patients with IDD have psychotropics increased or added due to negative mood or behavior caused by the drug that is being added or increased.

Genetic Testing for People with Intellectual and Developmental Disabilities

Matthew Rucker; Braden Friedman; Takahiro Soda, MD

Overview

Genetic testing is becoming an important part of the standard of care for people with IDD. It offers significant benefits not only to patients, but also to caregivers and families. Integrating genetic information into clinical practice promotes patient self-advocacy and enhances healthcare equity for individuals with developmental disabilities. Table 1 shows the Genetic Testing Guidelines from Key Organizations.

Table 1: **Guideline Summary from Key Organizations**[1]

Organization	Recommendation
American Academy of Child and Adolescent Psychiatry (2020)	Chromosomal microarray (CMA) and Fragile X (FMR1) testing; consider exome sequencing (ES) if etiology remains unclear
American Academy of Pediatrics (2014, 2020)	CMA and FMR1 repeat analysis; refer for ES if necessary
American College of Medical Genetics	Recommend ES or genome sequencing (GS) as a first- or second-tier test for individuals with ASD or developmental delay

Benefits of Genetic Testing

- **Medical Explanation:**[2] Genetic testing provides a clear, actionable medical explanation, replacing vague or non-specific causes.
- **Decreased Stigma:**[2] Identifying genetic causes of IDD or ASD can help reduce stigma by reframing the diagnosis as biological rather than purely psychiatric.
- **Targeted Management:**[1] A confirmed genetic diagnosis guides clinicians and caregivers in anticipating comorbid conditions and planning appropriate care.
- **Ends the Diagnostic Odyssey:**[1] A conclusive genetic diagnosis can bring clarity after years of inconclusive or fragmented evaluations.
- **Informs Reproductive Decision-Making:**[1] Know whether variants are inherited or de novo can help families assess future pregnancy risks.

Considerations for Testing

Prescribers should know that insurance coverage for genetic testing varies between Medicaid, Medicare, and commercial insurance plans.[3,4] Insurance coverage also varies across states, particularly for Medicaid.[4] Prior to ordering the genetic testing, it is important to confirm if the recommended genetic test is covered by the patient's insurance plan and provide appropriate documentation for the testing, such as the developmental history, physical exam findings, and recommended tests.

Prescribers should obtain informed consent, discuss the potential benefits, limitations, and ethical implications of genetic testing.[5] Patients and families should be informed regarding the need for prior authorization or out-of-pocket costs. Involving a genetic counselor or geneticist, if accessible, can help guide the process, test selection, and interpretation.[5]

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Psychiatric Assessment Considerations

L. Jarrett Barnhill, MD, DFAPA, FAACAP; Lauren R. Charlot, PhD, LICSW; Dan Baker, PhD; Joan B. Beasley, PhD

Overview

Studies suggest that 30-40% of people with intellectual and developmental disabilities (IDD) experience mental health disorders.[1] The true prevalence may be an underestimate due to under-diagnosis and misdiagnosis of underlying medical/neurological disorders as mental health conditions.[2]

There are several key factors that need to be considered in the psychiatric assessment process:[3-6]

- Level of intellectual disability
    - Provides some framework to understand the patient's needs
- Overreliance on IQ score and level of ID may undermine diagnosis and treatment as they may not accurately portray the patient's capacity to communicate or benefit from treatment
- How a person communicates
- Ecological and psychosocial vulnerabilities
- Diagnostic overshadowing (e.g., pain and discomfort may present as externalizing, disruptive behaviors that can be misattributed to a psychiatric condition)

Assessment teams should adopt adaptive and holistic approaches that include:[4-5, 7]

- Direct communication with the patient: Consider their communication style and preferences (including differences between receptive and expressive language)
- Use of assessment tools designed for people with IDD whenever possible
- A detailed biopsychosocial history
- A mental status examination
- Systematic evaluation of medical, psychological, and genetic issues
- Observational data from the patient, family, and care providers

- A holistic-transactional mindset to look beyond simply treating an illness: Behavioral and psychiatric disorders represent evolving conditions that are profoundly influenced by ongoing transactions between biology and the environmental/social context.
- Recognition of resilience and positive psychological forces to promote wellness and maximize adaptive skills.[8,9]

Initial Psychiatric Assessment

Given the challenges inherent in assessing psychiatric symptoms in people with intellectual and developmental disabilities (IDD), including communication barriers, limited insight, or fluctuating presentation, clinicians benefit from structured tools to guide both diagnosis and monitoring. The following instruments have been validated or adapted for use with people with IDD and can supplement, though not replace, direct patient interviewing.[1,10]

Table 1: **Mental Health Assessment Tools for People with IDD**

Assessment Tool	Description
DMID2[1]	Companion guide to the DSM developed for the diagnosis of mental disorders in people with IDD.
Symptom Monitoring Checklists	Monitor vegetative signs and symptoms when unable to rely on the accuracy of the self-reporter or informant.
The Glasgow Mental Health Screeners[11]	Self-report measures of mental health symptoms (e.g., anxiety, depression, psychosis) for people with IDD.
Anxiety Depression and Mood Scale (ADAMS)[12]	A 28-item questionnaire that screens for psychiatric disorders in people with intellectual disabilities. Items are scored based on how they interfere with daily life.
Moss Psychiatric Assessment Schedules (ID)[13]	Used to collect symptom information directly from an informant via a semi-structured interview procedure or can be completed based on knowledge already possessed about the person.

Components of Comprehensive Psychiatric Assessment for Patients with IDD

Several developmental, biological, and psychosocial factors might influence altered mental status. These should be considered as part of regular assessment for patients with IDD.

Table 2: **Components of Comprehensive Psychiatric Assessments for Patients with IDD**[1,10]

Component	Description
Medical Concerns	As many as 40% of people with IDD referred for an inpatient psychiatric stay have a missed or under-treated medical problem that was the actual reason for challenging behaviors that led to the admission.
Syndromes Associated with IDD	Several syndromes, primarily genetically mediated, may cause the occurrence of an IDD and contribute to patterns of executive function deficits, increased risk for certain medical comorbidity, and even elevated risk for psychiatric symptoms and syndromes.
Psychosocial and Systemic Vulnerabilities	Vulnerabilities include challenges related to cognitive factors and information processing including executive functions, communication (especially functional and social-emotional communication), sensory sensitivities, restricted and repetitive behaviors, trauma histories, residential and programmatic services. As suggested, such vulnerabilities may provoke problems or impact the shape they take. Intersectionality in the form of culture and disability is a significant consideration as well.
Cognition/ Level of Intellectual Disability	It can be helpful to know a person's ID designation and their patterns of skill areas, however, there is extreme variability within these characterizations in how people process information, communicate, remember things, problem solve, and plan. These differences impact *what* is experienced as stressful, the *degree of stress* experienced, and *how a person responds.* Coping skills are important to know as well.
Executive Function (EF)	The term executive function is used to describe a set of cognitive functions that control and regulate other abilities and behavior. This includes planning, organizing, focusing, paying attention, and problem solving. Patients with lived experience in IDD tend to benefit from support with initiating activities, communicating, coping, paying attention, finishing tasks, tolerating frustration, and regulating emotions, which impacts the ways the person navigates everyday life.
Communication	People with IDD present with a very wide range of abilities and challenges about communication, both expressive and receptive. It is critical to help caregivers understand that *speaking* is different from *problem solving and planning.* Many people with IDD learn "scripts" but may not have insight into the meaning.

Table 2: **Components of Comprehensive Psychiatric Assessments for Patients with IDD, continued[1,10]**

Component	Description
Sensory Sensitivities	Sensory sensitivities may occur in conjunction with a tendency to be *easily over aroused or under aroused*. Sensitivities to sounds are most common, but also to space (being too close), light touch, clothing tags on the skin, and to overly visually busy environments are other examples.[14,15]
Repetitive Behaviors	Perseveration and repetitive tendencies are common concerns for many with IDD. In some cases, especially ASD, there is a deep need for things to remain the same, and increased stress when they change. Repetition can be a way to cope, manage arousal, understand something better, to resist change, which is upsetting, and at times just for enjoyment (having a self-stimulatory aspect). If a repetitive behavior is aimed at stress or anxiety reduction, a replacement must be provided if it is to be eliminated.

Thinking Beyond Pharmacologic Interventions[16-18]

Psychopharmacological assessments are frequently reductionistic and limit consideration of the psychosocial and ecological forces that influence the emergence and course of psychiatric disorders. All too often, the efficacy of medication is overestimated; psychotropics are not solutions. While medications may be a piece to the wellness puzzle, it is not the only one. Medications do not take the place of primary care, educators, therapists, friends, or family members but are an intervention designed to alter the underlying biology of behavior.

Conclusion

Assessment is the most important part of any treatment program. It needs to provide a comprehensive picture of a person's symptoms in a biopsychosocial context and work towards holistic solutions to adverse life experiences. Assessment should consider culture issues and the person's experience with receiving support. The goals of assessment are to identify and develop strategies and interventions to help the person make gains in their life.

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Developmental Considerations that Impact Psychiatric Assessment

Lauren R. Charlot, PhD, LICSW

Executive Functions or Cognitive Skill Areas	What Does This Mean?	How Problems Develop That Look Psychiatric or Behavioral (Case Examples)
Theory of Mind: Understanding Competing Perspectives	• Some people with IDD (especially ASD) have challenges in social understanding and awareness, even when other cognitive capacities are less challenged • May struggle to notice language pragmatics and say things that appear socially odd (e.g., talk aloud to self, quote movies, talk at length about a topic that the other person is clearly not interested in, ask very personal questions) • May not realize they did something offensive • Differs from typical antisocial behavior and is based on neurodevelopmental challenges	*Mark, a 20-year-old with ASD, told the teacher what the kids did when she was out of the room. The kids got angry with Mark and he doesn't understand why* *Mark gets picked on and lashes out* *School counselor thinks he is antisocial or conduct disordered* *Mark is seen as uncaring because he is aggressive when upset. Afterwards, he asks people to play cards with him, which frustrates people. Mark has panic attacks in response to loud noises. He expresses care for his housemates and support staff. His actions are not mean, plotted, or planned.*
Challenges to Mental Flexibility	• Has a hard time switching from one way of doing things to another, despite simple, clear instructions • Does not easily incorporate new information so does not change the way something is done • The person may panic when unexpected changes occur in daily routines	*David screamed and hit staff when told he cannot go to lunch using the same hallway as normal due to some building painting* *Described as "non-compliant"* *David's frontal lobe executive function is compromised, and switching to a new rule/path is difficult*
Understanding Time Concepts, Waiting	• Very limited sense of the passage of time and needs things to be anchored to concrete events • May not understand how long, "in an hour" or "next week" or in a "few days" is • Schedules may need to be laid out (e.g., "After you wake up, we will have breakfast." When breakfast is finished, we will…" • Avoid planning events with a person too soon, as this can provoke anxiety	*Cindy loves the park and gets excited when she hears her group going there. She had an outburst because she wanted to go to the park immediately and didn't realize that they weren't going for another 2 hours.* *Cindy didn't realize what 2 hours meant or felt like.* *She was described as "throwing a tantrum because she didn't get her way"* *Her "outburst" was like what happened last month at her ISP meeting when they discussed her 5-year plan to move. She became very upset because she thought she was moving soon and wasn't ready.*

Developmental Considerations that Impact Psychiatric Assessment, continued

Executive Functions or Cognitive Skill Areas	What Does This Mean?	How Problems Develop That Look Psychiatric or Behavioral (Case Examples)
Differences Between Speaking and Understanding	• A person may learn a variety of "scripts" or things to say in various situations, without understanding the full meaning or implications • Sometimes people may not admit that they don't understand because they are embarrassed. This leads to agreeing to things without really knowing what it means • May be viewed as purposefully doing ill-intentioned things when independent problem solving is a major challenge • Ability to use past experiences to inform current choices (generalization) is impaired • Create a structure of reminders and rehearsals, to support positive responding	*People say that Damien has a great memory and can recall anything because he can describe all the stores at the mall that sell tech items, gaming software, and other things he likes in detail.* *Damien had a major event with a housemate this week because he was teased. He promised his staff that he would walk away and ask for help if it happened again.* *A couple days later it happened again, and Damien ended up striking the teasing housemate. People thought he was ignoring their guidance and direction.*
Thinking in Pictures	• Many with IDD, especially ASD, learn new things best using a combination of words and pictures. • May speak in complete sentences and complete many tasks independently, but may have difficulty understanding verbal instructions, especially multiple step instructions. • Using pictures (real pictures are best), create communication tools and schedules, especially for changes in routines or multi-step processes.	*Deneesha speaks in complete sentences and completes all her daily self-care independently. She was told about a new assessment and seemed anxious. When she saw pictures of the evaluation showing what would happen, she relaxed.*
Functional Communication (FC)	• Many with IDD do not use speech functionally to reliably describe what they need or want • May repeat many words, sentences, or "script," but not ask for water when thirsty • Some speech may be "cue dependent" • May communicate better in pictures or with multiple forms (signing, showing a picture, and speaking)	*Data collection to determine the function of communication can be very helpful.*

Challenges in Assessing Persons with Intellectual and Developmental Disabilities[1]

Joan B. Beasley, PhD, and Dan Baker, PhD

Presentation	Explanation	Example	How to Address
Diagnostic Overshadowing	Professionals wrongly assume that symptoms are attributed to one diagnosis and do not take other factors into consideration	Sometimes clinicians explain away sudden self-injury, saying "Don't all people with autism slap themselves?"	Not all people with ASD express themselves through SIB. Consider the last time the patient was doing "well," what did they look like? Regardless of frequency of self-injury, SIB is a sign of distress and must be examined as a symptom; bio medical issues ruled out.
Baseline Exaggeration	Challenging behavior that exists at a low rate and low intensity may increase dramatically when one experiences stress or a mental health condition	Inability to sit still	A person with ASD may express a variety of issues through the same challenging behavior. If attributed to their ASD, these will be missed. An increase in intensity and duration is a sign of medical or mental health acuity. Pain and discomfort are often present. Consider dental and primary medical conditions. Symptoms of mania, depression, and anxiety can all be expressed through baseline exaggeration.
Intellectual Distortion	Difficulty for a person to determine if what they are experiencing is reality	When asked the question, "Do you hear voices?" a person might answer yes.	Interview the patient using plain language. Ask the patient to elaborate in their own words, explore beyond yes, or no answers.
Psychosocial Masking	Misunderstanding of developmental delay	A delusion of being the chief of police may be mistaken for a harmless fantasy An imaginary friend may be mistaken for a delusion	A more detailed account of the delusional presentation is required, including its disruption in vegetative function. Consider trauma and triggers/instigators.
Cognitive Disintegration	Response to stress that is part of the human condition but can be more pronounced for people with IDD. People may dramatically decompensate under stress	A person who recently lost a family member is bereaved. They used to do their own laundry and make small meals, but their ability to navigate the completion of daily living activities is compromised.	This can also include "tantrums," where the person's executive functioning/coping is severely compromised. Like many issues, understanding the context and pattern of medical issues, negative events, and loss of skills is key. Knowing baseline skills and what transpired after (when the person is doing well) is key.

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Best Practices in Mental Health Diagnosis and Treatment

Trauma and Stressor Related Disorders

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> "We need to presume the clients we serve have a history of traumatic stress and exercise 'universal precautions' by creating systems of care that are trauma informed."[1]

Overview

Trauma is a common reality in the lives of people with intellectual and developmental disabilities (IDD) and autism spectrum disorders (ASD). There are several typologies of trauma that people with IDD might experience, and the list below represents the most commonly reported of those experiences (people may have one or more of these during their lifetime).

Most Commonly Reported Traumatic Experiences[2]

- Physical, emotional and sexual abuse, or exploitation
- Neglect or abandonment (food insufficiency, unmet basic needs, or homelessness)
- Death of a parent
- Divorce
- Family life that includes substance use, parental incarceration, or domestic violence
- Loss of placement/frequent moves
- Rape
- Serious chronic or acute illness/disease
- Exposure to war, combat, or civil unrest

- Catastrophic loss due to natural disasters
- Witnessing horrific events involving violence or death/serious injury (ex: car accident)
- Bullying or social exclusion
- Medical procedures

Presentation of Trauma Related Disorders in Persons with IDD

Several variables influence the clinical presentation of trauma and stressor related disorders: gender, age of the person at the time of the traumatic experience, type of triggering event, frequency and persistence of trauma, and/or the source of trauma (family member, stranger, natural phenomena). Each vulnerability factor represents psychosocial sources that interact with neurobiological vulnerabilities such as genetic risk factors, temperament, intensity of physiological response, and co-occurring neurodevelopmental and/or psychiatric disorders. For people with IDD, additional considerations include factors that contribute to resilience including the degree of cognitive impairment, problem solving abilities, communication skills, and adaptive skills, along with social supports.

Social trauma frequently goes unnoticed and under-reported by informants involved in the lives of people with IDD. Left unaddressed, chronic stressors such as bullying, isolation, and exclusion can serve as risk factors and/or create more vulnerability. Repeated exposure to stressors can be traumatic and result in the development of trauma symptoms. Core symptoms of ASD and other IDDs may predispose people to stressful experiences, as many present with overarousal. Other common features of note in this regard include tendencies to miss social cues, executive function challenges, and significant sensory sensitivities. Neurodevelopmental cognitive and social-emotional features can significantly increase a person's susceptibility to stress, often triggering intense and sometimes overwhelming reactions. This heightened reactivity may contribute to misdiagnoses and, consequently, the prescription of less effective or inappropriate treatments.[3-5]

The prevalence of trauma and stress-related disorders therefore may be largely underestimated and should be considered in diagnosis and treatment planning. The DSM-5[1] and DM-ID-2[2] provide a diagnostic framework for Trauma and Stressor-Related Disorders.

Trauma and Stressor Related Disorders (DSM-5 TR)[6]

- Posttraumatic stress disorder for children 6 and under
- Acute stress disorders
- Adjustment disorders
- Reactive attachment disorder
- Disinhibited social engagement disorder
- Posttaumatic stress disorder

Posttraumatic Stress Disorder[6-7]

Posttraumatic stress disorder (PTSD) is the most well-known and commonly diagnosed trauma and stressor related disorder. Diagnosis of PTSD requires exposure to actual or threatened death or serious harm (direct, witnessing, or learning of violent event for close family member/friend). It has been suggested that people with neurodevelopmental disorders such as ASD may require a broader definition of trauma for diagnosing PTSD. This would be one that is based on the person's perception of the traumatic event.[4] Symptoms associated with PTSD are included in the table on the next page.

Table 1: PTSD Symptom Presentation in Persons with IDD[7-9]

PTSD Symptom Category	Examples	Presentation in Persons with IDD
Intrusive Symptoms	• Intrusive memories, images, or perceptions • Recurring nightmares • Intrusive daydreams or flashbacks • Exaggerated emotional and physical reactions • Dissociative experiences (feeling disconnected from one's body and environment)	Re-experiencing the event may manifest in symptoms that are more overtly behavioral (concrete) and may include self-injury and trauma-specific re-enactments. Re-enactments can look bizarre, and it is important to distinguish such symptoms from psychotic disorder symptoms.
Avoidance	• Avoidance of memories, thoughts, feelings • Avoidance of external reminders –people, places, activities, objects	Can sometimes be seen or described as non-compliance or escape based challenging behavior Of note: punishment tactics in behavior plans are ineffective with PTSD symptoms and may worsen them
Alterations in Cognition and Mood	• Inability to remember event • Negative beliefs about oneself or others - "I am bad," "no one can be trusted" • Negative emotions – fear, anger, guilt, shame • Difficulty experiencing positive emotions • Reduced interest in activities • Feelings of detachment from others	Negative emotional states may present in externalizing behaviors People may lack understanding of competing perspectives or theory of mind, and struggle to explain internal feeling states
Alterations in Arousal and Reactivity	• Exaggerated startle response • Irritability and angry outbursts • Recklessness • Hypervigilance: Being on guard much of the time • Insomnia and other sleep disturbances • Difficulty concentrating	Aggressive behavior is often described as "coming out of nowhere" Being easily over aroused and anxious can provoke "fight or flight" responses to what may seem small provocations, often one's caregivers miss

Each of these neurodevelopmental and emotional/behavioral responses relate to the acuity and severity of traumatizing events, level of activation of the stress response (fight, flight, or freeze), and duration of symptoms. The differences between them should remind us of the heterogeneity of trauma responses because of the unique perspectives of each person. For people diagnosed with PTSD, several factors relate to chronicity and the evolution of new behavioral and psychiatric comorbidities. A clue to the presence of transformed PTSD is the presence of treatment of refractory mood, psychotic, behavioral, and substance use disorders in the context of comorbid PTSD or history of past trauma. These people may experience multiple medication trials and failures but make significant gains with trauma-informed therapeutic interventions. Medications not usually found to be effective in treating PTSD may worsen the clinical picture. Consideration of each person's strengths for learning replacement stress responses that are safe and effective is required. Educating caregivers regarding the need to build a sense of safety and trust and work on anxiety reduction is key to effective care.

To accurately assess PTSD for people with IDD/ASD, differing presentations to common symptoms should be considered, as described in Table 1. There are also some additional adaptations to consider that are provided below.

Adaptations for Diagnostic Criteria for PTSD[7]

- Investigate history for possible traumatic exposure. Caregivers may or may not be aware of exposure to trauma.
- It is essential to ask the person how they felt about the events.
- Bear in mind that adults with IDD may express trauma in overt, behavioral ways rather than via verbal expression.
- When caregivers report "non-compliance" as a problem, consider the presence of avoidance.
- Hyperarousal may present as irritability and/or aggression and can be misdiagnosed as mania.
- Fight or flight trauma driven behavioral responses to stress and adverse conditions may be viewed as representing learned negative behavior or evidence of psychosis.
- The most common psychiatric comorbidities are found among people with a history of adverse life experiences and trauma are anxiety and depression.[10]

Trauma Informed Care and Psychotherapeutic Interventions

It can be difficult to accurately diagnose PTSD in people with IDD, and there are limited studies regarding appropriate treatment. Characteristics of therapies for treating PTSD include increased caregiver support, psychoeducation, and training along with a need for multiple therapists and trainers to address individual needs. Most available evidence points to treatment using Trauma Focused-Cognitive Behavioral Therapy (TF-CBT) and Eye Movement Desensitization and Reprocessing (EMDR).[11-13]

One therapeutic approach postulated as effective for all people with IDD is a ***trauma-informed care approach.***[14-16] This is a recommended way to address trauma without addressing it directly. In some cases, approaching trauma directly could lead to worsening symptomatology due to inability for abstract processing of traumatic events, leading to unnecessary and inadvertent re-traumatization. Other times when trauma therapy focused on processing events is contraindicated are when acute psychiatric instability, severe suicidality, or self-injury are present.

Trauma Informed Care[16]

> Trauma Informed Care empowers patients with a sense of control over their lives, promotes healing, and wellness.

Core Concepts

- Awareness of the prevalence of trauma in the IDD community
- Prioritize physical and emotional safety
- Build the person's trust in caregivers
- Choice and empowerment, utilizing strengths
- Preventing re-traumatization
- Transdisciplinary

Key Components

- Emphasis on the environment, educating caregivers on trauma effects and how to support patients in a positive way
- Educate caregivers on removing triggers and learning appropriate interventions to deal with challenges
- Structured activities revolving around strengths, preferences, and choices
- Removal of potential environmental triggers in the patient’s immediate environment
- Empathetically addressing challenges as they arise

Psychopharmacological Interventions

Medications may serve as useful adjuncts to psychotherapeutic treatment modalities. One drawback to pharmacological management of PTSD is the complex pathophysiology of its core symptoms. For example, trauma can alter sleep (nightmares, night terrors), and affect emotional regulation, fear conditioning, and generalization (sensitization and neuroplasticity) among other things. Trauma affects brain neurocircuitry and functional neuroanatomy by essentially kidnapping the entrainment of stress response networks. Dysregulation can occur when there is an upset to the balance between sympathetic and parasympathetic nervous systems and the hypothalamic-pituitary-adrenal (HPA) axis. Changes in selectivity and reactivity of the HPA axis contribute to the dysregulation of cortisol responses to stress. These alterations interfere with a person’s ability to respond to stressful situations in adaptive ways, regulate, and discriminate safe conditions from those that activate “fight or flight” responses.

Antidepressants have been the most studied medications in the pharmacologic treatment of PTSD, and more specifically, selective serotonin reuptake inhibitors (SSRIs) are the treatment of choice. There are other psychopharmacological interventions recommended based on the display of symptoms as described in the table on the next page.

Table 2: **Psychopharmacological Treatment Approaches for PTSD in Patients with IDD**[18,7]

PTSD Symptoms	Drug Class	Most Commonly Used and Recommended Medications
- Intrusive thoughts - Avoidance - Irritability - Mood lability - Hypervigilance - Reactivity	Selective serotonin reuptake inhibitors (SSRIs)	- Sertraline - Paroxetine - Fluoxetine
	Serotonin-norepinephrine reuptake inhibitors (SNRIs)	- Venlafaxine
- Sleep disruption - Nightmares	- Adrenergic agents - Non-stimulant ADHD medications	- Prazosin - Clonidine - Guanfacine

Considerations When Selecting Psychiatric Medications

Careful attention must be paid to family history of response to medication and comorbid conditions. For people with bipolar disorder, antidepressants can cause a switch from depression to mania and worsen outcomes. In this case, antidepressant medications may be contraindicated, and a mood stabilizer may be indicated instead. Also, a robust response from a close family member may indicate a potential response for the person. Other considerations in patients with IDD include higher levels of general medical conditions and side effects from medications. **Because of this, any medication administration must be paired with a thorough medical evaluation and frequent monitoring for potential adverse medication effects.**

Vignette

John, a 20-year-old student at a local high school, is diagnosed with moderate ID, ASD, and generalized anxiety disorder. When he arrived at school one day, John was told that Linda, the teacher's assistant he works with in class, was not coming back to school for a month because she was having surgery. Linda had been the teacher's assistant in John's high school class for two years and was someone he could go to when feeling anxious. Upon hearing about this, John spiraled into a state of panic. No matter how many times he was told she would go to the hospital, come home and rest, and then return to school, he could not regain calm. He ended up turning over desks and running out of the school. He was so upset that his family was contacted to pick him up. This was portrayed as something John did because he was angry at Linda or to get out of his work.

What school personnel didn't know is that John is fearful of losing people he cares about. When he was 4 years old, his mother unexpectedly became ill and died. The illness was sudden, and records regarding what occurred are not available. However, what is known is that she went to the hospital one morning and did not return. John was very worried about Linda and her health but was unable to articulate how he was feeling and then panicked at the thought that Linda would never return. This traumatic response was seen as anger when really John was scared. When Linda returned after recovering from her surgery, the IEP planning team decided that she should not return to the same classroom because John was too "attached," and might have more "behavioral issues." Therefore, John became further isolated. His need for emotional support was misinterpreted and his trauma unaddressed.

Discussion: If a historical and comprehensive review of John's history was known to the school, they would have learned about his past experiences and loss. In addition to the abrupt loss of his mother, his 3 older siblings have left home, and he and his father live in the house alone. This historical information would trigger a referral to psychotherapy and the provision of trauma informed care interventions within the school.

According to Rumball[18], an outline for treatment interventions and modifications for John would look like the following:

- Trauma informed care interventions applied in the classroom and considered as part of the IEP planning process. Recognition that John had a fear response instead of being labeled as "non-compliant" would result in a plan for Linda's return that was not contingent on "behavior"
- EMDR therapy using adapted storytelling methods taking John's moderate intellectual disability into consideration
- Adapted trauma focused cognitive behavioral therapy to reduce intense response to stressors
- Psychopharmacological interventions: Zoloft 100 mg, Guanfacine 1.5 mg for anxiety and irritability

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Anxiety and Anxiety Disorders

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Overview

This chapter provides a brief overview of the adjunctive role for psychotropic medications in treating anxiety disorders (AD) in people with Intellectual and developmental disabilities (IDD) and autism spectrum disorders (ASD). In this context, pharmacotherapy is part of a comprehensive treatment plan, rather than a stand-alone intervention.

ADs are the most common psychiatric disorders among people with IDD.[1] The higher prevalence rates of anxiety reflect an imbalance between resilience, negative life experiences (including trauma) and other susceptibility factors.[2,3] Diagnostic uncertainty stems from cognitive and communication impairments, misinterpretation of baseline exaggeration, and diagnostic overshadowing.[4] In people with severe/profound IDD, distinguishing AD subtypes is difficult, often limiting the diagnosis to unspecified AD (overlapping trauma or adjustment disorder), AD due to another medical disorder, and generalized anxiety disorders.[5-7]

From Anxiety to Anxiety Disorders

Anxiety is a ubiquitous emotional response and arises from environmental, temperamental, and psychosocial factors. Typically, anxiety is transient, follows a developmental trajectory, and does not cause significant functional impairment.[8] Pathological anxiety is a step beyond, arising from trauma, early loss, family chaos, and significant skill/problem solving deficits.[9] Anxiety presents as internalizing and externalizing symptoms without meeting full criteria for anxiety disorders. In at-risk children (genetically/environmentally at risk), ADs may also represent prodromal or subsyndromal forms of anxiety disorders. Progression to a full anxiety disorder is influenced by genetic risk, life stressors, and compromised resilience.[1]

Anxiety disorders (AD) cause functional impairment and meet DSM-5-TR[10] and/or DM-ID-2[3] diagnostic criteria (see Table 1). People who meet criteria for ADs are more likely to respond to psychotherapies and adjunctive pharmacotherapies. People with transformed or complex AD frequently have a history of multiple diagnoses and polypharmacy because of persistent treatment resistance, creating obstacles for engagement in community programs.[11]

People with complex ADs experience a reduced quality of life, intense emotional distress and suffering, a mixture of externalizing and internalizing patterns of behavior, as well as mood and psychotic-like symptoms, and chronic disruptive behaviors.[12] Their developmental histories frequently reveal early onset of symptoms, family and ecological dysfunction, adverse childhood experiences/trauma-related symptoms, and vulnerability to substance abuse. Many such individuals require extensive treatment interventions.

Treatment selection may also depend on the subtypes of anxiety. Current transdiagnostic approaches applying the Research Domain Criteria are moving away from specific diagnosis to a shared trait and biomarkers approach to treatment.[13-15] This approach transcends the scope of this chapter, but Table 1 provides a glimpse into the process.

Table 1: **Categories of Anxiety Disorders**

Category	Anxiety Disorder
Fear Related	• Panic disorder; social anxiety (performance); specific phobias; separation anxiety • Fear or aversion conditioning, generalization, or extinction are also involved. Trauma-related disorders have an analogous conditioned response but also involve problems with extinction, pattern separation, and safety recognition
Anxious Anticipation of Threat / Anticipatory Anxiety	• Agoraphobia; selective mutism.
Excessive Worry and Misery	• Generalized anxiety disorders; mood-anxiety disorders • Social anxiety disorder (generalized)

Table Notes:

AD due to another medical condition, unspecified, and anxiety/trauma anxieties may fall within each of the categories above.

Trauma-focused interventions are important regardless of a documented history of adverse experiences and/or trauma.

Frontline Treatment for Anxiety Disorders: Psychotherapy

- Positive psychology, interactive behavior therapy, CBT with modifications with/without exposure response prevention, and other systemic family/ecological psychosocial interventions are preferred frontline treatments.
- Current literature suggests that despite differences in types of etiology and presentation, various psychotherapies have similar response rates to frontline psychotropic medications (SSRIs and SNRIs).[2-3,16,18]
- Combining therapies is a practical solution, but this may be a case-by-case decision.
- Psychological therapies are useful for bracketing pharmacotherapies – used prior to assess need, and as a tool in reduction/elimination strategies as a means of relapse prevention.

Pharmacotherapy[16-18]

Meta-analytic studies also suggest that algorithmic approaches may be useful (see treatment algorithm for anxiety disorders). There are a variety of drug classes and possible mechanisms of action in treatments. The treatment algorithm does not address the problems associated with co-morbidities and issues with polypharmacy in medical, neurological, or psychiatric settings.

- SSRIs and then SNRIs as first-line pharmacotherapy treatment.
- If SSRIs or SNRIs are ineffective or intolerable, and diagnostic and pharmacokinetic parameters are not contributory, then interclass exchanges within Tier 1 and/or moving to the next tier, or augmentation is next.
- Early during treatment, the decision to move down the algorithm or add adjunctive / augmentative strategies is on a case-by-case basis.
- CBT-ERP therapist, if not already on board, should be consulted and a referral to systems/ ecologically minded psychotherapists. Conjoint therapy can be effective, but remission may be a long-term outcome.
- A common approach to non-responders to several medications(e.g., SSRIs) usually warrants a change to a less commonly utilized SSRI (fluvoxamine), clomipramine, or SNRIs.
- The second and third treatment tiers are frequently older treatments or those without sufficient research support. There are occasions when older treatments (tricyclics, benzodiazepines) can serve as replacements for ineffective SSRI/SNRIs.

- The third-tier treatments are consistent with a high degree of variability within AD drugs. They can be effective in general Anxiety and social anxiety disorders (performance specifier). The need for second and third tier treatments reinforces the biopsychosocial complexity of ADs in people with IDD.

Consensus Treatment Algorithm-Anxiety Disorders

TIER 1

- First Line Treatment: 1st and 2nd generation SSRIs (e.g., fluoxetine, sertraline) or SNRIs (e.g., duloxetine, venlafaxine)
- Short term benzodiazepines
- Beta-blockers (social anxiety-performance related)
- Buspirone

Treatment non-responders: review diagnoses and current team-based treatment plan

TIER 2

- Mirtazapine
- Pregabalin – pregabalin is used in limited fashion due to side effect profile
- Benzodiazepine and other GABA-Calcium channel mediating treatments
- 3rd generation SSRI (e.g., vortioxetine)
- Tricyclic Antidepressants- clomipramine

Treatment resistance: define tier level and comfort zone. Do not hesitate to seek second opinions/consults. It is useful to refer for a second opinion.

TIER 3

- Reversible and standard MAO-A and B Inhibitors
- Valproic acid and other anticonvulsants
- 2nd and 3rd generation antipsychotic augmentation
- Beta-blockers
- TMS, low dose NMDA antagonists, and somatic therapies

Phase 1. Interface between temperament, attachment, separation anxiety, and preventive interventions

AK was a four-year-old male, referred by his parents who were concerned about acute school avoidance upon starting Pre-K. AK presented as shy with slow to warm up temperament, rarely speaking outside the family setting. His medical history included: premature birth at 32 weeks, significant intrauterine growth retardation, mild Cerebral Palsy (left side weakness), and Articulation Disorder. Early intelligence testing suggested borderline/mild ID. Family history was positive for panic disorder in Ms. K. and mild OCD in Dr. K. Examination revealed mild delays in most motor milestones, mild spastic left hemiplegia, mutism, and mild separation anxiety. AK responded quickly to a brief school-based exposure-response prevention, graduated desensitization program, and speech therapy. There were no clear signs for short-term, adjunctive pharmacotherapy.

AK's presentation illustrates the importance of an adaptive and stable family system in matching temperament, attachment needs, and enhanced resilience in early childhood. It is important to understand the complex roles genetic risk, behavioral inhibition, articulation disorders, and neurodevelopmental issues can play in anxiety disorders. A positive family history of panic disorder and behavioral inhibition may contribute to separation anxiety, Selective Mutism and later onset anxiety and mood disorders.

Phase 2. Interface between loss and grief, increasing anxiety, and a panic attack in a child vulnerable to panic disorder

The eighth grade presented new challenges for AK. First, his maternal grandfather died suddenly. Then in rapid succession, AK had his first panic attack, an intensification of worries about dying, and "not keeping up" at school. AK described worries about his mother's sadness, his father's constant worrying, and missing his sisters, who entered college. The mental status exam revealed significant grief response and growing anticipatory anxiety about another panic attack. The patient's therapist noted similar findings. His working diagnosis was anxiety disorder (suspected panic disorder). CBT-ERP was less effective than hoped. At this point, his therapist and family agreed, and AK assented to a trial of sertraline. Within weeks, AK was euthymic and less anxious, but his sporadic nocturnal panic attacks persisted. After two years on sertraline and modified CBT, we slowly tapered then discontinued his SSRI but continued his CBT.

Phase 3: Interface between transitions, worry, resurgence of panic attacks, and newly emergent seizure disorder

AK did well off sertraline until the beginning of his final year in high school. In May, his father called to report an intensifying of his panic attacks and sleep episodes. AK described a "funny feeling" in his belly that "felt like a mouse running up chest" that anteceded his "scary spells." His parents and soccer coach noted that AK "had an odd look" then froze for a few seconds before he started fumbling with his clothes. The episodes ended with a period of confusion.

Clinically these ictal events suggested "complex partial seizures" intertwined with worsening anxiety. His paternal uncle, with complex partial seizures, responded extremely well to valproic acid (VPA). They consented to VPA, so we titrated doses to a serum trough level of 85 mcg/d. He was free of seizure activity, but his panic disorder relapsed with mild depressive features. On VPA his seizures improved, but his panic attacks and depressed mood persisted. We restarted outpatient CBT and titrated his sertraline to 200 mg/d. His mood improved over the next 2 months.

Treatment: How to Get the Fly Out of the Bottle

The vignette highlights two issues:

1. The diagnosis and treatment of anxiety disorders require a longitudinal, systemic/ecological perspective for mapping his changing clinical status.
2. The potential for diagnostic overshadowing of disorders can represent a two-way street. AD, neurodevelopmental, medical, and/or neurological disorders are not an either/or situation. Focusing exclusively on one or the other can backfire.

These caveats support the concept that diagnoses are working and evolving hypotheses, not written in stone.

Conclusion

This review provided an overview of AD in people with IDD and the role of pharmacotherapy in their treatment. SSRIs and SNRIs, along with several psychotherapeutic interventions are generally front-line, trans-diagnostic treatments that are effective across the spectrum of anxiety disorders (including comorbid or externalizing variants).

In general, “starting low and going slow” is the most sensible approach but even at “therapeutic ranges,” prescribers can struggle with low remission, high relapse rates, and substantial numbers of non-responders to both psychotherapy and pharmacotherapies. One should remain cognizant that psychotropic medications are adjunctive treatments, and that their true value lies in the context of ecologically based interventions.

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Obsessive Compulsive Disorders

L. Jarrett Barnhill, MD, DFAPA, FAACAP

Overview

The Obsessive-Compulsive and Related Disorders (OC-RD) category includes a range of diagnoses including Obsessive Compulsive Disorder, Body Dysmorphic, Trichotillomania, and Excoriation Disorders within the Related Disorders subsection.[1,2] These disorders differ in clinical expression, apparent motivational state, and affective responses. Studies find that nearly 40% of patients with OCD have comorbid conditions.[3] These comorbidities include mood and anxiety disorders, anorexia nervosa, Tic Disorders, and ADHD.

Studies estimate 17% of people with autism spectrum disorder (ASD) and 0.7-3.5% of people with intellectual disability (ID) experience OCD.[4-7] The presence of ASD and ID may overshadow estimates of the prevalence rates for OC-RD due to limitations in the capacity for self-awareness and self-reporting of inner experiences or insight. These limitations can make it difficult to distinguish obsessive compulsive behaviors from the core features of ASD (stereotypic, restrictive, and repetitive behaviors) or ritualistic behaviors in people with severe ID. Referrals for people with intellectual and developmental disabilities frequently involve high levels of co-occurring disruptive stereotypies and complex ritualistic behaviors, self-injury, and aggression.[8,9] The presence of comorbid ADHD, tic disorders, or specific behavioral phenotypes often lead to referral, and diagnosis of OC-RD emerges during these assessments. In many clinical settings, OC-RD is over-diagnosed based on overshadowing by repetitive or ritualistic behaviors. Accurate diagnosis requires defining the boundaries between compulsions and the restrictive-repetitive behaviors associated with ASD, and stereotypic and ritualistic behaviors in people with ID.[10,11]

A second set of overlapping issues involve boundaries with tic and other movement disorders, and the interrelationships with trauma (obsessions as intrusive images and thoughts), neurodegenerative disorders, and comorbid mental health disorders. Each of these issues interfaces with the developmental nature of OC-RD and its role in the assessment, treatment, and clinical course of OC-RD. Table 1 outlines many of these issues.

Table 1: Common Issues in Assessment and Diagnosis of Obsessive Compulsive and Related Disorders[9]

Characteristics	**Symptoms**					
Topography	Recurring obsessions	OCD - cleaning, checking	Touching, arranging, counting, need for symmetry	Abnormal movements and compulsive SIB	Bizarre rituals, delusions accompanied by psychotic features	Dementia subcortical and frontotemporal types
Abnormal Movements	Less common	Less common	Common	Choreoathetoid, motor vocal tics	Oro-facial movements dysfluent movements	Chorea, myoclonic
SIB	Alternatives to verbalized thoughts, images with violent, sexual content	Less common	Skin picking, repetitive low intensity rubbing, severe SIB sensory tics, done until it feels right	Severe mutilation SIB	Analgesia, low intensity self-stim	Lip biting with neuroacanth ocytosis
Other Developmental Disorder	Less common with central nervous system disorder	ASD as a comorbid condition	Autistic spectrum disorder, Tourette's disorder	Lesch-Nyhan	Schizophrenia spectrum	Degenerative disorders, loss of function
Level of IDD	Uncommon in severe IDD	Problem with recognition	Recognition and awareness	Self-injurious behavior draws attention of clinicians	Psychosis akathisia	Loss of skills, apathy
Other Psychiatric Symptoms	Anxiety, mood disorders, relationship to delusions	Anxiety, mood disorders	ADHD, impulsivity, early onset, Family history of tic disorders	Mood disorders, compulsive behaviors, self-restraining	Thought disorder, bizarre behaviors	"mania" disinhibition, perseveration
Temperament	High harm avoidance, internalizing	Internalizing, behavioral inhibition	Externalizing, impulse dyscontrol	Mood disorders, pain threshold unaffected	Varies with stage of illness	Mood disinhibition, irritability depression early
Treatment Response	SSRIs, CBT, response prevention more difficult	SSRIs, CBT	Less responsive to SSRIs, dual treatment is often necessary	SSRI trials, second generation APDs	Antipsychotic drugs; SSRIs added after stabilization	Palliative, progressive disorders

Assessment

Diagnostic criteria[1] involve the presence of:

- at least one obsessive and one compulsive inclusion behavior
- active involvement in these events for 1 hr./day
- sufficient functional impairment
- an extensive list of rule outs and co-occurring disorders

Vignette

> RB is a 26-year-old male with ASD, borderline intellectual functioning, Tourette's disorder, and compulsive hand washing. He failed to sustain improvement on standard treatments for OC-RD and Tourette's disorder. As expected, the characteristic waxing and waning of his tic disorder complicated treatment, especially when changes in OC-RD symptoms were in synchrony with the severity of his tic disorder.
>
> His primary compulsion of hand washing arose amid contamination fears associated with agoraphobia and social avoidance. Anxieties about touching contaminated surfaces initiated his compulsive hand washing rituals. Now he fears contaminating others interspersed with catatonic episodes. These responded to lorazepam and clonazepam. He was admitted to a residential program where he responded to the structure and intensive behavioral interventions. Shortly after his discharge, a tropical storm dumped nearly 20 inches of rain in his area, and he regressed during the chaos surrounding this catastrophe.
>
> RB has taken 3 SSRIs (including Fluvoxamine) augmented with SGA for both tics and OC-like symptoms. In addition, Amantadine, Memantine, Riluzole, Ondansetron, N-acetlycystiene, acomprosate, and low dose mu antagonists have been tried. The unsuccessful treatment approaches were integrated with an ongoing combination of increased structured activities outside the home, socials skills, and a very slow successive program of exposure and limiting time he could wash his hands (decreasing from three hours to under 30 minutes/day). These evolved as part of adapted cognitive behavioral therapy with exposure and response prevention (CBT- ERP) and habit reversal therapy (HRT) techniques. The modified HRT intervention was

> helpful initially, but his therapist left the practice and finding a replacement therapist comfortable with ASD was an issue. Restricted behaviors continued with active avoidance strategies such as keeping his hand in his pockets and not touching any objects except with his shoulder. He was reaching a point where Deep/Theta Burst Transcranial Magnetic Stimulation (TMS), Direct Current Stimulation, or more invasive somatic procedures were under investigation.

Treatment Strategies[12-14]

OC-RD is a heterogeneous group of repetitive behaviors with multiple etiologies and comorbidities. With new patients, clinicians may need to consider from a horizontal perspective the impact of each co-occurring/comorbid condition. This should remind clinicians that traumatic experiences can have a major impact on people with ASD, and relapsing OC-RD. In this case, the duration of the nonresponsive phase created, lack of insight, comorbid severe tic disorder, and long duration of symptoms, and repeated adverse life events can accentuate problems with sensitization and kindling like phenomena. For many, treatments begin with generalized strategies, which may be effective in two-thirds of patients. Each decision step beyond this point requires careful assessment and thoughtful intervention strategies. In cases with significant comorbidity, step one is to focus on combined interventions for the most problematic conditions. For example, in people with ASD and ID, ADHD and externalizing behaviors, OC-related symptoms and tic disorders are common co-occurring conditions.

For complex referrals, OC-RD occurring in the context of IDD should be viewed longitudinally. The impact of genetic loading, gender dimorphism, and early age of onset generally have a negative impact on clinical course and treatment efficacy. By adulthood, many people like RB no longer present with a straightforward problem. A new diagnostic framework convened for RB must capture the evolving, intersecting trajectories of tic disorder, ASD, trauma, and environmental stressors — not as discrete pathologies, but as components of a lifelong developmental dynamic demanding integrative, individualized treatment planning.

Generalized Strategies for OC-RD:

- Cognitive Behavioral Therapy (CBT)
- Exposure Cognitive Behavioral Therapy
- Exposure Response Prevention (ERP)
- Habit Reversal Training (HRT)

Common Psychopharmacologic Treatment Strategies for OC-RD

- SSRIs
- Clomipramine

Treatment for OC-RD is associated with Four Basic Approaches[12-16]

TIER 1

Uncomplicated OCD

Treatment of uncomplicated OCD usually begins with CBT/ERP with modifications for ASD and ID. If ineffective or significant residual symptoms occur, then HRT is tried. This may accompany SSRI monotherapy.

The best predictor of SSRI response is high harm avoidance temperament, suggesting behavioral inhibition, increased sensitivity to negative contingencies, internalizing symptoms, intolerance of uncertainty, and high threshold for risk taking.

There are several caveats to declaring a Tier 1 treatment approach ineffective:

- Patients with OC-RD generally require a prolonged latency of response, longer duration of treatment, and higher doses of SSRI/SNRIs.
- Most treatment strategies contribute to improvement but fewer remissions, and rarely complete recovery from OC-RDs.
- The symptoms may wax and wane, intensify during periods of distress, loss, or trauma, and on occasion intensify after medical illnesses (Beta- Hemolytic Strep, auto-immune, inflammatory/ infectious diseases).
- Many people with chronic medical or neurological illness may also develop obsessions and rituals surrounding health care. These may require additional focus on the impact of the primary disorder and on the impact of chronic illnesses on psychological adaptation.
- OC and other repetitive behaviors can occur in several forms of neurodegenerative disorders. They are generally differentiated based on the co-occurrence of positive neurodiagnostic or genetic studies, and present with perseveration, difficulties with set shifting and declining neurocognitive and executive functions.

TIER 2

OCD-RD with Co-Occurring Tics

If standard Tier 1 treatment is ineffective or OC-RD co-occurs with tic disorders, the following should be considered:

- ERP/CBT/HRT, SSRIs augmented with alpha-agonists, or SGAs and/or in exceptional cases clonazepam.
- Treating OC symptoms and tics first means overcoming concerns about the adverse effects of treating psychiatric co-morbidities that can increase irritability, SIB, aggression, and increase repetitive behaviors associated with OC-RD. For example, stimulants used to treat ADHD might, in some cases, increase irritability in people with ASD.
- Remain aware of drug-drug interactions when using augmentation strategies. Reassess the need for combined treatments at frequent intervals. Remember the waxing nature of both OCD and tic disorders as well as the special ecological adaptations needed for ASD and ID.
- Clinical judgment and consultation or referral to peers and experts may be useful. These complex co-occurring conditions suggest more neuropharmacological heterogeneity. OC-RD is not a single neuro-transmitter condition, and NE, DA, GABA, glutamate, and neuropeptide/opioid are players in its pathophysiology.
- Consider the presence of genetic disorders associated with SIB (e.g., Lesch-Nyhan syndrome), neurodegenerative disorders, cerebrovascular conditions, and TBI. Both ASD and ID are associated with behavioral phenotypes and a large array of genetic and metabolic disorders.

TIER 3

OC-RD with Psychiatric Comorbidities

Comorbidities might include ADHD, mood disorders, anxiety, TBI, impulse control disorders, trauma/PTSD, schizophrenia, substance use, and fronto-temporal dementia. In these situations, treat the primary condition first. See other chapters of this guide for treatment recommendations for these conditions.

TIER 4

OC-RD, ID, and ASD

Research on alternative biological treatments has excluded people with IDD/ASD in controlled studies of TMS, Direct Electrical Current, treatment for PANS or PANDAS, deep brain stimulation, or capsulotomy.

Conclusion

OC-RD is a heterogeneous group of repetitive behaviors with multiple etiologies and comorbidities. For many people, treatment begins with generalized strategies (CBT/ERP/HRT and SSRIs/clomipramine). These may be effective in two-thirds of patients. Each decision step beyond this point requires careful assessment and thoughtful intervention strategies. Combined therapies are common, but we must do our best to avoid unnecessary polypharmacy, and apply ecological interventions, and psychotherapies in each subsequent treatment tier.

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Depressive Disorders

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Overview

This section provides a brief overview of depressive disorders in people with Intellectual and Developmental Disability (IDD) and Autism Spectrum Disorders (ASD). Depressive disorders are common among people with IDD with lifetime prevalence rates of 37%.[1] Common antecedents for depression in people with IDD include personal loss (e.g., caregiver, friend, staff), isolation, marginalization, lack of autonomy, trauma, bullying, victimization, or other adverse experiences. It is important to ask about these losses as they should impact the therapeutic intervention chosen.

Assessment

The core features of depressive disorders are a depressed and/or irritable mood with a marked change from a person's baseline and impairment in functioning.[1,2] The severity of a person's ID impacts their presentation of depression. People with mild to moderate ID may report feeling sad or depressed, making depression easier to recognize. People with a more significant intellectual impairment may not verbalize their internal feelings, making a depression diagnosis more nuanced.[3] For all people, observation of presentation and collateral information are key.

The diagnosis of Depressive Disorders requires meeting current diagnostic criteria for one of the following: Disruptive Mood Dysregulation Disorder, Major Depressive Disorder, Persistent Depressive Disorder, Pre-menstrual Dysphoric Disorder, Other Specified and Unspecified Depressive Disorders, and Depressive Disorder Due to Another Medical Condition.[1] These disorders are frequently comorbid with anxiety disorders. Consider utilizing a standardized rating scale when assessing and treating depression such as the PHQ-9.[4] Adaptations to the PHQ-9 have been made for people with IDD.

For moderate to severe depression, consider a combination of therapy plus antidepressants.[6,7] There is a lack of research on psychopharmacologic treatments for people with depression and IDD.[8] Psychotropic medications to treat depression in the general population are utilized for people with IDD as well.[9] It is important to start antidepressants at a low dose and slowly titrate and consider comorbid medical issues and drug-to-drug interactions. Consider utilizing a SSRI as the initial pharmacologic treatment based on their efficacy and tolerability (Figure 1).[11] If an SSRI is not appropriate, then consider serotonin-norepinephrine reuptake inhibitors, atypical antidepressants, and serotonin modulators (Figure 1).[11] Studies show the efficacy of the various antidepressants as comparable across and within the different classes for both acute and maintenance treatment. The selection of an antidepressant is based on the following: symptoms, comorbid diagnosis, safety, side effect profile, drug-to-drug interaction, patient preference, cost, first-degree relative with a history of a positive response to an antidepressant, and patient's previous response to medications.[11]

Some side effects[12] to consider when selecting an antidepressant include the following:

- Citalopram: increase in irritability for people with ASD; QT prolongation
- Sertraline: higher rates of diarrhea
- Venlafaxine: more nausea and vomiting
- Bupropion: less sexual dysfunction; contraindicated in eating disorders
- Mirtazapine: greater weight gain, sedating

Tricyclic antidepressants and monoamine oxidase inhibitors are typically not utilized as initial treatment for depression given their more serious side effect profile and elevated risk with overdose.

After initiation of an antidepressant, improvement can be seen in 2-4 weeks. If the person is not improving and tolerating the antidepressant, then titrate the antidepressant in stepwise increments as tolerated up to lowest effective dose.

Key Components in Assessing Depression in People with IDD[3,13]

- Comprehensive history with self-report when possible, and collateral information including behavioural observations from caregivers, residential staff, day staff, etc.
- Good understanding of individual's baseline functioning and change from baseline
    - What does the individual look like when they are doing well?
    - When did they last appear that way?
- Symptoms of depression include 4 or more of the following:
    - Depressed mood and/or irritable mood
    - Loss of interest or pleasure
    - Change in appetite or weight
    - Insomnia or hypersomnia

  - Psychomotor agitation or retardation
  - Fatigue or loss of energy
  - Feelings of worthlessness or guilt (people with severe/profound intellectual disability do not have cognitive capacity to display this symptom)
  - Decrease in concentration
  - Recurrent thoughts of death or suicidal ideation or attempts
- Timeline and Severity
  - When did the patient begin having symptoms?
  - On a scale of 0-10, how severe are the symptoms with 10 being the worst?
  - Previous episodes of mania and depression and response to treatment
- Assess for episodes of mania or hypomania to rule out bipolar disorder
- Comorbid substance use/abuse/dependence
- Assess for psychosocial stressors and abuse
- Family history of mental health issues and suicide attempts or completions

Physical examination: Assess for illnesses that can be associated with depression (e.g., Hypothyroidism, Epilepsy, Stroke, Anemia).

Review individual's medication list. Assess if medications are causing/contributing to depression.

- Ask about complementary and alternative medications.
- Some classes of medication can cause depression (e.g., cardiovascular drugs, chemotherapeutics, antiparkinsonian, anti-infective and antiretroviral agents, anticonvulsants, hormones, antihistamines, and sedatives).

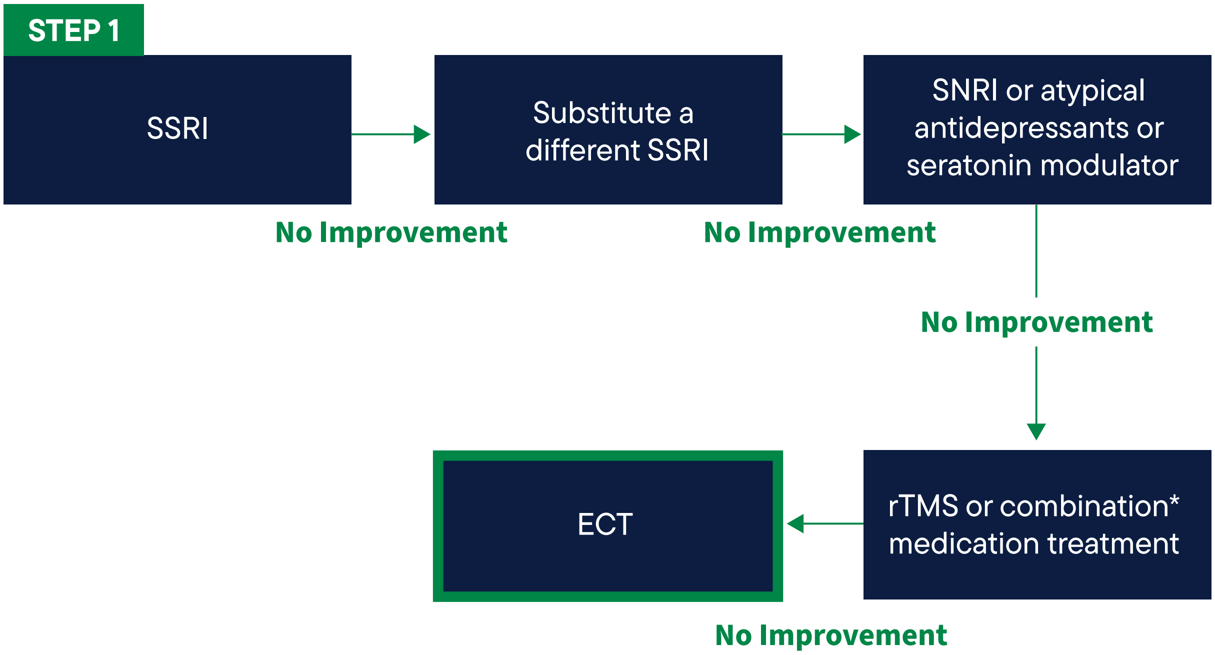
Mental Status Examination: Assess suicidality and homicidality, psychotic symptoms, catatonic symptoms, and future orientation.

Labs to consider: Thyroid stimulating hormone (TSH), complete blood count (CBC), vitamin D level, liver function tests (LFTs), renal function tests.

Treatment Resistance[1,12-13]

For people not showing improvement with antidepressant treatment, consider re-evaluating their diagnosis and treatment compliance. Switching antidepressants should be considered if symptoms fail to improve after a 6 to 12-week medication trial at a therapeutic dose (See Figure 1). If the individual shows a partial response to treatment, then consider augmenting the initial antidepressant with second-generation antipsychotics (aripiprazole, quetiapine, brexpiprazole, and risperidone), lithium, or other antidepressants. **The risks and harms of adding additional medications must be carefully considered.** After adequate trials of antidepressants, if the individual continues to have significant symptoms of depression, consider neurostimulation such as repetitive transcranial magnetic stimulation (rTMS) or ketamine/eskatamine, or electroconvulsive therapy (ECT). ECT should only be utilized when symptoms are severe, refractory to medication treatment, or due to intolerable side effects from medications.

Figure 1: **Consensus Psychotropic Treatment Algorithm — Depressive Disorders**



[*] Combination Medication Treatment with medications that complement each other such as Buproprion plus SSRI, TCA plus SSRI

Comorbid Treatment

- For people with severe suicidality or malnutrition secondary to depression and food refusal: consider electroconvulsive therapy.
- For people with psychotic symptoms: add an antipsychotic to antidepressant treatment.
- For people with catatonic features due to depression: add a benzodiazepine to antidepressant treatment.

Vignette

Mr. F is a 28-year-old male with mild ID. When doing well, Mr. F is friendly, funny and enjoys spending time with others. He has been living with a caregiver for the past 5 years. Mr. F's caregiver scheduled the initial appointment due to a concern that Mr. F does not want to get out of bed in the morning.

At the interview it was reported that Mr. F is pacing more than usual, no longer engages in his preferred activities, needs more encouragement to do things, is irritable, and makes statements that he is bad, he wishes he were dead or not here. While you didn't learn about this initially, through additional inquiry about recent stressors, you also learned that there was a recent change in staffing at his day program, and that he has intermittent tearfulness, which is new. Mr. F's biological family has a history of schizophrenia, depression, and anxiety.

Mr. F is diagnosed with a major depressive disorder. The PHQ-9 completed by Mr. F's caregiver is consistent with depression. Mr. F is connected to a therapist; however, there is a wait of several weeks to start. In the meantime, Mr. F's caregiver is encouraged to purposefully schedule enjoyable and meaningful activities in which to engage Mr. F. The caregiver is encouraged to validate the feelings of loss Mr. F is experiencing. Mr. F is started on an SSRI to treat depression. Mr. F begins modified CBT several weeks later. His therapist reviews his previous neuropsychological assessments to target Mr. F's therapy to his cognitive strengths. Mr. F's depression resolves in several weeks with combination treatment of SSRI, modified CBT, encouraged engagement, and validation of his feelings regarding losing a preferred staff. He remains on his SSRI for 1 year, and it is slowly tapered with no re-emergence of depressive symptoms.

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Bipolar and Related Disorders

Jennifer McLaren, MD

This chapter provides a brief guide to bipolar disorder in people with intellectual and developmental disabilities (IDD) and autism spectrum disorders (ASD).

Assessment

The core features of bipolar disorder are manic or hypomanic episodes, depressive episodes, and a marked change from a person's baseline.[1] The severity of a person's intellectual disability will influence the presentation of symptoms for bipolar. People with mild to moderate intellectual disability may report their internal feelings and observations of their own behavior.[2] People with a more significant intellectual impairment may not be able to verbalize their feelings and observations. For all people, observation of overall presentation and vegetative function along with collateral information are key. The prevalence of bipolar disorder is lower than anxiety and depressive disorders in this population and requires clear knowledge of the presentation to prescribe effectively.[3,4]

The diagnosis of Bipolar and Related Disorders requires meeting current diagnostic criteria for one of the following: Bipolar I Disorder, Bipolar II Disorder, Cyclothymic Disorder, Substance/Medication-Induced Bipolar and Related Disorder, Other Specified and Unspecified Bipolar and Related Disorders, and Bipolar and Related Disorder Due to Another Medical Condition.[1]

Vignette

> Nancy is a 23-year-old female with mild intellectual disability. She had a chaotic childhood. Her parents had significant mental health issues, and Nancy also had multiple psychiatric hospitalizations, though these records are unavailable. She currently lives in a family setting with a married couple and their adult daughter.
>
> The family notes that Nancy has both very dark periods and happier times that are distinct changes from her baseline. The caregiver describes episodes where Nancy sleeps only a couple of hours per night, becomes very bossy, and believes she is the director of her day

program. During these times, her speech is louder and quicker. She seems to jump from topic to topic and activity to activity. She is up all night arranging and re-arranging her room. These episodes last for 2 weeks at a time and then Nancy crashes into sadness.

During times of sadness, Nancy sleeps more and will not get out of bed. She seems irritable, withdrawn, has low energy, and nothing gives her pleasure.

Nancy begins Lithium, and it is titrated to a therapeutic blood level. She does well for 6 months then begins to frequently miss her Lithium as she does not like how she feels while taking it. She experiences another manic episode and during this period and she begins planning her wedding even though she is not in a relationship. Her caregiver can also hear her talking to herself loudly in her room and at the dinner table. This is different than Nancy's typical self-talk as she is distressed and notes she would like the voices to go away. Nancy is started on quetiapine with resolution of manic and psychotic symptoms. She also did not experience a depressive episode. Nancy continues to take her quetiapine regularly at a follow-up appointment and by all reports (Nancy and her family caregivers) she is doing better.

Summary

This vignette highlights several important points:

- Potential family history of bipolar.
- Grandiosity in someone with ID or ASD may be exaggerated claims of skills or accomplishments.
- People may have difficulty adhering to treatment for many reasons. One reason may be medication side effects. Include the patient and supporters in discussions and decision making.
- Auditory hallucinations are intrusive and distressing. They look different from an individual's baseline self-talk.
- When choosing a medication, you may consider one that will treat as many symptoms as possible to avoid polypharmacy (e.g., quetiapine to target acute mania, depression and psychotic symptoms).

Key Components in Assessing Bipolar and Related Disorders in People with IDD and ASD[3-5]

- Comprehensive history with collateral information including behavioral observations from caregivers, residential staff, day staff, etc.
- Good understanding of a person's baseline functioning and change from baseline
    - What does the person look like when they are doing well?
    - When did they last appear that way?
- Symptoms of mania or hypomania include a persistently elevated, expansive, or irritable mood with the following symptoms
    - Mania: symptoms lasting at least 1 week and causes functional impairment
    - Hypomania: lasting 4 consecutive days
        - 3 or more of the following symptoms or 4 or more if the mood is irritable
        - 2 or more if limited expressive language skills or 3 or more if mood is irritable
        - Inflated self-esteem or grandiosity
        - Decreased need for sleep
        - More talkative or pressure to keep talking
        - Flight of ideas or racing thoughts
        - Distractibility
        - Increase in goal directed activity
        - Excessive involvement in pleasurable activities
- Timeline and Severity
    - When did the patient begin having symptoms?
    - On a scale of 0-10, how severe are the symptoms with 10 being the worst?
    - Previous episodes of mania and depression and response to treatment
- Assess for psychosocial stressors and abuse
- Comorbid substance use/abuse/dependence
- Family history of mental health issues and suicide attempts or completions
- Physical examination: Assess for illnesses that can be associated with bipolar disorder (e.g., Hyperthyroidism, Lupus, Epilepsy, Stroke)
- Review person's medication list. Assess if medications are causing/contributing to mania/hypomania.
    - Ask about complementary and alternative medications.

    - Some classes of medication can cause mania (e.g., corticosteroids, antidepressants, stimulants, baclofen, bromide, bromocriptine, captopril, cimetidine, cyclosporine, disulfiram, hydralazine, isoniazid, levodopa, metrizamide, procarbazine, procyclidine)
- Mental Status Examination: Assess suicidality and homicidality, psychotic symptoms, catatonic symptoms, and future orientation.
- Labs to consider: Thyroid stimulating hormone (TSH), complete blood count (CBC), liver function tests (LFTs), renal function tests, and urine drug screen.

There is a lack of research on psychopharmacologic treatments for people with bipolar and IDD.[6,7] The psychotropic medications to treat bipolar in typically developing people are utilized for people with IDD.[8,9]

Treatment of Mania[10-13]

It is important to provide psychoeducation about the chronicity and course of bipolar treatment and the importance of adherence to treatment. Manic and hypomanic episodes are treated with the same psychotropic medications. A variety of medications show comparable efficacy in treating mania and are considered first line medications including lithium, quetiapine, divalproex, asenapine, aripiprazole, paliperidone, risperidone and cariprazine. Amongst these medications, lithium, valproate, aripiprazole, risperidone, and quetiapine have a favorable safety and tolerability profile and a stronger evidence base in patients with IDD and ASD. These medications should be considered first to treat mania in people with IDD and ASD.

Which Medication to Choose?

The choice between lithium and valproate, and the choice of the antipsychotic should be based upon the following:

- Person's past response to medications
- Family members with bipolar disorder past response to medications
- Symptoms
- Comorbid general medical illnesses

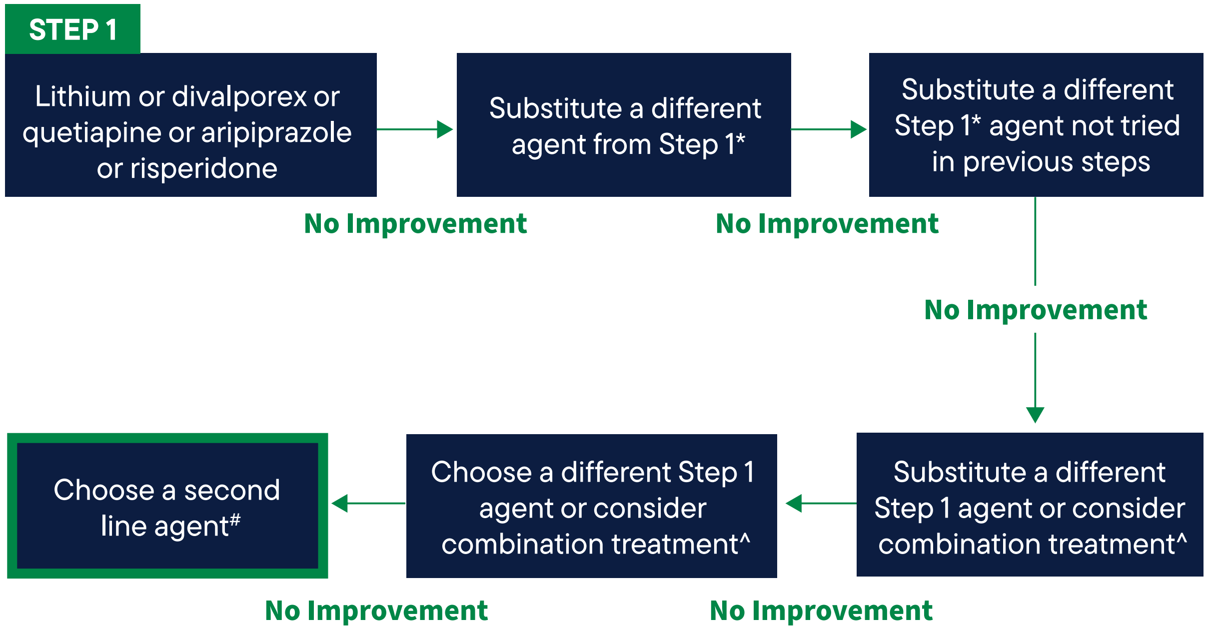
    - If a patient has epilepsy and is treated with valproate for their epilepsy, then optimize the dose of valproate to treat mania. Valproate's therapeutic blood level for epilepsy is lower than for mania.
    - Liver disease: avoid valproate
    - Renal disease: avoid lithium
    - Obesity: avoid olanzapine
- Drug-drug interactions
- Patient preference
- Cost

Response to anti-manic agents is typically seen in 1-2 weeks. If manic symptoms are not controlled, then consider dosing optimization and medication adherence. If the response to medications remains suboptimal once these factors are optimized, then a re-evaluation of the diagnosis should be considered. If the diagnosis of mania remains consistent and a person does not respond to a first line agent, substitute a different first line agent before proceeding to second line agents. The second line agents include olanzapine, carbamazepine, haloperidol, lithium plus valproate, olanzapine plus valproate or lithium, and electroconvulsive therapy (ECT). Figure 1 illustrates an algorithm for treatment of mild to moderate mania in people with IDD.

Treatment of Depression[10-14]

Consider positive cognitive behavioral therapy to help the person learn coping skills to manage depression. First line psychotropic medications to treat depression in bipolar include the following: quetiapine, lithium, lamictal, lurasidone, or lurasidone with lithium or divalproex. Second line agents include the following: divalproex, SSRIs, bupropion, ECT, cariprazine, and olanzapine-fluoxetine. Maintenance treatment is important in bipolar disorder, as people require it to prevent future episodes of mania and depression.

Figure 1: **Consensus Psychotropic Treatment Algorithm-Manic Episode Mild-Moderate Severity**



[*] Step 1 agents: lithium, valproate, aripiprazole, risperidone, and quetiapine

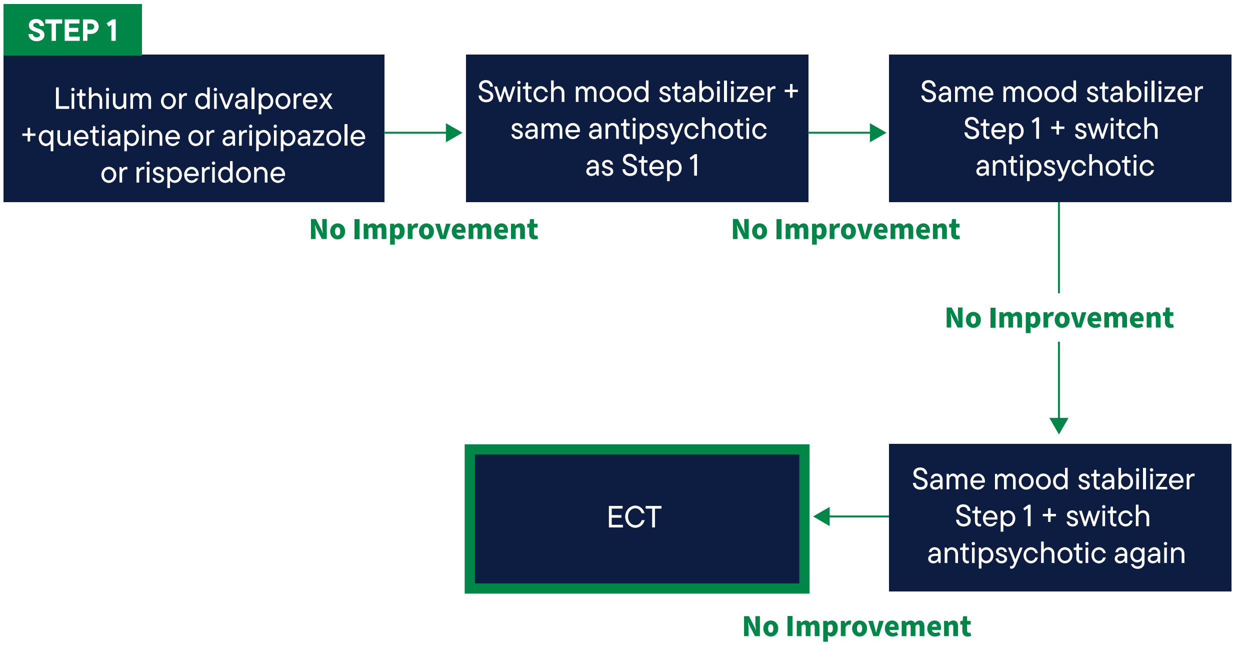
[^] Combination treatment if symptoms becoming more severe: lithium or valporate plus quetiapine, aripiprazole or risperidone

[#] Second line agents: olanzapine, carbammazepine, ziprasidone, haloperidol, lithium plus valproate, olanzapine plus valproate lithium, and ECT

Severe Mania[10-14]

For patients with severe mania, consider initial treatment with lithium plus an antipsychotic or valproate plus an antipsychotic. A severe manic episode that does not respond to one medication combination should be treated with a second medication combination such as switching the mood stabilizer: lithium to valproate or vice versa. If the individual fails to respond after 1-3 weeks of treatment, then switch the antipsychotic to another antipsychotic. After 1-3 weeks, if there is no response then switch to a different antipsychotic or try ECT.[15] ECT should only be utilized when symptoms are severe, refractory to medication treatment or due to intolerable side effects from medications. Figure 2 illustrates an algorithm for the treatment of severe mania in people with IDD or ASD.

Figure 2: **Consensus Psychotropic Treatment Algorithm-Severe Manic Episode**



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Grief and Loss

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Overview

There is an extensive body of research in the general population that focuses on the relationship between typical grief, bereavement, and situations in which the process of recovery is prolonged or never reached, culminating in the addition of prolonged grief disorder as a formal diagnosis in DSM-5-TR.[1–2] Many clinicians assessing and treating people with intellectual and developmental disabilities (IDD) and autism spectrum disorder (ASD) may not be familiar with this body of work. This chapter will investigate typical bereavement and prolonged grief in people with IDD and outline helpful treatment approaches and resources.

DSM-5 TR Changes of Assessment and Diagnosis and Prolonged Grief

The authors of the DSM-5-TR1 recently added prolonged grief disorder as a formal diagnosis to the DSM. The context for the formal addition of prolonged grief was linked to the COVID-19 pandemic and the resulting death, loss, and grief. The criteria (as summarized from DSM-5-TR below) are clearly different from those of major depressive disorder (MDD), and common, self-resolving grief responses. A person with IDD presenting with prolonged grief should also be assessed for MDD as well and may meet criteria for both.

Prolonged grief diagnosis requires at least 12 months of symptoms following the loss and “is characterized by intense longing/yearning for the deceased person and/or preoccupation with thoughts and memories of the lost person to a clinically significant (i.e., impairing) degree, nearly every day for at least the past month.”[3]

Criteria for Prolonged Grief Disorder (cited directly from the DSM-5 TR)[1]

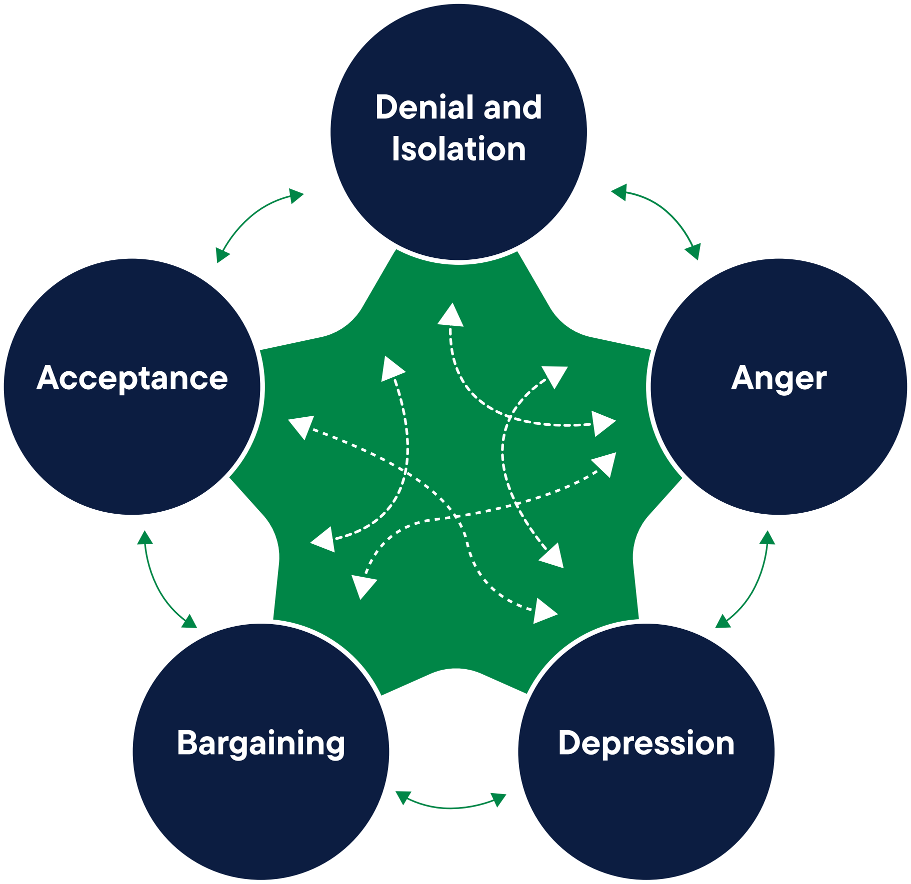
Symptoms include:

- Identity disruption (such as feeling as though part of oneself has died).
    - Marked sense of disbelief about the death.

- Avoidance of reminders that the person is dead.
  - » Intense emotional pain (such as anger, bitterness, sorrow) related to the death.
- Difficulty with reintegration (such as problems engaging with friends, pursuing interests, planning for the future).
  - » Emotional numbness (absence or marked reduction of emotional experience).
  - » Feeling that life is meaningless.
  - » Intense loneliness (feeling alone or detached from others).

Bereavement lasts longer than might be expected based on social, cultural, or religious norms.

Figure 1: **5 Stages of Grief**[4,5]



Grief Is a Normal Part of Life

Grief as a result of loss is experienced by all people at some point in their lives. A wide variety of losses may impact a person including loss of pets, home, family members, employment, and other things that make up a person's identity. Kubler-Ross[4] developed a five-stage model of grief to describe the various stages and experiences of a person when bereaved. Later, Kessler[5] amended the model to include a 6th stage, meaning. People do not follow each stage independently from the other, rather they pass through phases fluidly based on their emotional and physiological state.

Table 1: **Six Stage Model of Grief (Kubler-Ross, Kessler)[4,5]**

Stage	Description
Denial	Numbness, 'it's a mistake', false hope
Anger	Frustration, irritability, blaming others: "Why me?", 'it's not fair!
Bargaining	If I only did..., "what if"
Depression	Emptiness, feeling overwhelmed, possible suicidal thoughts
Acceptance	Emotions stabilize, new reality, more good days than bad
Meaning	Finding peace and hope for the future

Considerations for Patients with IDD

As with other stressful life events, the impact of personal loss may be underestimated in people with IDD. This is at odds with the finding from a meta-analysis that people with IDD are actually likely to experience complicated bereavement at a clinically significant level.[6] Access to interventions is undermined by misconceptions that people with IDD do not understand death and need to be "protected" from facing emotional experiences. As a result, people with IDD may not be told of deaths in a timely fashion or not permitted to go to a funeral out of concern they will "get upset." Even if a person with IDD does not understand the concept of death, one can still experience the emotions of grieving.[7] That said, as a result of these biases, people with IDD may not be permitted to grieve with their family, attend funerals or memorial services, or be provided psychological supports to cope with the loss. One poignant response may involve the person waiting or searching for the deceased, not fully understanding that death is irreversible. Such responses may create more distress for other grieving family members as well.[6]

The other potential complications that implicate misdiagnosis are the underuse of grief counseling and the overuse of ineffective treatments. For example, developmental features can cloud the presentation of a person's response to loss such that separation anxiety, severe withdrawal, aggression, or self-injury are misattributed to another condition. This mischaracterization can result in the person receiving treatment (including medications to treat different conditions) that are not indicated for grief and thus potentially less effective.

People with IDD have a lifetime of loss and devaluing experiences such as decreased contact and/or inability to live with family, friends, and other natural supports. As life expectancies among those with IDD increase, bereavement around loss of parents is more frequent.[7] They may also experience the loss of meaningful work, their home, and housemates, all of which have a significant impact. A major loss like the death of a parent, relative, friend or caregiver occurs in the context of multiple other losses potentially magnifying the impact further. Unrecognized or undiagnosed grief may result in inadequate grief resolution and put the person at greater risk of prolonged grief disorder. In this sense, grief resembles untreated trauma in terms of its transformation into a more complex and difficult to treat disorder.

The grief response for people with IDD can be a complicated process that contributes to a decline in cognitive, social, and emotional presentation. There is a tendency to misattribute many emotional and behavioral features of an evolving grief response to major forms of psychopathology. The expression of grief also follows a developmental trajectory and depends in part on age, cognitive and adaptive abilities, communication skills, and a host of other psychosocial factors, all of which shape a person's response to loss. In many cases, the expression of externalizing behavioral symptoms overshadows emotional responses, and the recognition of grief as a root cause is under-appreciated. Separation distress symptoms appear to occur more frequently than traumatic grief-type symptoms among people with IDD.[8] Reports have described *"...developmental slowing or regression motivated by desires to stay connected with the deceased by remaining stuck in the same developmental stage, life circumstances, or immature/self-defeating behavior patterns one was in while they were still alive."*[8,2,9] Some common symptoms of grief are described in Table 2. Of note, among the general population, an estimated 80% of people with prolonged grief disorder have impaired sleep long-term.[10] While this still needs study among people with IDD, issues with sleep should be considered in a patient presenting with prolonged grief. Alvis and colleagues[2] studied the ways in which developmental phenomena impact symptomatic manifestations of complicated grief in youth with a neurotypical developmental history that may provide clues to variable presentations of grief displayed by people with neurodevelopmental disorders. They emphasize the key role of caregivers in grieving.

Table 2: **Emotional and Behavioral Symptoms of Grief in IDD[11-13]**

Emotional Symptoms	Observable Symptoms
• Sadness • Anxiety • Fearfulness • Irritability and anger • Guilt/blame • Confusion • Loneliness • Numbing	• Fatigue • Poor concentration • GI symptoms • Sleep problems such as nightmares • Physical complaints • Onset of incontinence • Aggression or self-injury • Restlessness • Imitation of the deceased • Declining school or vocational performance • Anxiety, i.e., fight or flight

Effective Psychosocial Treatment Options for People with IDD

The few large-scale scientific studies have not helped to guide many clinicians seeing patients with IDD who experience grief, and in many circumstances, interventions known to be effective with other populations are extrapolated.[13,14] For example, preventative or proactive interventions may take advantage of frequent, less extreme situations to help the person learn how to cope with loss and change. These strategies may translate into greater resilience by preparing people for later, more significant losses. Giving the person with IDD choice and opportunities to be part of natural grieving, funerals and other religious and social responses to death is an important and necessary intervention. For bereaved adults with IDD, informal tactics include such activities as an acknowledgment of loss, supportive listening, involvement in rituals, memorialization, bibliotherapy, addressing spiritual beliefs, and life story work along with concrete related activities. Focus on relationships, coping mechanisms, and training for and coordination with residential group home staff has been helpful. Group supports and planned activities may also be effective, including visits to funeral homes, making memory tables, memory boxes, and "comfort bags." For some, concrete memorializing is especially helpful.

Bereavement counseling can benefit people with IDD, including the full range of levels of severity, regardless of the length of time since death. There are adapted, manualized grief counseling resources available. Formalized complicated grief therapy[15,16] remains validated in people with IDD. It is a 16-session treatment intervention including the understanding of grief, managing emotions, finding a promising future, relationship building, telling the story of the death, learning to live with reminders, and connecting memories with the deceased.

When Bereavement Requires Psychopharmacological Intervention

Psychopharmacological intervention may be beneficial when the bereaved person with IDD meets the criteria for clinical depression, has significant impairment in daily functioning, and/or is experiencing suicidal ideation. Anti-depressant treatment does not seem to treat the core symptoms of prolonged grief per se but will address related depressive and anxiety symptoms and has resulted in higher grief-focused therapy completion rates.[17]

Vignette

George was a 60-year-old man with mild ID and autism. George lived at home with his younger brother and parents for his entire childhood. His mother homeschooled him for multiple years during his school years. George's immediate family has always been remarkably close and involved in caring for and supporting George. His father died when he was 16 years old, and his brother moved out of the family home when he went to college. Thereafter, George and his mother lived together for many years until his mother died when he was in his mid-50's. At that time, George moved to a group home for people with IDD. Before moving to the group home, George attended a day program 5 days per week. He also received occasional weekend respite and was involved in his church. Upon moving to the group home, new service providers needed to be established. Although he still had some support from his brother, the brother did not live in the same state.

George was referred for psychiatric assessment at an IDD specialty service due to "aggressive behaviors," limiting his day program to only twice/week. His sleep was disrupted, resulting in him waking in the middle of the night often. He appeared irritable and would cry frequently. Upon assessment and symptom tracking, it was noted that George often spoke about his childhood and his family. When he did speak of his parents and his "old life," as he called it, he would cry. This often led to self-injury (hitting himself on the head, chest, and thighs), yelling and property destruction. Occasionally, it escalated to physical aggression toward others.

Taking symptom trends into consideration, it was determined that a diagnosis of prolonged grief disorder should be considered. In-home support was coordinated with the group home to provide them with additional assistance. Given related symptoms of depression, George began a trial of an SSRI and was enrolled in bereavement focused psychotherapy. Sadly, George passed away during the COVID-19 pandemic. In remembering him, his team of clinicians fondly recalled how he loved to visit a particular hot dog restaurant in Brooklyn where he used to go with his family. George was the inspiration for this team's interest in loss and grief in IDD, and his contribution is much appreciated, culminating in this chapter.

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Schizophrenia and Other Psychotic Disorders

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Overview

Psychoses represent a class of disorganizing experiences and clinical disorders associated with significant impairments in perception (hallucinations), delusions, disorganized behaviors, and "reality testing."[1] Although some disorders like Brief Psychotic Disorder are short term, many psychotic disorders evolve into chronic conditions associated with significant long-term functional impairment. Delirium and other neuro-medical complications need to be ruled out early in evaluation. Schizophrenia spectrum disorders are characterized by positive and negative symptoms as well as long-term deficits in cognitive, social, and occupational functioning. The DSM-5-TR[2] and DM-ID-2[3] classify psychotic disorders as follows:

- Schizoaffective Disorder
- Delusional Disorder
- Brief Psychotic Disorder
- Psychotic Disorder Due to Another Medical Condition — People with delirium require immediate assessment to treat their potentially life-threatening conditions.
- Psychotic Disorder Due to Substance/Medication-induced Disorder — Psychotic states and specific disorders can be associated with a wide range of medical, neurological, immunological, pharmacological, and genetic/metabolic disorders, thus requiring appropriate medical work-up and interventions. Late onset psychoses and delirium arise from a wide range of cerebrovascular, neoplastic, chronic medical conditions, and neurodegenerative disorders.
- Catatonia Associated with Another Medical Disorder and Catatonia Specifier — less well recognized but may affect more than 15% of people with ASD.[2,4]
- Other Specified and Unspecified Schizophrenia Spectrum and other Psychotic Disorder-Psychotic symptoms can also occur with mood, anxiety, and stressors/trauma-related disorders. Co-existing psychosis relates to severity of primary psychiatric disorders and frequently requiring more intensive treatments.

Complexity of Psychotic Disorders

Psychotic disorders lie on a continuum that ranges from short-lived states (experiences that include severe psychological trauma and other ecological events) to severe and persistent mental health disorders with either recurrent or chronic symptoms.[5] An early age of onset along with neurobiological insults, adverse life events, and co-existing neurodevelopmental disorders (IDD/ASD etc.) influence the developmental trajectory SSD.[6-7] These biopsychosocial events may interfere with early treatment and increase the risk for chronicity and treatment resistance.

SSD Symptom Consideration in People with ASD and IDD

SSDs are complex, polygenic, neurodevelopmental disorders associated with significant clinical heterogeneity. The overlap in symptom presentation of ASD and IDD adds to diagnostic complexity. Like other psychotic disorders, SSDs include positive symptoms (hallucinations, delusions, thought and behavioral disorders, and neuro-motor impairments like catatonia). In the past, treatment approaches focused on these positive symptoms. The observations that negative symptoms and neurocognitive deficits had a greater influence on morbidity and outcome shifted focus towards developing better treatments for these traits.

Table 1: **SDD Symptoms and Description**[2]

Symptom	Description
Negative Symptoms	Motivational impairment, anhedonia, apathy, and isolation; Persistent despite adequate treatment for the more obvious positive symptoms.
Cognitive Symptoms	Deficits in attention, verbal, and visual working memory, social–emotional processing, thought processes, social communication, and executive functions.
Symptoms Associated with ASD and IDD	Frequently overshadow assessment of both negative and cognitive symptoms and may be overlooked in the assessment and diagnosis of SSDs.
Negative and Cognitive Symptoms	Less responsive to standard antipsychotic treatments contribute to significant functional impartment for many including in the following domains: educational, occupational, psychosocial, interpersonal.

Neurodevelopmental, Genetic, And Psychosocial/Ecological Issues

SSDs are highly heritable, but the effects of other biopsychosocial factors cannot be underestimated. Family, twin, and genetic studies support a stress-diathesis model in which inherited vulnerability interacts with environmental stressors, secondary biological hits, and socio-cultural factors to shape the clinical expression of SSDs. Investigating these elements and their impact is essential to our understanding of SSDs in the context of ASD/IDD.

Vignette

Description of the Person and Background

MB is a 31-year old female with a ten year history of auditory hallucinations (pictures on the walls talking about her, shadows doing things to her, voices laughing and threatening her), occasional visual hallucinations (monsters dressed in black and white capes), increased social isolation and avoidance, and recurring thoughts of being watched by the police. On multiple occasions, she became extremely agitated for no obvious reason and struck wildly at unseen objects. Her local psychiatrist diagnosed her with treatment resistant Psychosis due to Other Medical Condition. She also had a poorly controlled mixed seizure disorder that required multiple anticonvulsants. There was no family history of primary psychiatric disorders.

MB presents with a complex neurodevelopmental syndrome. Her differential diagnosis is a long one, but her symptoms suggest metamorphosis over the past 5 years. She experienced a stepwise regression that created a major shift in her temperament, personality, social interests, and social-communication abilities. She meets the diagnostic criteria for a psychotic disorder (suggestive of schizophrenia) based on clinical symptoms, duration of functional impairment, and episodic catatonic symptoms. There was nothing in her extensive work-up to suggest underlying metabolic or neurodegenerative disorders. There was no substantiated evidence of abuse, neglect, traumatic brain injury, or adverse drug reactions. There was documentation of failed trials of olanzapine, quetiapine, lucosamide, and multiple mood stabilizers. Extensive interviews with the patient, family, group home staff, vocational staff, and reviews of past psychological, medical, and neurological history suggested “visual hallucinations in early childhood” that waxed and waned over time. Her “psychotic symptoms” markedly intensified during her early twenties.

Examination

The examination reveals short stature, widely spaced eyes, expanded nasal bridge, and palmar creases. Her mental status examination was complicated by her catatonic muteness, and pre-occupation with the ceiling fan. She screamed about a monster riding on the blades mocking her. She had no EPS or dyskinesias, but occasional facial grimacing. Her labs show low serum calcium and mild blood abnormalities, Low Vit D3 and folic acid levels. Her genetic studies reveal a 22q 11.2-deletion syndrome- Velo-cardio-facial Syndrome (VCFS) without DiGeorge's syndrome. MB's current treatments include risperidone 2 mg/d, Fluoxetine 10 mg/d and valproic acid 1500 mg BID (serum drug level of 105), but no psychotherapies or major ecological interventions. MB has a history of complex partial seizures, surgically corrected tetralogy of Fallot (congenital cardiac abnormality), submucosal cleft, moderate ID and previous diagnoses of ADHD, social anxiety, and mild ASD.

Discussion

MB meets the criteria for treatment resistant schizophrenia-like psychotic disorder but lacks a positive family history for schizophrenia. The intriguing point in this case is the presence of 22q11.2 deletions syndrome. MB presents with core features of this deletion syndrome (large Copy Number Variant or CNV). The most interesting part of the story is the convoluted relationship between VCFS and late-onset schizophrenia-like syndrome. This behavioral phenotype has attracted significant attention as a rare CNV that, while representing only a small fraction of schizophrenia-associated CNVs and single nucleotide polymorphisms, is notable because nearly 30% of individuals with velocardiofacial syndrome (VCFS) develop SSDs. 11-12 There are genes involved that affect early brain development and regulation of neurotransmitters, inflammatory, and mitochondrial activity. The treatment of VCFS in part depends on the length of the VCFS copy number variant (missing genes), the presence of co-occurring ID/ASD, ADHD, and epilepsy (less common) as well as a range of psychosocial factors.

Nonpharmacological Interventions

Comprehensive treatment requires a thorough review of medical and family history, past interventions, assessment, differential diagnosis, and careful review of treatment options with close monitoring. Modified Cognitive Behavioral Therapies (CBT), Trauma-Informed Care, family and environmental interventions, and other wellness-based programs are an important part of the treatment plan. The goals of effective non-pharmacological intervention include relapse prevention, enhancing pharmacotherapy, and long-term improvements in resilience and health outcomes.[13-14]

Modified forms of CBT are particularly helpful during premorbid, and prodromal (attenuated psychosis) periods, as well as during maintenance treatment and medication tapering. Family involvement, social support, community services, and employment opportunities are essential components of a comprehensive treatment plan.[15-16]

Effective treatment programs depend on these factors:[17]

- **Early intervention:** Promptly address prodromal, attenuated symptoms and rapid activation during the first episode of psychosis. Utilize CBT, trauma focused therapy, educational/ support interventions to reduce the duration of untreated psychosis and enhance treatment compliance.
- **Assess Symptoms:** Assess symptom severity and distribution of positive, negative, and cognitive symptoms. Negative and cognitive symptoms often do not improve with pharmacotherapy alone; therapy should focus on cognitive, motivational, and behavioral strategies, which appear more effective in improving these symptoms.
- **Goal Attainment:** Design cognitive and behavioral strategies to train and support enhanced psychosocial, interpersonal, educational, and occupational programs.
- **Community and Social Integration:** Organize communities, social networks and activities and work-related programs that focus on developing a sense of personhood, place/belonging, and sense of purpose.

Integration of Pharmacotherapy with Psychosocial Interventions

Pharmacotherapies are important but adjunctive to treatment. Since introduced in the 1950's, antipsychotic drugs (APDs) have improved SSD treatment options. There were many advances in APD technology based on a broader understanding of pharmacokinetics, pharmacodynamics, and pharmacogenomics. These hypothesis-driven modifications still leave us without a cure and facing problems with residual negative symptoms, cognitive impairment, treatment resistance, polypharmacy, and persistent, adverse drug reactions. At the same time, the use of APDs expanded into the realm of generalized drug treatment for a variety of nonpsychotic disorders. Nevertheless, we have learned a few things along the way.[1, 21-25]

- The recovery rates are better for acute, first episode of schizophrenia if the duration until treatment is short, positive symptoms dominate, and there is rapid response to antipsychotic treatments (improvement by six weeks).
- The outcome is less optimistic when the onset is insidious, there is a long duration until treatment of psychotic symptoms, noncompliance and lack of insight are impaired, EPS occurs with limited improvement, negative and cognitive symptoms dominate, and there are comorbid psychiatric, personality and substance use disorders.
- The definition of treatment resistance is usually 2 or 3 drug treatment failures. Some treatment failures are due to noncompliance or side effects such as EPS/akathisia, significant weight/ metabolic syndrome (hyperlipidosis/Type 2 Diabetes), and cardiovascular side effects.
- In addition to noncompliance, treatment resistance is abetted by undertreated comorbid mood disorders (and OCD), unrecognized EPS (including akathisia), high dosing schedules that can mimic negative symptoms, and substance use.
- Long-acting injectable APDs can reduce noncompliance but still can cause side effects such as akathisia and tardive dyskinesia.
- Diet and exercise education programs, access to enjoyable wellness activities, adequate medical care, smoking cessation, and occasionally metformin can be helpful in reducing health care risks associated with APD treatment.
- APDs should be initiated at low doses, slowly titrated with close attention to drug-drug interactions.
- Clozapine is the most effective treatment for refractory patients. Clozapine requires vigilant monitoring for weight gain, cardiovascular toxicity (myopathy), GI complaints, hematological/ stem cell suppression, and serum level dependent forms of epilepsy (myoclonic and other generalized seizure disorder).
- If considering tapering antipsychotics for someone with SSDs then consider implementing nonpharmaceutical supports, variants of CBT, and well-structured, a slow, stepwise, and flexible dose reduction schedule of the antipsychotic. It is essential to have close follow-up, and recognition of the difference between clinical relapse and extinction spurts. Clinicians should very slowly taper to prevent withdrawal, dyskinesia, and other side effects.
- Newer treatments for refractory SSDs are being studied including direct-electrical stimulation, Transcranial Magnetic Stimulation, and novel pharmacological treatments.

Conclusion

Psychotic disorders are complex disorders and require careful assessment in people with ASD and IDD. Psychotherapeutic and social interventions are important parts of a comprehensive treatment plan. The successful treatment of SSDs/psychoses in people with IDD is still a work in progress. This chapter touched on many factors and workable solutions and includes evidence that the first- and second-generation antipsychotics work better for managing acute positive symptoms or assisting in maintenance treatment protocols. However, these same drugs are less helpful for chronic SSD with high levels of negative symptoms and cognitive impairments.

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Crisis Assessment and Intervention for People with Intellectual and Developmental Disabilities

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Overview

This chapter gives an overview of emergency care for people with Intellectual and Developmental Disability (IDD) and autism spectrum disorders (ASD). Acute crises are likely to occur when the intensity of stressors overwhelms the person's social, cognitive, emotional regulation, and adaptive skills, concurrent with mental health symptoms. For people with IDD and mental health disorders, an adverse life event can trigger relapse, exacerbation of baseline challenges, or contribute to persistent vulnerability. The prescriber must focus on the relationship between preventative and resilience factors and adverse events.

What is a Crisis and Who is Vulnerable?

- Crises can be singular or recurring events that lead to difficulties for the person in adapting or resolving the situation, significant changes in emotional states (internalizing), expressed behaviors (externalizing) or relapses in pre-existing mental disorders.
- Patients with IDD are heterogeneous with varying characteristics that need to be considered
- Etio-pathogenesis, genetic/metabolic/medical and behavioral comorbidities, temperamental traits, and patterns of attachment.
- Vulnerable people may experience a relapse of pre-existing mental health condition, or the onset of a new diagnosis.
- Unresolved crises can contribute to life-threatening circumstances or worsening physical or mental health conditions.

Triage

- Rapid triage based on a quick assessment of nature, severity, and ecological context of the presenting symptom.
- Rule out potentially life-threatening illness or injury.
- Provide a protective environment to minimize any further physical or emotional trauma.
- Conduct a more focused assessment (see section below for assessment).

Where is the Best Place to Evaluate?

- The patient should be evaluated in the least restrictive setting that can safely manage their crisis (e.g., outpatient versus emergency department versus mobile crisis team)
- Consider alternatives to unnecessary ED visits (ED environments are busy, loud, and overwhelming environments that can lead further stress for the person)
- Consider non-pharmacologic strategies to minimize stress in ED or other settings

Non-Pharmacologic Strategies to Minimize Stress in the Emergency Department and Other Settings

- Attempt to verbally de-escalate the person through reassurance and positive engagement (trauma informed approaches are best)
- Find out what is comforting (blankets, etc.), soothing (topics, snacks, music) or enjoyable to the person- consider utilizing strength-based approaches
- Reduce stimulation in setting: Quiet room, minimize non-essential monitoring equipment, dim fluorescent lighting
- Ensure safety, consult with, or have available people familiar with the patient's and their history
- Ask the person how they prefer to communicate. If a family member or supporter is present, they can also assist.
- Consistent staff, minimize intrusive or nonessential contacts
- Explain or demonstrate what is about to be done and consider utilizing a preferred person to do this
- Minimize physical restraints or PRN injections[5-7]
- See chapter on Sensory Considerations for Prescribers in this guide for further recommendations.

Comprehensive Assessment

An assessment begins with obtaining enough history to determine deviations from previous functional baselines, a search for predisposing and precipitating factors. Three timelines are useful:

1. Track the description of the emotional states or evolving signs/symptoms- time of appearance, escalation, frequency, and level of intensity.
2. Develop biopsychosocial and ecological timelines and maps of current life stressors.
3. Develop a timeline of interventions during this crisis and previous episodes.[1,2]

Several sources of information are critical. Personal information can be from the person with IDD, care providers, parents/guardians, or other treatment team members familiar with the patient. The status of nonverbal people or those with severe-profound ID often hinges on careful observation of nonverbal and physiological expression of emotional and physical states. The purpose of data collecting is to address predisposing factors, precipitating events, circumstances that place the person for relapse or chronicity (persistence). Although sometimes difficult to carry out in a busy ED, it is also helpful to explore the relationship between protective/resilience factors and ongoing ecological/psychosocial stressors.[3] The goal of this data collection is to develop an overall treatment plan that includes further diagnostic workup, putting acute strategies in motion, and developing long term programs to maximize wellness and adaptive functioning. The integration of psychotherapies and adjunctive pharmacotherapies is also part of this decision-making process. Table 2 outlines a useful mnemonic and key methodology in assessing patients in crisis.

Key Components in Assessing Patients with IDD in Crisis

- Understand the person's baseline functioning (what do they look like when they are doing well and when did they last appear that way)
- Assess for medical/neurologic disorders (use the HEAD TO TOESS acronym as a guide)[1,2,4]
  - » Headache and other pain (ingrown toenails, calluses)
  - » Epilepsy
  - » Aspiration Pneumonia or dysphagia
  - » Drugs: Assess for adverse medication effects or interactions; ask about complementary and alternative medications; understand recent changes
  - » Teeth: Examine the person's teeth for dental pain, infection, abscesses, or impacted teeth
  - » Ocular and Otolaryngology Issues: Earache, hearing issues, sinusitis, vision problems, and obstructive sleep apnea

    - Tummy: GERD, Constipation, Bowel obstruction, and volvulus
  - Osteoporosis and atypical fractures, pressure sores, spasticity
  - Etiology/cause of IDD: Genetic syndromes can have acute presentations
    - E.g., Calcium Disturbance in William's Syndrome
    - Serious or new onset illness can present atypically (hypothyroidism, DM I or II)
    - Look for subtle signs that the person is very ill such as not drinking/eating
    - Screen for abuse [2,4]
- Assess for psychosocial stressors including personal loss (e.g., caregiver, friend, staff, etc.), change in program, residence, etc.
- Assess for comorbid substance use/abuse/dependence
- Assess for comorbid psychiatric disorder
- Physical examination: Conduct a full and comprehensive physical examination
- Mental Status Examination: Assess suicidality and homicidality, psychotic symptoms, catatonic symptoms, and future orientation
- Labs to consider thyroid stimulating hormone (TSH), complete blood count (CBC), vitamin D level, liver function tests (LFTs), renal function tests, urine drug screen, (any other pertinent labs based on exam and history).
- Consider imaging based on history and physical examination (e.g., Abdominal imaging for constipation, etc.)

Psychotropic Medication in Crisis Stabilization

The use of psychotropic drugs in crisis stabilization is both a balancing act and an art. In some contexts, the ED can be an overstimulating setting and the person's expressed emotional state, and stress responses interfere with a thorough assessment. Unfortunately, sedation imposes severe limitations on data gathered by close observation of behaviors. On the other hand, a severely agitated person can disrupt comprehensive evaluation. Non-pharmacological strategies (noted in Table 1) can be extremely helpful in resolving this conundrum.

When to Prescribe?

The decision to use psychotropic drugs in crisis intervention is a complex, context dependent process that exceeds the space allotted here. The algorithmic nature of the decision-making steps is outlined later in this guide. Each section in this guide provides guidelines for medication selection for psychiatric disorders.

Who Should Get Psychotropic Medications?

Externalizing behaviors like aggression, self-injury, agitation, and loud vocalizations are heterogeneous and arise from many sources. There are no one-size-fits-all answers for pharmacological treatments. Table 1 provides an outline of many medical factors that can contribute to crisis. The presence of a psychiatric disorder does not eliminate the possibility that one or more of these medical issues is the culprit. Frequently, treating the underlying psychiatric disorder or medical condition will mitigate the crisis. The same approach applies to many internalizing symptoms.

Irritability is a transdiagnostic pattern of behavior (occurring across many diagnostic categories) that may respond to a variety of medications. Evidenced-based choices frequently include broad-spectrum treatments such as risperidone and other second and third generation antipsychotics. Other options include anticonvulsant mood stabilizers, benzodiazepines, psychostimulant-type drugs for patients with comorbid emotional lability, SSRIs and SNRIs.

One major issue involved in pharmacological crisis intervention hinges on factors such as patterns of co-occurring symptoms, lack of specificity of a drug for a specific presentation, delivery systems (IM, PO etc.), and a prolonged latency of absorption and response. Each of these factors can also limit the efficacy of many drugs as PRNs. Equally problematic is the challenge of polypharmacy, multiple complex patterns of drug-drug interactions, and the increased likelihood of an adverse drug reaction mimicking psychiatric symptoms.

Unfortunately, there is a modicum of research on psychopharmacologic treatments for patients with IDD in crisis. We have the usual guidelines of “start low and slowly titrate” based on response to treatment with consideration of comorbid medical issues and drug-to-drug interactions. The patient should be closely monitored for response or adverse reaction to treatment. Selection of the medication is based on symptoms, comorbid diagnosis, safety, side effect profile, drug-to-drug interactions, and historical response to a medication/or class of medications.[5] If the patient needs medication, the goal should be to calm the patient and not completely sedate them.[6] Oral medication administration is preferred over intramuscular or intravenous route.[7] Problems with maintaining IVs and the risk of prolonged QTc intervals and other cardiac side effects restrict the use of IV antipsychotics. Some combinations of IM antipsychotic and benzodiazepine are a mainstay for treatment of acute agitation. In the emergency department setting, these include haloperidol 5 mg with lorazepam 1-2 mg, or IM olanzapine or ziprasidone 10 mg.[5] Side effects to consider when selecting a medication include the following.

- Antipsychotics: may cause acute dystonic reactions, akathisia, or QT prolongation
- Benzodiazepines: over sedation, respiratory depression, and some patients with IDD may have a paradoxical reaction to benzodiazepines and become more agitated instead of more calm/sedated.

While medications may calm the patient, it is important to recognize that they are not diagnostic tools. The real work requires establishing the cause for the emergency/crisis and then the team creates a plan of care and then takes steps to carry out that intervention.

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Polypharmacy in the Mental Health Treatment of Patients with Intellectual and Developmental Disabilities

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Overview

People with IDD are vulnerable to high-risk prescribing practices such as polypharmacy or the overuse of antipsychotics.[1,2] Polypharmacy, often defined as the use of 5 to 10 or more medications in a person's regimen, affects 11% to 60% of people with IDD.[3-5]

Appropriate Versus Problematic Polypharmacy

Appropriate polypharmacy: "the use of multiple medications that are clinically indicated, optimized, and prescribed according to best evidence. They extend life expectancy and improve quality of life for the patient."[6]

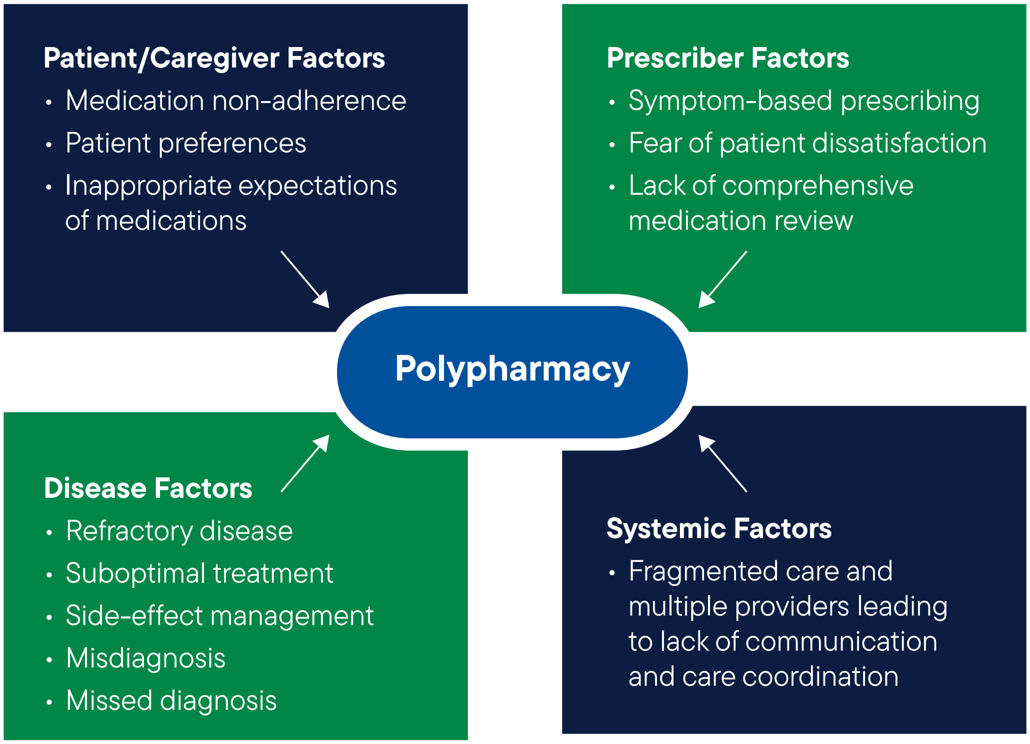
Problematic polypharmacy: the use of medicines that are no longer appropriate, overuse of high-risk medications (e.g. second-generation antipsychotics, or anti-epileptics in absence of a seizure disorder), the benefits do not outweigh harm, combinations cause or risk harm and usage become unmanageable or distressing.

- Prescribing cascade: adding additional, potentially avoidable medications to drug regimens, often without dropping an existing medication or reducing a dose.[7]
- This commonly occurs with psychotropic medications and people with IDD.[8-9]
- Polypharmacy with psychotropic medication leads to an increase in adverse events and drug interactions that negatively affect quality of life.[9-11]

Factors Contributing to Polypharmacy

There are many factors that can contribute to polypharmacy. It is important to understand these factors and how they relate to the patient you are caring for; Figure 1 illustrates these factors.

Figure 1: **Contributing Factors to Polypharmacy**[12]



Patient/Caregiver Factors
- Medication non-adherence
- Patient preferences
- Inappropriate expectations of medications

Prescriber Factors
- Symptom-based prescribing
- Fear of patient dissatisfaction
- Lack of comprehensive medication review

Polypharmacy

Disease Factors
- Refractory disease
- Suboptimal treatment
- Side-effect management
- Misdiagnosis
- Missed diagnosis

Systemic Factors
- Fragmented care and multiple providers leading to lack of communication and care coordination

Risks and Consequences of Polypharmacy

Patients treated with polypharmacy are at increased risks that prescribers should consider. Health risks are summarized in Table 1, while additional risks are detailed in Tables 2 and 3.

Table 1: Health Risks Associated with Polypharmacy

Health Risks	Examples of High Risks with These Medications or Combination of These Medications	Consequences
Metabolic Side Effects	• Second Generation Antipsychotics (e.g., clozapine, olanzapine, risperidone) • Anti-epileptics (e.g., valproic acid) and second-generation antipsychotics	Obesity, hyperlipidemia, and diabetes
Seizures	• Antipsychotics (e.g., clozapine, olanzapine, chlorpromazine, haloperidol) • Antidepressants (e.g., Bupropion, Tricyclic Antidepressants, and Selective Serotonin Reuptake Inhibitors) • Stimulants • Lithium • Antibiotics (e.g., Penicillin, Cephalosporins, Quinolones) • Analgesics (e.g., tramadol)	Decrease in seizure threshold
Cardiac	• Antipsychotics and SSRIs/TCAs (e.g., Haloperidol and Citalopram • Antipsychotics and Macrolide antibiotics • Antipsychotics and Methadone	QTC prolongation and arrhythmias
	Clozapine and Benzodiazepines	Myocarditis, Hypotension, Cardiac Arrest
	SSRIs and Beta Blockers	Bradycardia and hypotension
	Antipsychotics and TCAs	Tachycardia, orthostatic hypotension, QT Prolongation
	Lithium and Diuretics/NSAIDS/ACE Inhibitors	Bradycardia and T wave changes

Table 1: Health Risks Associated with Polypharmacy, continued

Health Risks	Examples of High Risks with These Medications or Combination of These Medications	Consequences
Akathisia	• Antipsychotics • SSRI/SNROs • Stimulants • Antiemetics • Lithium • Anticholinergics	Increased restlessness, irritability, or agitation
Extrapyramidal Symptoms	• Antipsychotics + Antipsychotic • Antipsychotic + SSRI/SNRI or Lithium or Valproate • Antipsychotic + Cholinesterase Inhibitors • Antipsychotics + Metoclopramide or prochlorperazine	Parkinsonism, dystonia, tardive dyskinesia, or neuroleptic malignant syndrome
Liver Injury	• Valproate + Antipsychotic or Lamotrigine or Atomoxetine • Carbamazepine + Antipsychotic or Antidepressant • Phenobarbital + Phenytoin + Psychotropics • Nefazodone + Psychotropics	Mild enzyme elevations, severe hepatoxicity, to acute liver failure
Constipation	• Antipsychotics (e.g., clozapine) • TCA • Opioid • Anticholinergics	Constipation or decreased gastrointestinal motility
Sedation	• Antipsychotics • Benzodiazepines • Mood Stabilizers (e.g., valproate, carbamazepine) • Antidepressants (e.g., trazodone, mirtazapine) • Other sedative agents (e.g., melatonin, hydroxyzine)	In people with IDD, sedative effects may be more significant and increase risk of falls, cognitive impairment, and reduced functioning.

Table 2: **Quality of Life Risks with Polypharmacy**

Quality of Life Risks	Consequences
Financial	Increased costs due to multiple medications or may limit access to needed medications.
Time	Increased time picking up and managing medications and monitoring
Physical Health	Potential decline in physical health
Daily Functioning and Cognitive Functioning	Potential decline in physical and cognitive functioning

Table 3: **Prescribing and Administration Risks with Polypharmacy**

Prescribing and Administration Risks	Consequences
Prescribing Errors	Can lead to inappropriate drugs being prescribed, increasing risk of side effects or adverse reactions.
Dosing Errors	Incorrect dose can lead to ineffective treatment or toxicity.
Mistakes in Taking or Administering Medications	Complex medication regimens increase the risk of patient or caregiver errors.
Potential Difficulties with Monitoring	Harder to track benefits and side effects of medication when multiple medications are prescribed

Appropriate Prescribing

It is imperative that the prescribing of psychotropic medication to people with IDD is aligned with evidence-based prescribing practices and is guided by clinical practice guidelines. Guidelines help ensure that patients receive treatments that are most appropriate for their care.

- OPTIMA-ID (Optimizing Pharmaco-Therapy and Improving Medication for Ageing with Intellectual Disability) is a guide to optimization of medication regimens for older adults with intellectual disability, developed by healthcare providers as well as persons with intellectual disability.[13]
- Twenty-two of the 67 criteria in OPTIMA-ID focus on psychotropic medications. Incorporating education and training with implementation of guidelines is another approach to working to ensure appropriate prescribing of psychotropic medications.
- STOMP initiative (Stopping over-medication of people with intellectual disability, Autism, or both -STOMP), was developed as an intervention to improve the prescribing of psychotropic medications taken by persons with ID living in the United Kingdom.
- Implementation of the STOMP initiative has led to increased awareness of prescribing practices of psychotropic medications for persons with ID in the UK.[14]

It is important for clinicians and caregivers to investigate physical, environmental, and social factors when challenging behaviors are present, which may respond to non-medication approaches such as cognitive behavior therapy and positive behavior support.[15] Because of the adverse effect profile of psychotropics, and antipsychotics, the decision to use these medications as an intervention for challenging behavior should be carefully rationalized.[16,17]

Key Steps in Deprescribing Psychotropic Medications[18]

- Obtain a complete list of all the medications that the patient is taking and the reason for each medication.
- Understand the effect of the medication on the patient (e.g., if it was helpful or not, if it has caused side effects and what side effects)
- Conduct a complete evaluation of the patient, including a thorough understanding of what is going well and what is not going well in their life.
  - Full review of systems

- Obtain any indicated measurements: e.g., BMI, Labs, rating scales, etc.
- Develop a crisis/safety plan.
- Understand why the patient was put on polypharmacy (coordinate with other prescribers and have an interdisciplinary approach).
- Consider each medication's potential benefits against its potential risks or burdens, both now and in the future.
- Provide psychoeducation to patients and caregivers and/or guardians about polypharmacy, the potential benefits, and the potential risks. Consider deprescribing with patient and caregiver and/or guardian.
  - Discuss the pros and cons of deprescribing
- Consider deprescribing the medication with the lowest benefit or lowest risk of withdrawal or medication that is causing side effects.
- Slowly Taper the medication and closely monitor.
- Most medications should be slowly tapered in a systematic and stepwise approach (e.g., 10-25% of dose every 2-4 weeks until discontinuation).
- Some medications (e.g., stimulants) can be discontinued without a taper).
- Use rating scales to monitor the underlying condition the medication was intended to treat (e.g., aberrant behavior checklist for behaviors that challenge).
- Consider more frequent visits to check on the patient for improvement or side effects.

Conclusion

Polypharmacy is a common and concerning practice for people with IDD. While some cases of polypharmacy are appropriate, many involve inappropriate prescribing practices that can lead to adverse outcomes. Thoughtful, evidence-based prescribing is important, and active deprescribing of unnecessary medications is also a particularly important intervention.

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Appendix

Considerations for Psychotherapeutic Accommodations

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It takes an interdisciplinary treatment village to promote wellness. Psychotherapy is a powerful tool for enhancing wellness, emotional wellbeing, and mastery while enhancing life skills. In this appendix is a list of evidence-based, frequently used therapeutic modalities and resources regarding the efficacy of the modalities for persons with IDD.

The following are considerations for adapting psychotherapy and other intervention methods during treatment involving persons with IDD

- **Speed:** Adaptations of speed refer to providing intervention at a slower pace and allowing the additional time to process the content and respond. This adaptation is commonly used in providing accommodations for academic testing when learners are given additional time during exams.
- **Number:** This accommodation refers to providing either more or less exemplars to the patient. Either of these might be appropriate for a patient depending on the learning abilities and profiles they have. If the patient requires additional practice for acquiring a skill or concept, the adaptation would be to increase the number of exemplars used. If the patient has difficulty generating responses, fewer responses could be required.
- **Abstraction:** Adaptation based on abstractness involves reducing the level of abstraction and improving content concreteness. This is accomplished by using objects, drawings, and role play rather than lecture, discussion, or reading materials.
- **Complexity:** These adaptations generally involve breaking content down into smaller chunks or units. This is familiar to special educators in the instructional technique of Task Analysis.

Resources by Therapeutic Approach

There are many evidence-based practices that have been successfully adapted to improve health and wellness for people with IDD. While the list below is not all inclusive, it provides options for treating mental health conditions for persons with IDD.

Positive Psychology

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Positive Identity Development

- Harvey K. Positive Identity Development: An Alternative Treatment Approach for Individuals with Mild and Moderate Intellectual Disabilities. *Adv Ment Health and Intellect Disabil.* 2011; 5(6):57-58.

Trauma Informed Care

- Peterson C, Seligman ME. Character strengths and virtues: A handbook and classification (Vol. 1). New York, NY: Oxford University Press; 2004.
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- McNally P, Irvine M, Taggart L, Shevlin M, Keesler J. A framework for the implementation of trauma-informed care in residential and supported living services for adults with a learning disability. Ulster University; 2022.

Interactive Behavioral Therapy

- Razza NJ & Tomasulo DJ. *Healing trauma: The power of group treatment for people with intellectual disabilities.* Washington, DC: American Psychological Association; 2015.
- Tomasulo DJ. Positive group psychotherapy modified for adults with intellectual disabilities. *J Ment Health Res Intellect Disabil.* 2014; 18 (4): 337-350.

Cognitive Behavioral Therapy

- Harley SL, Esbensen AJ, Shaley R, Vincent LB, Mihaila MI, et al. Cognitive behavioral therapy for depressed adults with mild intellectual disability: A pilot study. *J Ment Health Res Intellect Disabil.* 2015: 8(2): 72-97.
- Jahoda A. Cognitive-behavioural intervention for people with intellectual disability and anxiety disorders. *J Appl Res Intellect Disabil.* 2006: 19 (1):91-97.

Positive-Cognitive Behavioral Therapy

- Mira A, Breton-Lopez J, Enrique A, Castilla D, et al. Exploring the incorporation of a positive psychology component in cognitive behavioral internet-based program for depression symptoms. Results throughout the intervention process. *Front Psychol.* 2018; 9:2360.
- Ramirez de Arellano M, Lyman R, Jobe-Shields L, George P, Dougherty RH, et al. Trauma-focused cognitive behavioral therapy: assessing the evidence. *Psychiat Serv.* 2014; 65(5):591-602.

Dialectical Behavioral Therapy

- Brown JF, Brown MZ, & Dibiasio P. Treating individuals with intellectual disabilities and challenging behaviors with adapted dialectical behavior therapy. *J Ment Health Res Intellect Disabil.* 2013; 6(4):280–303.

Acceptance and Commitment Therapy

- Brown FJ, & Hooper S. Acceptance and commitment therapy (ACT) with a learning-disabled young person experiencing anxious and obsessive thoughts. *J Intellect Disabil.* 2009; 13(3):195-201.

- Levin ME, Aller TB, Klimczak K, Donahue ML, Knudsen F. Digital acceptance and commitment therapy for adults with chronic health conditions: results from a waitlist-controlled trial. *Behav Res Ther.* 2025;104729. doi:10.1016/j.brat.2025.104729.
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Motivational Interviewing

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Exposure Therapy

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Wellness

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- Young H, Erickson ML, Johnson KB, Johnson M, & McKully K. A wellness program for individuals with disabilities: Using a student wellness coach approach. *Disabil Health.* 2015; 345-352.

Solution Focused Interventions

- Roeden JM, Bannink FP, & Curfs LM. Solution-focused brief therapy with people with mild intellectual disabilities: A case series. *J Policy Pract Intellect Disabil.* 2011; 8(4): 247-255.
- Stoddart KP, McDonnell J, Temple V, & Mustata A. Is Brief Better? A Modified Brief Solution-Focused Therapy Approach for Adults with a Developmental Delay. *J Systemic Therap.* 2001; 20(2): 24-40.

Eye Movement and Desensitization Re-processing (EMDR)

- Gilderthorp J. Is EMDR an effective treatment for people diagnosed with both intellectual disability and post-traumatic stress disorder? *J Intellect Disabil.* 2015; 9(1): 58-68.
- Biofeedback
- Yucha CB, & Montgomery D. *Evidence-based practice in biofeedback and neurofeedback.* Nevada: Association for Applied Psychophysiology and Biofeedback; 2008.

Conceptual, Social, and Practical Abilities Based on Level of Intellectual Disability

Originally developed by Jill Hinton, PhD (2016); Modified by Joan B. Beasley (2/2020; 7/2025)

Level[1]	**Conceptual Domain** (learning, abstract thinking, planning, flexibility, memory, strategizing, academic skills)	**Social Domain** (language, communication, social skills)	**Practical Domain** (personal care, employment, health care and legal, recreation, transportation, shopping, money management)
Mild	• Difficulties learning academic skills • Impaired executive functioning, abstract thinking, short term memory • Concrete approach to problem solving	• Communication, conversation, and language are concrete • May have difficulty regulating some emotions and expression • May have impaired social judgment and limited understanding of social risks • May have marked differences in expressive and receptive language	• May function independently in personal care • May need support in complex daily living tasks • May live semi-independently or independently • Competitive or supported employment. • May need support for health care decisions and childcare
Moderate	• Throughout development, conceptual skills are behind those of peers. • Academic skills develop slowly and are limited compared to peers. • Adult academic skills are at an elementary level. • Support needed for conceptual tasks of day-to-day life.	• Marked difference in social and communication across development • Spoken language used, but much less complex than peers • Social judgment, communication, and decision making may require support in work and social settings • May have marked differences in expressive and receptive language	• Can learn to care for personal needs but may need extended period of teaching • May need reminders, schedules life-long • Employment with considerable support to manage social expectations and job complexities • Require support for scheduling, transportation, health issues, and money management • Typically, adaptive strategies are needed to learn new skills over an extended time.

Conceptual, Social, and Practical Abilities Based on Level of Intellectual Disability, continued

Level[1]	**Conceptual Domain** (learning, abstract thinking, planning, flexibility, memory, strategizing, academic skills)	**Social Domain** (language, communication, social skills)	**Practical Domain** (personal care, employment, health care and legal, recreation, transportation, shopping, money management)
Severe	• Attainment of conceptual skills is limited • Little understanding of written language or math/money concepts • Need extensive support for problem solving throughout life.	• Spoken language is limited • Speech may be single words and phrases • Language is focused on here and now • Relationships with family and familiar others are a source of comfort and help	• Requires support for all activities of daily living • Needs significant support in making decisions about well-being of self or others. • Long-term teaching and support required for participation in home, recreation, and work.
Profound	• Conceptual skills involve physical world rather than symbolic processes • May use objects in goal-directed way • Visual spatial skills such as sorting, and matching may be acquired • Co-occurring motor and sensory impairments may also affect ability to use objects in s functional way	• Limited understanding of symbolic communication • May understand simple instructions and gestures • Expresses desires through nonverbal, non-symbolic communication. • Enjoys relationships with well-known family members and familiar others	• Dependent on others for all aspects of daily physical care, health, and safety • May assist with simple tasks at home • Simple actions with objects may be basis of involvement in vocational activities • Recreational and leisure often involve sensory activities – music, walks outside, water activities – with support from others. • Co-occurring motor and sensory impairments may be barriers to participation

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