NATIONAL CENTER
for START SERVICES™
Institute on Disability
University of New Hampshire

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

These guidelines were developed by the National Center for START Services at the University of New Hampshire Institute on Disabilities with funding from the WITH Foundation.

PI, Joan B. Beasley, PhD

Contents

The first edition of *The Integrated Mental Health Treatment Guidelines for Prescribers in Intellectual and Developmental Disabilities* was made possible with funding from the WITH Foundation. Content developed as part of this project is provided at no-cost.

Thank you to all of our project contributors, focus group respondents and participants.

Following review and use of *the IDD-MH Prescriber Guidelines*, please take a few minutes and complete this survey. Responses are confidential and will be reviewed by the editors during the development of future editions of this guide.

Senior Editors

Barnhill, L. Jarrett, MD, DFAPA, FAACAP, Professor and Founding Director, Program on Neurodevelopmental Psychiatry, UNC School of Medicine; Co-Editor, Diagnostic Manual-Intellectual Disability

Beasley, Joan B., PhD, LMHC, Research Associate Professor, University of New Hampshire College of Health and Human Services, Institute on Disability/UCED, Director, Center for START Services, UNH IOD

Caoili, Andrea, LCSW, Director of Research & Quality Assurance, Center for START Services, University of New Hampshire Institute on Disability/UCED

Hecker, Melanie, MPA, Self-Advocate, Research and Training Assistant, Center for START Services, University of New Hampshire Institute on Disability/UCED

Klick, Susan, Family Member

Contributing Editors

Charlot, Lauren, PhD, LICSW, Adjunct Professor, Department of Psychiatry, Brody School of Medicine, Eastern Carolina University; Assistant Professor, Department of Psychiatry, UMass Medical School; Clinical Consultant, NY START Region 4 Triborough (YAI); Clinical Reviewer, US Department of Justice

Rubin, I. Leslie, MD, Associate Professor, Department of Pediatrics, Morehouse School of Medicine, Adjunct Associate Professor, Department of Pediatrics, Emory University School of Medicine, Co-director, Southeast Pediatric Environmental Health Specialty Unit, Emory University School of Medicine

Diane Jacobstein, PhD, Clinical Psychologist/ Adjunct Associate Professor of Pediatrics, Georgetown University Center for Child and Human Development-UCEDD

Contributing Authors

Baker, Daniel, PhD, NADD-CC, Jenson Internal Reviewer and Positive Support Compliance Specialist, Minnesota Department of Human Services

Baldor, Robert, MD, FAAFP, Professor of Family Medicine and Founding Chair, Department of Family Medicine, University of Massachusetts Medical School-Baystate

Benson, Alyce M., LCSW, Project Facilitator, Center for START Services, University of New Hampshire Institute on Disability/UCED

Blanco, Roberto, MD, Clinical Assistant Professor, Child and Adolescent Psychiatry, Co-Director, Program on Neurodevelopmental Psychiatry, UNC School of Medicine; Medical Director, NC START Central

Grosso, Elizabeth, MSW, Director of Training and Professional Development, Center for START Services, University of New Hampshire Institute on Disability/UCED

Harvey, Karyn, PhD, Director of Training and Program Development, The Park Avenue Group, LLC

Hinton, Jill, PhD, Clinical Director, Center for START Services, University of New Hampshire Institute on Disability/UCED

McLaren, Jennifer, MD, Assistant Professor of Psychiatry, Dartmouth Geisel School of Medicine; Co-Director, Neurodevelopmental Psychiatry Clinic at Dartmouth Hitchcock Medical Center; Medical Director, New Hampshire Bureau of Developmental Services, Chief Medical Advisor, Center for START Services, University of New Hampshire Institute on Disability/UCED

Stratigos, Katharine, MD, Assistant Clinical Professor of Psychiatry, Columbia University Department of Psychiatry; Medical Director, NY START Region 4 Triborough

Tomasulo, Dan, PhD, MFA, MAPP, Academic Director, Spirituality Mind Body Institute (SMB) MA Degree Program, Core Faculty Dept of Clinical Psychology, Teachers College, Columbia University; Assistant Instructor, University of Pennsylvania Master of Applied Positive Psychology; Director, NYC Certification in Positive Psychology, Open Center

Weigle, Karen L., PhD, Associate Director, Center for START Services, University of New Hampshire Institute on Disability/UCED

Yielding, Jeni, OTR/L, Occupational Therapist, Consultant

Introduction

L. Jarrett Barnhill, MD, DFAPA, FAACAP, Joan B. Beasley, PhD, and Andrea Caoili, LCSW

Background

The Integrated Mental Health Treatment Guidelines for Prescribers in Intellectual and Developmental Disabilities offers an overview of integrated health and psychopharmacological guidelines in the treatment of patients with intellectual and developmental disabilities (IDD) and autism spectrum disorders (ASD). Prior to the development of this guide, a series of focus groups was conducted with individuals with lived experience, family members, clinicians, and prescribers. Focus group responses were analyzed and used to inform the development of the guide's content and vet accompanying resources.

The editors would like to thank all contributors: persons with IDD and mental health service experiences, family members, and an interdisciplinary group of experts in IDD, including members of the National START Medical Directors (MD) Practice Group. The MD group is organized and facilitated by Center for START Services (CSS) at the University of New Hampshire Institute on Disability/UCED. To learn more about the Center for START Services, please visit www.centerforstartservices.org.

The development of the *IDD-MH Prescriber Guidelines* (as this guide has come to be called) and accompanying resources was made possible with funding from the WITH Foundation and was field tested prior to publication. The aim of the editors is to continue to expand upon this foundation and provide additional best practice content to prescribers with periodic updates. All feedback is welcome.

How to Use These Guidelines

The IDD-MH Prescriber Guidelines offers content on specific topic areas with regard to best practices in the diagnosis and treatment of individuals with IDD/ASD and mental health needs. Within each section, readers will find case vignettes and resources referenced for additional information.

The sections in this guide are:

1. *The Lived Experience Perspective: Working with Patients and Supporters*
2. *Psychiatric Assessment Considerations*
3. *Medical Assessment Considerations*
4. *Best Practices in MH Diagnosis and Treatment*
5. *Prescribing in Mental Health Crises*

The recommendations presented here are based on the most current scientific evidence, including a broad review of international literature. In some instances, the information may differ from prescribers' current practice, reflecting advances in the field. The resources to accompany this guide are diverse and comprehensive. Relevant journal articles, texts and other writings are provided at the end of each section and a full list of references can be found at the conclusion of guide.

Disclaimer: All medication should be used with caution and should not be used as primary frontline treatment. The IDD-MH Prescriber Guidelines is not a diagnostic tool or textbook. It provides general guidance with regard to evidence-based best practices in prescribing.

Foreword: 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 the 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[2] himself thought his patients' "expectations, colored by hope and faith" mostly explained treatment success or failure. Karl Menninger[3] viewed hope as the essential ingredient of healing and encouraged psychology practitioners to study it. More recently, Irvin Yalom[4], the celebrated existential and group therapist, identified the instillation of hope as a crucial factor in the therapeutic process. Today, Martin Seligman[5], the "father of positive psychology," and Chris Peterson[6] have elevated hope as one of the 24 core character strengths that make human beings flourish. Additionally, Steven Maier[7] and Martin Seligman offer specific research which suggests that hope arises when there is an expectation that future bad events will be temporary, specific, and manageable.

Other researchers, like Snyder[8,9], Cheavens[10], and Lopez[11] suggest that hope involves having a pathway to achieve goals and the agency, or motivation, to reach these goals. Others, like Barbara Fredrickson[12], 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[13] have found that hope and healing happens 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 potentiality. 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.[14] 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 death. 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 that 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
- Reduced post-traumatic stress disorder symptoms
- Improved adaptive coping strategies
- Reduced rumination
- Less catastrophizing about pain
- Diminished neuroticism
- Improved executive function
- Decreased impulsivity
- Better sleep
- Increased emotional stability
- 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
- 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.[1] 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. Introduction of strategies to cultivate hope is 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.

[1] Tomasulo D. *Learned Hopefulness: The Power of Positivity to Overcome Depression.* Oakland, CA: New Harbinger Publications; 2020.

[2] Freud S, Strachey J. *The Psychopathology of Everyday Life.* New York, NY: Penguin Books; 1975.

[3] Menninger KA. *The Human Mind.* New York, NY: The Literary Guild of America; 1930.

[4] Yalom ID. *The Theory and Practice of Group Psychotherapy.* New York, NY: Basic Books; 1970.

[5] Seligman ME. *Flourish: A Visionary New Understanding of Happiness and Well-being*. New York, NY: Atria Paperback; 2013.

[6] Peterson C, Seligman ME. *Character Strengths and Virtues: A Handbook and Classification.* Washington, DC: Oxford University Press; 2004.

[7] Maier SF, Seligman ME. Learned helplessness at fifty: Insights from neuroscience. *Psych Review*. 2016; 123(4): 349.

[8] Snyder CR. Hope theory: Rainbows in the mind. *Psychol Inq.* 2002; 13(4):249-275.

[9] Snyder CR, LaPointe AB, Crowson JJ, Early S. Preferences of high-and low-hope people for self-referential input. *Cogn Emot*. 1998; 12(6):807-823.

[10] Cheavens JS, Heiy JE, Feldman DB, Benitez C, Rand KL. Hope, goals, and pathways: Further validating the hope scale with observer ratings. *J Positive Psychol.* 2019; 14(4):452-462.

[11] Lopez SJ. *Making Hope Happen: Create the Future You Want for Yourself and Others*. New York, NY: Simon and Schuster; 2013.

[12] Fredrickson BL. Positive emotions broaden and build. *Adv Exp Soc Psychol.* 2013; 47:1-53.

[13] Herth K. Abbreviated instrument to measure hope: development and psychometric evaluation. *J Adv Nursing.* 1992; 17(10):1251-1259.

[14] Long KNG, Eric ES, Chen Y, Wilson MF, Worthington EIJ, VanderWeele TJ. The role of hope in subsequent health and well-being for older adults: An outcome-wide longitudinal approach. *Global Epidemiology.* 2020; 100018.

Fundamentals of Psychopharmacology

L. Jarrett Barnhill, MD, DFAPA, FAACAP

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:

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 individuals with IDD.

The prescriber requires a working knowledge of the 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 also 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 treatment to match the data.

Treatment Response Monitoring Systems

- 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

2. Many prescribing decisions are contingent on an accurate diagnosis.

The brain changes and adapts throughout our lifecycle. Behavior, cognition and complex brain functions are vulnerable to many physiological, genetic/metabolic, 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, a number of these early-onset conditions can also predispose individual vulnerability to behavioral and psychiatric disorders.

Pain, constipation, dental abnormalities and medication side effects frequently contribute to an 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) are 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.

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 individual 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 but 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 for both positive and negative treatment responses. The decision 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 evidenced-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 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 individuals 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.

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 individual, caregivers, and other team members about potential problems.

The Lived Experience Perspective: Working with Patients and Supporters

Melanie Hecker, MPA, Susan Klick, and Beth Grosso, MSW

Communicating with Patients with IDD and Their Family Members

DO	DON'T
Talk directly to the patient.	Talk around or over patients.
Engage the patient's family member/caregiver that they invite into the appointment—they can be one of the best resources you have!	Hesitate to engage the patient's family member/caregiver in the discussion.
Actively listen.	Miss the value in what patients have to say.
Explain why you are recommending a medication, treatment, etc. in a way the patient can understand.	Assume that the patient knows what you know or use medical jargon that the patient may not understand.
Ask a lot of exploratory questions.	Simply ask, "What brings you here today?" Assume patients will bring up things independently.
Value the importance of your patient trusting you—with trust comes greater insight and disclosure.	Have an expectation that every patient automatically trusts you.
Seek to understand what a patient's disability means to them and how it uniquely affects them.	Assume that everyone with a particular disability has the same needs.
Explore medical/behavioral phenotypes associated with a patient's genetic syndrome.	Make diagnoses without fully understanding a patient's biopsychosocial vulnerabilities.
Seek to understand how a patient's mental health has been treated in the past and how this may affect current presentation.	Label a patient as "difficult/challenging."
Remain open to feedback from your patients.	Believe that your patients have nothing to teach you.
Take the patient's entire life into consideration: Where do they live? Where do they work? School? Family? Cultural background? LGBTQ+ status? Skills/interests? Etc.	Focus solely on the reason for their visit today- the context of their lives may give helpful hints for treatment interventions.
Treat the symptom and address the larger contributing contexts.	Focus solely on reducing/resolving the primary symptom.
Ask with an open mind whether the patient uses any homeopathic or traditional remedies and if so, what? When? How?	Overlook the importance of asking questions which can provide insight not only into potential contraindications but may also present alternate options to medications and/or lifestyle modifications.
Explore the opportunities a patient has to be meaningfully engaged in activities each week.	Overlook the role that boredom/inactivity may be having on a patient's presenting symptoms.
Seek to understand how a patient takes medication—do they have someone 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.	Assume that because you prescribe a medication it will be taken as directed.
Prioritize a patient's medication history—find out if other providers prescribe medication.	Assume you are the sole prescriber.
Recognize that you may not be the best fit for a patient's treatment needs and offer a referral.	Continue to provide care when there may be another provider better suited to the patient's needs.
Practice patience and kindness at all times, especially when a patient is in crisis—this goes for the patient and their family members/caregivers. They may be in crisis too! It can be hard toremember even the simplest of details when you are stressed.	Become upset/irritated with a patient and/or family member if they seem unable to provide the relevant history needed to provide treatment.
Invite people with lived experience to come to a grand rounds/professional development session. Engage with your local disability advocacy group and continuously strive to build competency and promote inclusion.	Overlook the importance of asking questions which can provide insight not only into potential contraindications but may also present alternate options to medications and/or lifestyle modifications.
Explore how a patient typically responds to pain/needles/shots.	Wait until a procedure is scheduled to ask questions around pain/needles and shots.
Ask: "What are some of the challenges with my recommendations?"	Assume patients will bring up things independently.

Considerations for Waiting Rooms

Waiting room conditions are often overlooked. Doctors' offices leave an important first impression on your patients. The waiting room should be as accommodating as possible and avoid common triggers. To ensure your patient's well-being and maximize successful outcomes, the following recommendations should be considered:

- Ensure that your waiting room staff know basic information about how to communicate with people with Intellectual and Developmental Disabilities (IDD), including those with Autism Spectrum Disorder (ASD).
- Instruct your waiting room staff how to respond to noisy or agitated patients without anger or reprimand, as these may escalate patients' anxiety.
- Have calming tools such as squeeze balls and fidget cubes available in your waiting room (https://www.stimtastic.co/stim-toys. Every purchase benefits Autistic people).
- Institute a practice-wide policy of no strong fragrances. Share this new policy in your newsletters, email communications, and new patient paperwork.
- Pale blue creates a calming atmosphere and is the best paint color for your waiting room. Green, pink and lavender are also calming colors.
- Fluorescent lighting can be difficult for people who have visual sensory issues. Consider more ambient lighting options such as floor lamps and LED lights for ceiling fixtures.
- 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 space or "calm room" in case your waiting room becomes overstimulating for people with sensory issues. This is especially important for large, busy hospital waiting rooms.
- Delays are an inevitability. People may have difficulty waiting. Some may be using pre-arranged transportation to get to the office. Consider delay announcements, a visual display of estimated wait times, or prioritizing appointment times for patients who do not do well with waiting (who dislike crowds, who have difficulty waiting long periods, or who may have other sensory challenges).
- Even with environmental accommodations, it can sometimes be difficult for some patients to spend time in the waiting room. In situations like this, consider the option of having patients remain in their vehicle until their appointment time.

Sensory Considerations for Medication Prescribers

Melanie Hecker, MPA, Karen Weigle, PhD, Alyce Benson, LCSW, and Jeni Yielding, OTR/L

Sensory sensitivity is a hallmark of many Intellectual and Developmental Disabilities (IDD). Sensory differences impact about 20% of the entire population of people with IDD,[1] and can include being over- or under-sensitive to sensory input. Often over-sensitivity can lead to problems with physical exams and the ability to interact with health care providers. This type of sensitivity does 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 or strong sensory stimulus is present, a person with IDD may not be able to focus on anything other than the trigger, such as the words you say, your face, gestures, or other things in the environment. Sensory triggers are unique to each individual and patients may have different combinations of triggers. In some cases, exposure to sensory triggers can cause dysregulation, a sure sign that the person is in extreme distress. 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. Prescribers and office staff should explain or show each and every piece of equipment used and what it is going to do, demonstrating on someone other than the patient (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.

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: *Avoid fluorescent or strobe lighting in your practice and quickly change any flickering light bulbs. The use of lamps or natural lighting is 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 to avoid approaching the person straight from the front, which may be scary, cause anxiety and a fight/flight response. Instead, approach from the side (e.g. for tongue depressor, light in nostril, to palpate the neck, or listen to heart).*

Audio

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

Considerations: *Quickly be able to turn off or turn down any music or television you may have playing in your practice. 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 a common 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 them know.*

Tactile

There are many common tactile triggers. For many people with IDD, another person's touch 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 individual 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, briefly distract the 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 can 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. Some fruit juices should be avoided with certain medications, so patients should always check with their doctor or pharmacist prior to taking medications with 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 nutrition 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.*

[1] Committee to Evaluate the Supplemental Security Income Disability Program for Children with Mental Disorders; Board on the Health of Select Populations; Board on Children, Youth, and Families; Institute of Medicine; Division of Behavioral and Social Sciences and Education; The National Academies of Sciences, Engineering, and Medicine; Boat TF, Wu JT, (Eds). Mental Disorders and Disabilities Among Low-Income Children. Washington (DC): *National Academies Press*; 2015.

Sensory Considerations for Medication Prescribers

Melanie Hecker, MPA, Karen Weigle, PhD, Alyce Benson, LCSW, Jeni Yielding, OTR/L

	Triggers	Considerations
VISUAL 	· Flickering, fluorescent and strobing lights (even very subtle) · Bright, contrasting colors · Too many "things" · Straight on physical approach	· Avoid fluorescent or strobe lighting; use lamps or natural lighting as much as possible. · Change flickering light bulbs as soon as possible. · Use pastel or pale colors as opposed to bright colors to decorate office spaces. · Reduce clutter/over-decorating - fewer items and wall hangings are more calming. · Approach patients from the side (for tongue depressor, or light in nostril, to palpate the neck).
AUDIO 	· Loud or unexpected noises are the most common sound trigger · High-pitch, low-pitch, or repetitive noises · Some sound triggers are unique to the individual	· Ensure that staff can quickly turn off/turn down music or television in waiting room. · Avoid fluorescent lighting – low humming noises can be distracting. · Have a quiet, low sensory space set aside for patients who may need to leave an area due to a sensory trigger. · Have a few pairs of noise-cancelling headphones, made of material that can be disinfected frequently available. · If a procedure is going to produce a sound, even as common as a blood pressure cuff inflating/deflating, let your patient know beforehand.
SCENT 	· Strong scents · Specific scents (examples: air fresheners, perfumes, ammonia, alcohol, smoke and garbage	· Make your practice as scent/fragrance free as possible (discourage the use of perfumes and colognes, take out garbage promptly (nausea and irritability are strong, lasting responses). There is a very strong limbic stress response with aversive odors/scents, and one cannot block this out on his own).
TACTILE 	· Human touch – being touched in general, touched without warning, pressure (light vs firm touch) · Clothing – fabric type, tightness, tags, seams · Textures of certain objects (cotton balls, latex, chalk) · Food and medication texture	· Keep a supply of hospital gowns and slippers that are not scratchy and do not have seams. · Allow the person to leave their clothes on or wear only underclothes without a gown if hospital clothing cannot be tolerated. · Have non-latex gloves available. · When 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 (rubbing arms or legs to "wake up" the sensory system and decrease the startle response to further touch).
TASTE 	· Strong, bitter, sour, and salty tastes may impact medication administration as well as food eaten in regular diet	· Fill medications with a flavor coating. · Recommend taking the medication with a flavored beverage such as fruit juice, but patients should always seek prior approval from physician and pharmacist. · In the event of nutrition issues, make a referral to an occupational therapist, dietician or nutritionist.

Cultural Competency and Prescribing

Roberto Blanco, MD

Overview

All psychiatric diagnoses are based on culturally accepted norms of behavior in a patient population. How much a behavior or symptom cluster deviates from these norms typically determines pathology. As with any other patient population, cultural factors are present and important considerations in the care of individuals with Intellectual and Developmental Disabilities (IDD) and it is important to understand how patients and families view themselves and their goals within their communities. 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 are critical role in assessing and optimizing care for individuals with IDD. Best practices include utilization of tools such as the Cultural Formulation Interview[1], 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 have knowledge of 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.

As a physician working with individuals from varied cultural backgrounds and with diverse cultural identities, it is important to be aware of biases that may exist at an unconscious level. While these tools are not perfect, testing for implicit biases to a range of potential components of background and identity can be an effective tool in gaining a general awareness of an individual clinician's potential biases. This awareness can be a good first step and can activate and engage providers in changing practices and providing more equitable care to groups of individuals that may have historically suffered from stigma and substandard care and health outcomes. To assess these implicit biases, one could utilize the implicit bias testing available for free at Harvard University's Project Implicit: https://implicit.harvard.edu/implicit/education.html

The following questions are useful to get to know someone's cultural background, who they are as individuals, for diagnostic considerations which are based on culturally defined norms, and for culture-based beliefs about medications. Please also refer to the questions in the Cultural Formulation Interview in the DSM5 (American Psychiatric Association, 2013). The language in these questions may need to be modified due to communication difficulties, language barriers, cognitive difficulties or lack of access to natural supports:

- What kind of things are important to you? What kind of things are important to your family? Are the things that are important to you similar or different to the things that are important to your family? If so, in what ways?
- People have different ways of expressing symptoms. How would you explain your symptoms to someone who did not know you? How would you explain your symptoms to your friends and family?
- Why do you think this is happening to you? What do you think causes these symptoms? What does your family think cause these symptoms?

[1] American Psychiatric Association. Cultural formulation. In: *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*. Washington, DC: American Psychiatric Association; 2013:749-759.

- What are the most important aspects of your background or identity? Are there any aspects of your identity that make a difference – either make things better or worse?
- Doctors can sometimes misunderstand patients for a variety of reasons. Are you concerned that we, as doctors, might misunderstand you?
- What supports do you have to help you manage? For instance, your family, friendship group, or general community?
- What kinds of activities and interests do you enjoy? Do you have unique or different ways of coping that we might not know about?
- How do you typically like to take medications? Are there situations in your life that might make it difficult to taking medications at certain times?

If family or natural supports are available, you may want to ask:

- What kinds of things are important to the person?
- How would you explain the person's symptoms? What do you think has caused their symptoms?
- Doctors can sometimes misunderstand patients for a variety of reasons. Are you concerned that we, as doctors, might misunderstand this person?
- From your perspective, what would you say are the most important aspects of the person's background? How about medication and wellness? Are there any components of background or identity that make a difference for the person?

Culturally Competent Prescribing Resources

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

- American Psychiatric Association. Resource document on cultural psychiatry as a specific field of study relevant to the assessment and care of all patients. In *Diagnostic and statistical manual of mental disorders (5th ed.). Washington*, DC: American Psychiatric Association; 2013. Accessed from: https://www.psychiatry.org/File%20Library/Psychiatrists/Directories/Library-and-Archive/resource_documents/rd2013_CulturalPsychiatry.pdf

- Cultural Context Important in Psychiatric Diagnosis, Says Bolivar Award Winner [Video]. YouTube. https://www.youtube.com/watch?v=fnxPf-G0i_Y. Published May 10, 2013. Accessed May 3, 2020.

- Psychiatry of Intellectual Disability [Video]. YouTube. https://www.youtube.com/watch?v=COoOtsWJAGU. Published June 15, 2018. Accessed May 1, 2020

- Using the cultural formulation interview [Video]. YouTube. https://www.youtube.com/watch?v=8SjBG9di8ss Published May 1, 2019. Accessed May 1, 2020.

Psychiatric Assessment

L. Jarrett Barnhill, MD, DFAPA, FAACAP, Lauren R. Charlot, PhD, LICSW, and Dan Baker, PhD

Introduction

Epidemiological studies of people with Intellectual and Developmental Disabilities (IDD) suggest that a conservative estimate of the lifetime prevalence of behavioral and mental disorders is 30-40%.[1] The accuracy of these data remains questionable due to the frequency of under-diagnosis and misdiagnosis of underlying medical/neurological disorders as mental health conditions. In addition, level of ID and adaptive functioning impacts the process of assessment, especially when related ecological, psychosocial factors increase vulnerability to stressors. The level of ID also affects communication of and capacity for self-reporting symptoms, and likelihood of diagnostic overshadowing. For example, pain and discomfort may present as externalizing, disruptive behaviors that can be misattributed to a psychiatric condition.

Each of these factors contributes to misdiagnoses and sets a chain of events in motion that culminates in ineffective psychological and psychopharmacological interventions. The task of the assessment team is to minimize these shortcomings. The most successful way to accomplish this involves integrating a comprehensive description of the presenting biopsychosocial issues; medical, familial, psychosocial, and treatment histories; and systematic genetic, medical/laboratory, psychological, and mental status examinations with observational data from the patient, family, and multiple care providers. Such an approach reinforces the reality that psychiatric disorders do not arise in a vacuum. Behavioral and psychiatric disorders represent evolving conditions that are profoundly influenced by ongoing transactions between biology and the environmental/social context. A comprehensive assessment requires a holistic-transactional mindset in order to look beyond simply treating an illness. It takes into account resilience and positive psychological forces to promote wellness and maximize adaptive skills.

Initial Psychiatric Assessment

The goal of initial psychiatric assessment for a patient with IDD is to gain an understanding of the biopsychosocial vulnerabilities of the person, their symptoms and potential treatment options. Methods of assessment for someone with IDD varies slightly from the general population.

General Population	Patients with IDD
Establish relationship with person	Establish relationship with the person and a team
Conversation, detailed questions & answers	Verbal ability may be limited; interview informants to gather additional information; use plain language to engage the patient in discussion
Evaluate overall presentation	Atypical presentation is likely; recognize behavioral phenotypes related to genetic syndromes, ASD, ID, etc.
Discuss diagnosis and treatment plan directly with the person	Along with consensus with the patient, a "team" treatment negotiation also occurs

[1] Fletcher RJ, Barnhill J, Cooper S-A (Eds). *Diagnostic Manual-Intellectual Disability 2: A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability*. Kingston, NY: NADD Press; 2017.

Case Vignette

Sam: Sam is 34 years old and is diagnosed with Down Syndrome, moderate ID, and major depressive disorder. Sam also engaged in some level of self-injury since he was young, often expressing anxiety, worry, sadness or frustration by biting his hand, hitting his head, or other forms of self-harm. This month, his family noted an increase in self-injury compared to last month (40 incidents compared to an average of 5 per month for the previous 6 months). They also reported that the intensity of the incidents increased. Sam broke the skin on his hand from frequently biting it and they were concerned the wound might get infected. After an intense increase in self-injury during the month, coupled with lethargy to the point where Sam was unable to get out of bed, his parents took him to the emergency department for evaluation. He was sedated for the exam and the ER staff noticed a tumor in his abdomen causing kidney malfunction and pain.

Discussion: Situations of baseline exaggeration like Sam's are too uncommon for individuals with IDD. This situation is an important reminder that a person's increase in "behavior" needs to be recognized and addressed in the context of historical patterns of symptoms and cannot simply be evaluated as an event happening at one single point in time. If diagnostic overshadowing occurred and the ER physicians assumed that Sam was depressed, the underlying issue driving the exaggeration of symptoms would not be treated. Prescribers must remember that when a change in presentation occurs, there is usually a history to it. Understanding the potential reason for change increases success and efficacy of the treatment approach.

Case Vignette

WW: *The many faces of Bipolar Disorder:* WW is an 18-year-old male with mild Cerebral Palsy, Mild ID, and a long history of episodic hyperactivity, irritability, and aggression. His first contact with mental health services was at age five. His original diagnoses were ADHD, Oppositional Defiant Disorder, and Intermittent Explosive Disorder. He initially improved but had to discontinue both methylphenidate and dextro-amphetamine derivatives due to irritability and appetite loss. His PCP prescribed Risperidone 5 mg/d. His parents noted a significant reduction in irritability, but also noticed weight gain and increased motor activity (akathisia). The family tapered and discontinued risperidone. He seemed to return to his pleasant easy-going temperament. His family enrolled him in a developmental preschool program where he received physical therapy.

At age 8, WW presented with an episode of irritability, verbal outbursts, property destruction, and disruption. His working diagnosis was Intermittent Explosive Disorder despite persistent sadness, loss of appetite, and lethargy. His third-grade teacher voiced concerns about depression. His developmental pediatrician concurred and prescribed low dose fluoxetine (5 mg/d). The treatment plan called for a slow titration based on clinical response. WW improved initially but developed significant behavioral disinhibition on 20 mg/d. His outbursts returned and his prescriber tapered fluoxetine. Off fluoxetine, WW seemed to stabilize once again and thrived at school.

At age 12, WW's mother ended her life and the family was devastated. WW found his mother following her suicide and developed acute stress-related symptoms including nightmares, school avoidance, and multiple fears. These symptoms improved with therapy but his mood and level of interest in preferred activities (school and fishing) diminished. His developmental pediatrician attributed the mood changes to grief and trauma. Once again, his irritability and aggression intensified, and WW also developed panic attacks. His father sought out a local therapist who focused on trauma-related issues. WW improved over the next 3-6 months and therapy ended.

At age 18, WW developed an acute onset psychosis. He appeared delusional (he was an angel sent by his mother to save the world), hallucinations (voices commenting on his need to kill himself), and had disorganized thoughts, extreme hyperactivity, and marked increase in aggression. This resulted in his first psychiatric hospitalization. The treatment team agreed to initiate a rapid titration of an antipsychotic (Abilify) along with a medical and psychiatric workup. As his psychotic symptoms diminished, the team agreed that WW's symptoms seemed more consistent with mania (reduced need for sleep, pressured speech, hyperactivity and impulsivity).

During the hospitalization, his father noted that his mother had severe bipolar disorder and psychotic postpartum depression after WW's birth. Without her husband's knowledge some years later, she discontinued her lithium and stopped her psychiatric care. Her mood soon crashed after the discontinuation. She ended her life three days before WW's 12th birthday. With this new information, the inpatient team began a trial of lithium and as WW improved, they also began an Abilify taper. This was the first time that bipolar disorder was considered as a diagnosis for WW.

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.

Medical Concerns	As many as 40%[1] of individuals 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 give rise to an IDD and contribute to patterns of executive function deficits, increased risk for certain medical comorbidities, and even elevated risk for psychiatric symptoms and syndromes.
Psychosocial and systemic vulnerabilities	Vulnerabilities include challenges related to cognitive factors, information processing, and including executive functions; communication (especially functional and social-emotional communication); sensory sensitivities; restricted and repetitive behaviors; trauma histories; and residential and programmatic services. As suggested, such vulnerabilities may provoke problems or impact their expression.
Cognition/ Level of Intellectual Disability	It can be helpful to know a person's level of intellectual disability (mild, moderate, severe, profound), however there is extreme variability within these characterizations in how people process information, problem solve, and plan. These differences influence *what* is experienced as stressful, the *degree of stress* experienced, and *how a person responds*.
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 and paying attention and problem solving. Patients with IDD tend to benefit from support with initiating activities, paying attention, finishing tasks, tolerating frustration and regulating emotions, all of which impact the ways the person navigates everyday life.
Communication	People with IDD present with a very wide range of abilities and challenges with regard to communication. It is critical to help caregivers understand that *speaking* is not the same as *problem solving and planning*. Many people with IDD learn "scripts" but may not have insight into the meaning.
Sensory sensitivities	Sensory sensitivities may occur in conjunction with a tendency to be *easily over-aroused*. Sensitivities to sounds is most common. Sensitivities to space (being too close), light touch, clothing tags on the skin, and overly stimulating visual environments are other examples.
Repetitive behaviors	Perseveration and repetitive tendencies are common concerns for many with IDD. In some cases, especially with ASD, there seems to be a deep need for things to remain the same, and increased stress when there is change. Repetition can be a way to understand something better, to resist change, which is upsetting, and at times to experience enjoyment (when the repetition has 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.

Don't Forget the Power of Psychotherapy

There are many factors that contribute to the way a person feels or behaves. Most factors are not deterministic but are among a series of interactions through many life experiences. Psychopharmacologists should not assume that a psychotropic drug can teach someone social and adaptive skills, problem-solving, or methods for self-care. Psychotropic drugs can reduce behavioral excesses due to exaggerated brain-behavioral responses that frequently stand in the way of psychosocial well-being. Remember, it takes an interdisciplinary treatment village to promote wellness. Psychotherapy is a much more powerful tool for enhancing wellness, emotional well-being, and mastery while enhancing life skills. In the Appendix is a list of evidence-based, frequently used therapeutic modalities and resources for physicians regarding the efficacy of the modalities for persons with IDD.

Conclusion

Assessment is the most important part of any treatment program. It provides a comprehensive picture of a person's symptoms in a biopsychosocial context and work towards holistic solutions to adverse life experiences. 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 adjuncts, not solutions. While medication may be a piece to the wellness puzzle, it is not the only one. Medications offer an intervention designed to alter the underlying biology of behavior, but they do not take the place of primary care, educators, therapists, friends or family members. The goals of assessment are to identify and develop strategies to enhance adaptive skills, with psychopharmacologic treatment playing one role in the process.

Considerations for Psychotherapeutic Adaptations

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

- Speed: Adaptations are often needed to provide intervention at a slower pace, allowing additional time to process the content and respond. This adaptation is commonly used in accommodations for academic testing when learners are given additional time during exams.
- Number: Either more or fewer examples 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 concreteness of content. 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." Plain language is used to improve comprehension.

Resources by Therapeutic Approach

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

Positive Psychology

- Shogren KA, Wehmeyer ML, & Singh NN, eds. *Handbook of Positive Psychology in Intellectual and Developmental Disabilities: Translating Research into Practice.* New York, NY: Springer Publishing; 2017.
- Niemiec RM, Shogren KA, & Wehmeyer ML. Character strengths and intellectual and developmental disability: A strengths-based approach from positive psychology. *Ed Training Autism Dev Disabil.* 2017; 52(1):13-25.

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.
- Baker DJ, Blumberg R. *Mental Health and Wellness Supports in Youth with IDD.* Kinston, NY: National Association for the Dually Diagnosed. 2013.

Trauma-Informed Care

- Hales T, Kusmaul N, & Nochajski T. Exploring the Dimensionality of Trauma-Informed Care: Implications for Theory and Practice. *Hum Serv Organ Manag Leadersh & Gov.* 2017; 41(3):317-325.
- Keesler J. A call for the integration of trauma-informed care among intellectual and developmental disability organizations. *J Policy Pract Intellect Disabil.* 2014;11(1):34-42.
- Peterson C, Seligman ME. *Character Strengths and Virtues: A Handbook and Classification.* New York, NY: Oxford University Press; 2004;1.

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.

Trauma-Focused Cognitive Behavioral Therapy

- 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.

Motivational Interviewing

- Frielink N, & Embregts P. Modification of motivational interviewing for use with people with mild intellectual disability and challenging behavior. *J Intellect Dev Disabil.* 2013; 38(4): 279-291.

Exposure Therapy

- Symons FJ. An evaluation of multi-component exposure treatment of needle phobia in an adult with autism and intellectual disability. *J Appl Res Intellect Disabil.* 2012; 26(4): 344-348.

- Boyd BA, Woodard CR, & Bodfish JW. Feasibility of exposure response prevention to treat repetitive behaviors of children with autism and an intellectual disability: A brief report. *Autism.* 2011; 17(2).

Expressive Therapies

- Gortner E, Rude SS, Pennebaker JW. Benefits of expressive writing in lowering rumination and depressive symptoms. *Behav Ther.* 20-6; 37(3): 292-303.
- Thompson GA, Skewes-McFerran K. Music therapy with young people who have profound intellectual and developmental disability: Four case studies exploring communication and engagement within musical interactions. *J Intellect Dev Dis.* 2015; 40(1):1-11.
- Miller SM. Disability art: Potential intersections in studio practice with artists labeled/with intellectual and developmental disabilities. *Art Ther.* 2020; 37(2): 93-96.
- Tomasulo D, Szucs A. The ACTing cure: Evidence-based group treatment for people with intellectual disabilities. *Dramatherapy*. 2015; 37(2-3).

Wellness

- Anderson LL, Humphries K, McDermott S, & Marks B. The state of the science of health and wellness for adults with intellectual and developmental disabilities. *Intellec Dev Disabil.* 2013; 51(5): 385-398.
- 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.

Occupational Therapy

- Francisco I, & Carlson G. Occupational therapy and people with intellectual disability from culturally diverse backgrounds. *Aust Occup Therap.* 2002; 49(4):200-211.

Recreation Therapy

- Merrells J, Buchanan A, & Waters R. The experience of social inclusion for people with intellectual disability within community recreational programs: A systematic review. *J Intellect Dev Disabil.* 2018; 43(4):381-391.
- Garcia-Villamisar D, Dattilo J, & Muela C. Effects of therapeutic reaction on adults with ASD and ID: A preliminary randomized control trial. *J Intellect Disabil Res.* 2016; 61(4): 325-340.

References

American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders (5th ed.).* American Psychiatric Association; 2013.

Baker DJ, Blumburg R. *Mental Health and Wellness Supports in Youth with IDD*. Kingston, NY, National Association for the Dually Diagnosed. 2013.

Brown A, Ferrara R, & Campione B. Learning, remembering and understanding. In: JH Flavell, EM Markman, eds. *Handbook of Child Psychology.* 3rd ed. New York, NY: Wiley; 1983:77-166.

Charlot L, Abend S, Ravin P, Mastis K, Hunt A, & Deutsch C. Non-psychiatric health problems among psychiatric inpatients with intellectual disabilities. *J Intellect Disabil Res.* 2011; 55(2):199-209.

Barton EE, Reichow B, Schnitz A, Smith, IC, Sherlock D. A systematic review of sensory-based treatments for children with disabilities. *Res Devel Disabil.* 2015; 37:64-80.

Ben-Sasson A, Hen L, Fluss R, Cermak, SA, Engel-Yeger B, Gal E. A meta-analysis of sensory modulation symptoms in individuals with autism spectrum disorders. *J Autism Dev Disord.* 2009; 39(1):1-11.

Crocker AG, Prokić A, Morin D, Reyes A. Intellectual disability and co-occurring mental health and physical disorders in aggressive behaviour. *J Intellect Disabil Res*. 2014; 58(11):1032-1044.

Eack SM, Mazefsky CA, Minshew, NJ. Misinterpretation of facial expressions of emotion in verbal adults with autism spectrum disorder. *Autism.* 2015;19(3):308-315.

Einfeld SL, Ellis LA, Emerson E. Comorbidity of intellectual disability and mental disorder in children and adolescents: A systematic review. *J Intellect Dev Disabil.* 2011; 36(2):137-143.

Fletcher RJ, Barnhill J, Cooper S-A (Eds). *Diagnostic Manual-Intellectual Disability 2: A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability.* Kingston, NY: National Association for the Dually Diagnosed Press; 2017.

Green SA, Ben-Sasson A. Anxiety disorders and sensory over-responsivity in children with autism spectrum disorders: is there a causal relationship? *J Autism Dev Disord.* 2010; 40(12):1495-1504.

Gardner W, Whalen J. Discussion: a multimodal analytic model for evaluating the effects of medical problems on nonspecific behavioral symptoms in persons with developmental disabilities. *Behav Intervent.* 1996; 11:147-161.

Leyfer OT, Folstein SE, Bacalman S, Davis NO, Dinh E, Morgan J, Lainhart JE. Comorbid psychiatric disorders in children with autism: interview development and rates of disorders. *J Autism Dev Disord.* 2006;36(7):849-861.

Matson JL, Neal D. Psychotropic medication use for challenging behaviors in persons with intellectual disabilities: an overview. *Res Devel Disabil.* 2009; 30:572-86.

Mayes SD, Calhoun SL, Murray MJ, Ahuja M, Smith LA. Anxiety, depression, and irritability in children with autism relative to other neuropsychiatric disorders and typical development. *Res Autism Disord.* 2011; 5(1):474-485.

Morasky, R. Making counseling/therapy intellectually attainable. *The NADD Bulletin*. 2007; 10(3): 58-62.

Saloojee S. Routine pre-admission laboratory screening investigations in aggressive patients who require sedation in the emergency department–necessary or unnecessary. *S African J Psychiatry.* 2015;15(3):5.

Spencer D, Marshall J, Post B, Kulakodlu M, et al. Psychotropic medication use and polypharmacy in children with autism spectrum disorders. *Pediatrics.* 2013; 132(5):833-840.

Trembat D, Germano C, Johanson G, Dissanayake C. The experience of anxiety in young adults with autism spectrum disorders. *Focus.* 2012; 27(4):213-224.

Conceptual, Social and Practical Abilities Based on Level of IDD

Originally developed by Jill P. Hinton, PhD (2016); Revised February 2020.

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	• There may be no obvious conceptual difference in early childhood • Difficulties learning academic skills • Impaired executive functioning, abstract thinking, short term memory • Concrete approach to problem solving	• Immature in social interactions • Communication, conversation, and language are concrete • Difficulty regulating emotions and behavior • Impaired social judgment and limited understanding of social risks • Develops friendships and romantic relations in adulthood	• May function independently in personal care • Needs support in complex daily living tasks • May live semi-independently with support in money management, transportation, organization of household tasks • Competitive or supported employment • Support needed for health care decisions and childcare
Moderate	• Throughout development, conceptual skills behind those of peers • Academic skills develop slowly and are limited compared to peers • Adult academic skills at elementary level. • Support needed for conceptual tasks of day-to-day life	• Marked difference from peers in social and communicative behavior across development • Spoken language used, but much less complex than peers • Capacity for successful friendships and romantic relations in adulthood. • Social judgment and decision making are limited • Significant social and communicative support needed in work settings	• 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 require additional support and learning opportunities over extended period of time
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	• Require 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 generally involve physical world rather than symbolic processes • May use objects in goal-directed ways • 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 a 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 work 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

[1] American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders (5th ed.).* Washington, DC: American Psychiatric Association; 2013.

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	· May have challenges in social understanding and awareness, even when other cognitive capacities are less challenged · May struggle to pick up on appropriate ways to use language in social situations and say things that appear socially odd (e.g., talk out loud 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	*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. He gets picked on and lashes out, so the 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 actually 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. He is described as "non-compliant."* *David's frontal lobe and executive function are compromised, and switching to a new rule/path is difficult.*
Understanding time concepts, waiting	· Has 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 got excited when she heard her group was going there. She had a major 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 means or feels like. She was described as "throwing a tantrum because she didn't get her way."* *Her "outburst" was similar to 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.*

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	· May learn a variety of "scripts" or things to say in various situations, without actually understanding the full meaning or implications · May not admit that they don't understand because they are embarrassed. This leads to agreeing to things without really knowing what they mean · 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 greatly 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 of the stores at the mall that sell tech items, gaming software and other things he likes in great detail.* *Damien had a major clash 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	· Learn new things best by 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. · Use 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 of her daily self-care independently. She was told about a new assessment and seemed anxious. When she got to see pictures of the evaluation showing what would happen, she relaxed.*
Functional Communication (FC)	· Might not use speech functionally to reliably describe what they need or want · May repeat many words or sentences, but may not be able to ask for water when thirsty · Some speech may be "cue dependent" (requires a prompt) · May communicate better in pictures or with multiple forms (signing, showing a picture, and speaking)	*Data collection to determine function of communication can be very helpful.*

Challenges in Assessing Persons with IDD[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 IDD express themselves through SIB. Consider the last time the patient was doing well. What did they look like? Regardless of the frequency of self-injury, SIB is a sign of distress and must be examined as a symptom, and bio-medical issues ruled out.
Baseline exaggeration	Challenging behavior that exists at a low rate and low intensity may increase dramatically when the person experiences stress or a mental health condition.	Inability to sit still	A person with IDD may express a variety of feelings and reactions through a single challenging behavior. If attributed to IDD, their distress will be missed. Increase in intensity and duration is likely a sign of medical or mental health acuity. Pain and discomfort are often present. Consider dental and primary medical conditions. Symptoms of mania, depression, 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 although unsure.	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 of vegetative function. Consider trauma and possible 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 greatly compromised.	This can also include "tantrums," where the person's executive functioning/coping is severely compromised. Understanding the context and pattern of medical issues, negative events, loss of skills, is key. Knowing baseline skills (when the person was doing well) and change in functioning is key.

[1] Hurley, A.D. Identifying psychiatric disorders in persons with mental retardation: A model illustrated by depression in Down syndrome. *J Rehabil.* 1996; 62:27-33.

Medical Assessment Considerations for Patients with IDD-MH

Common acute and chronic health conditions that impact people with IDD and their mental health presentation

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

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.

- The person with IDD may have difficulty with language and be unable to describe their symptoms, making it difficult to explore a medical, emotional, social or environmental history, which are the cornerstones of a clinical diagnosis.
- For the individual who is unable to articulate symptoms, the behavioral expressions of the symptoms may not bear any resemblance to the actual cause of the pain or discomfort. At times, with individuals who are on the autism spectrum, there may be dramatic emotional reactions out of proportion to the symptomatology, or, even in the presence of significant pain, there may be minimal symptomatology.
- An individual with IDD is likely to be brought to the medical provider 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 individual. If the third party is a family member or 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.
- If a physical examination is necessary, the individual may be fearful and uncooperative, thus making it difficult to confirm clinical suspicions or explore physical conditions that may be causing the symptomatology.

With these provisos in mind, it behooves the prescriber to be aware of the limitations in making a diagnosis based on history and behavior. **The important lesson is to keep an open mind and consider a differential diagnosis of disorders of behavior including mental health considerations, as well as possible medical conditions or environmental factors that can result in behavioral manifestations of pain or discomfort.**

There are additional elements required in obtaining a good clinical history:

- Examine and explore the individual'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. 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 events, previous diagnoses, notes from specialty health care providers, as well as histories of allergies; past medications; medication responses and reactions; current medications, including the duration of the regimen, with exploration of possible drug interactions; previous emergency room visits; hospitalizations and past history of behavioral responses to medical, social and environmental experiences.

Answers to all these questions help to create a multidimensional picture of the individual and the complex interplay between physiological, 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, appropriate treatment and therapeutic recommendations, and favorable outcomes.

Etiological Considerations

Important to the clinical assessment of an individual 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, 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.

Knowledge of the etiological diagnosis is an invaluable aspect in the clinical assessment of an individual with IDD. Three illustrative examples will be offered: individuals on the autism spectrum who tend to have less obvious physical or medical co-morbidities; individuals with predominantly motor disabilities such as cerebral palsy, who are likely to have more complex physical and medical co-morbidities; and individuals with an underlying congenital chromosomal or non-chromosomal syndrome, such as Down Syndrome, which each have their own unique physical characteristics, pattern of 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 will vary greatly, and there may be overlapping diagnoses. So, an individual with Cerebral Palsy or Down Syndrome may also have 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 frequency and often to a greater degree. ***Thus, each person with IDD should be seen as unique, but with some likely physical and behavioral tendencies that will help to establish an accurate physical or mental health diagnosis.***

Autism Spectrum Disorders

Autism Spectrum Disorder (ASD) varies from person to person and the degree of difficulty varies, making it important for the prescriber to know the patient and their unique abilities. Individuals with 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 serious 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 misinterpreted in terms of behavioral pathology or a mental health disorder, so careful attention needs to be paid to the circumstances of any dramatic behavioral presentation.

Individuals 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 to more accurately understand the nature and thus the approach to management. Individuals with ASD also have psychiatric comorbidities such as ADHD, anxiety, OCD, sleep disorders, Tourette Syndrome, depression, bipolar disorder, episodic dyscontrol syndrome, and psychoses. These need to be factored into the diagnostic consideration and managed accordingly.

Because individuals with ASD have limited communication skills, a tendency for unusual over- or under-sensitivity to sensory stimuli and emotional overreactions, physical symptoms may manifest in behavioral reactions. This is best documented with gastrointestinal disorders such as gastroesophageal reflux (GERD) and constipation. Because individuals with ASD and/or IDD may be unable to describe their symptoms accurately, discomfort or pain may be expressed with a variety of symptoms from withdrawal (especially with constipation), to frustration associated with 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 with no 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 a 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

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 severity of symptoms of CP occur across a spectrum and the diagnosis is based on the presence of motor characteristics with significant functional implications, but the reality is that the Central Nervous System (CNS) lesions are often diffuse and involve other functional elements. The CDC reports that for those with CP, more than 40% have intellectual disability, 35% have epilepsy, and more than 15% have vision impairment. [1] The association of ASD and CP has been found in the US and other countries, as well.

Overall, the prevalence of behavioral and mental health disorders in CP is higher than the general population, especially as people age. When evaluating an individual 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 or because of other related stresses that may be emotional, social or even financial difficulty.

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

The critical clinical element for the health care provider is 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 acceptable, clinically, to prescribe laxatives if constipation is suspected and monitor the outcome, or to prescribe an antacid or anti-reflux mediation 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.

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*[2], first published in 1969 and now in its 7th 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*.[3] Although this text is not as comprehensive and inclusive in cataloging the multiple known and unknown syndromes, it does contain in-depth information on a select group of relatively common conditions with more detail on the medical complications of each of the syndromes discussed. It has a comprehensive review of all physical and mental health considerations as well as familial, educational and social aspects of health and health care.

Down syndrome is the most common and well-known of the genotypes associated with IDD. It 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 the congenital lesions are dramatic and require urgent care including surgery, it is the other conditions that people with Down syndrome are prone to that pose clinical challenges to the primary care provider as well as the mental health care provider.

[1] Center for Disease Control. Data and Statistics for Cerebral Palsy. Accessed: https://www.cdc.gov/ncbddd/cp/data.html#text-cooccuring

[2] Jones, KL, Jones, MC, Del Campo, M. *Smith's Recognizable Patterns of Human Malformation: Expert Consult 7th Edition.* Elsevier, CA; 2020.

[3] Rubin IL, Merrick J, Greydanus DE, Patel DR. *Health Care for People with Intellectual and Developmental Disabilities Across the Lifespan.* Dordrecht, NY: Springer; 2016:601-1606.

In these situations, the clinician should become familiar with the range and variety of medical conditions. For one, visual and hearing impairments are common and may affect behavior at any age, so it is very important to be aware of these possibilities and refer for evaluation when suspected. Like other individuals with 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. 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. Particularly worrisome is the tendency for atlanto-axial subluxation – involving cervical vertebrae C1 on C2, which may manifest in an inability to walk and is often 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 particularly important that the clinician is aware of these conditions and look beyond the Down syndrome diagnosis. Like everyone else, people with Down syndrome may have mental health conditions as well as adverse life experiences that shape their presentation. For the clinician taking care of people with Down syndrome it is important to be aware that they are more likely to develop Alzheimer's dementia at an earlier age than the general population and that it may present with unusual behaviors.

Medication Adverse Effects

A serious consideration for the clinician is that people with IDD may have additional neurological or medical conditions that require medication management, and that all medication may have side effects. Side effects can have metabolic, hematological or organ system effects, particularly if taken long term, and it is likely that there may be neuromotor, neurobehavioral or neuropsychiatric adverse effects. Medication should be thoroughly reviewed on a regular basis and, when assessing an individual for changes in behavior, it is important to determine the onset of the symptoms in relation to changes in medication administration. In relation to medication administration, it is critically important to be sure that the individual is indeed taking the medication, that is, knowing that it is given and that it is swallowed. One last medication consideration is that there may be a difference in effect between different generic medications, 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 or specialty provider, it is important to be aware of the physical health conditions that may manifest as mental health or behavioral health disorders. This section provides an overview for the reader to become familiar with the common medical 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 the needed responses. There are many conditions that are not obvious on physical examination. The most common, the most serious and the most often missed, are the gastrointestinal disorders of GERD and constipation, but, as reviewed above, there are many other possible conditions that need to be considered.

The important messages for the clinician are to:

- Conduct a broader-based examination than might be usual for patients without IDD. This means testing for common causes of irritability and aggression. Assistance with the clinical interview by someone who knows how to elicit accurate responses from the patient may be needed.
- Be aware of the medical conditions that may present with behavior changes or challenges. Obtain laboratory tests where appropriate and consult with specialty providers if necessary.
- When possible, take a good history from the patients themselves, family members, and other healthcare providers – sometimes the more perspectives, the easier it is to make a diagnosis. Review the medical, psychiatric, environmental and social histories.
- Ask informants to describe what they saw and heard, rather than hypotheses. A timeline that begins from baseline wellness to changes in presentation (medication changes, altered eating, drinking, sleeping, weight, etc.) may be helpful to understand potential contributing factors.
- Be aware that other practitioners may also have minimal historical information that can result in misdiagnosis.
- Realize that there are common psychotropic side effects that can often be missed. People with IDD have atypical nervous systems and other anomalies and have been found to be at an elevated risk not only for health problems but also for adverse drug events.

References

Aguilar JM, Del-Rey-Mejías A, Mayoral F, Rapado M, Peciña M, Barbancho MA, et al. Psychiatric comorbidities in autism spectrum disorder: A comparative study between DSM-IV-TR and DSM-5 diagnosis. *Int J Clin Health Psychol.* 2016; 16(3):266–275.

Alvarez A. Dementia and alzheimer's disease. In: Rubin IL, Merrick J, Greydanus DE, Patel DR. *Health Care for People with Intellectual and Developmental Disabilities Across the Lifespan.* Dordrecht, NY: Springer; 2016:995-1012.

Barnhill J. Integrated pharmacological management. In: Rubin IL, Merrick J, Greydanus DE, Patel DR. *Health Care for People with Intellectual and Developmental Disabilities Across the Lifespan.* Dordrecht, NY: Springer; 2016:601-1606.

Belardinelli C, Raza M, Taneli T. Comorbid behavioral problems and psychiatric disorders in autism spectrum disorders. *J Child Dev Disord.* 2016; 2:11.

Center for Disease Control. Data and Statistics for Cerebral Palsy. Accessed: https://www.cdc.gov/ncbddd/cp/data.html#text-cooccuring

Delobel-Ayoub M, Klapouszczak D, van Bakel MME, Horridge K, Sigurdardottir S, Himmelmann K, et al. Prevalence and characteristics of autism spectrum disorders in children with cerebral palsy. *Dev Med Child Neuro.* 2019; 59(7):738-742.

Downs J, Blackmore AM, Epstein A, Skoss R, Langdon K, Jacoby P, et al. The prevalence of mental health disorders and symptoms in children and adolescents with cerebral palsy: a systematic review and meta-analysis. *Dev Med Child Neuro.* 2016; 60(1):30-38.

Jones, KL, Jones, MC, Del Campo, M. *Smith's Recognizable Patterns of Human Malformation: Expert Consult 7th Edition.* Elsevier, CA; 2020.

McElhanon BO, McCracken C, Karpen S, Sharp WG. Gastrointestinal symptoms in autism spectrum disorder: A meta-analysis. *Pediatrics.* 2014; 133(5).

Rubin IL, Crocker AC. *Medical Care for Children and Adults with Developmental Disabilities, 2nd Edition.* Baltimore, MD: Paul Brookes, 2006.

Rubin, IL, Fahs, JJ, Beasley, JB. Delivery of health care for people with "dual diagnosis": From the person to the policy. *MH Aspects of Dev Dis.* 2007; 10:107-117.

Rubin IL, Merrick J, Greydanus DE, Patel DR. *Health Care for People with Intellectual and Developmental Disabilities Across the Lifespan.* Dordrecht, NY: Springer, 2016.

Skotko BG, Tenebaum A. Down Syndrome. In: Rubin IL, Merrick J, Greydanus DE, Patel DR. *Health Care for People with Intellectual and Developmental Disabilities Across the Lifespan.* Dordrecht NY: Springer, 2016:739-750.

Smith KJ, Peterson MD, O'Connell NE, Victor C, Liverani S, Anokye N, et al. Risk of depression and anxiety in adults with cerebral palsy. *JAMA Neurol.* 2018: doi: 10.1001/jamaneurol.2018.4147.

Winter S. Cerebral Palsy. In Rubin IL, Merrick J, Greydanus DE, Patel DR. *Health Care for People with Intellectual and Developmental Disabilities Across the Lifespan.* Dordrecht, NY: Springer, 2016:931-950.

Trauma and Stressor-Related Disorders

Roberto Blanco, MD, Karyn Harvey, PhD, Jill Hinton, PhD, and Andrea Caoili, LCSW

"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]

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 Table 1 represents a listing of the most commonly reported experiences (people may have one or more of these during their lifetime).

Table 1. Most commonly reported traumatic experiences

• Physical, emotional, sexual abuse, exploitation	• Rape
• Neglect or abandonment (food insufficiency, unmet basic needs, homelessness)	• Serious chronic or acute illness/disease
• Death of a parent	• Exposure to war, combat or civil unrest
• Divorce	• Catastrophic loss due to natural disasters
• Family life that includes substance use, parental incarceration, domestic violence	• Witnessing horrific events involving violence or death/serious injury (ex: car accident)
	• Bullying social exclusion

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 abuse, and/or the source of trauma (family member, stranger, natural phenomenon). 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 individuals with IDD, additional considerations include factors that contribute to resilience, including the degree of cognitive capacity, 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, both large ("big T") traumas and smaller (little "t") traumas such as bullying, isolation and exclusion can serve as risk factors that lower the threshold for persistent post-traumatic stress disorder.

The prevalence of trauma and stressor-related disorders therefore may be largely underestimated and should be considered in diagnosis and treatment planning. The DSM-5[2] and DM-ID-2[3] provide a diagnostic framework for Trauma and Stressor-Related Disorders.

Trauma and Stressor-Related Disorders (DSM-5)[2]

- Posttraumatic Stress Disorder for children 6 and under
- Acute Stress Disorders
- Adjustment Disorders
- Reactive Attachment Disorder
- Disinhibited Social Engagement Disorder
- Posttraumatic Stress Disorder

[1] Hodas GR. *Responding to Childhood Trauma: The Promise and Practice of Trauma-Informed Care.* Washington, DC: National Association of State Mental Health Program Directors (NASMHPD); 2006. Retrieved from http://www.nasmhpd.org/docs/publications/docs/2006/Responding to Childhood Trauma Hodas.pdf

[2] American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders (5th ed.).* Washington, DC: American Psychiatric Association, 2013.

[3] Fletcher RJ, Barnhill J, Cooper S-A (Eds). *Diagnostic Manual-Intellectual Disability 2: A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability.* Kingston, NY: NADD Press; 2017.

Posttraumatic Stress Disorder (PTSD)

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, learning of violent event for close family member/friend). Symptoms associated with PTSD are included in the table below.

Table 2. PTSD symptom presentation in persons with IDD

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-injurious behavior and trauma-specific re-enactments. Re-enactments can look quite 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
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
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"

Each of these neurodevelopmental and emotional/behavioral responses relates to the acuity and severity of traumatizing events, level of activation of the stress response (fight, flight or freeze response), and duration of symptoms. The differences among responses should remind us of the heterogeneity of trauma symptoms as a result 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-refractory mood, psychotic, behavioral and substance use disorders in the context of comorbid PTSD or history of past trauma. These individuals may experience multiple medication trials and failures but make significant gains with trauma-informed therapeutic interventions.

To accurately assess PTSD for people with IDD/ASD, differing presentations to common symptoms should be considered, as described in Table 2. There are also some additional adaptations to consider:

Adaptations of diagnostic criteria for PTSD

1. Investigate history for possible traumatic exposure; Caregivers may or may not be aware of exposure to trauma
2. It is essential to ask the person how they felt about the events
3. Keep in mind that adults with ID may express trauma in overt, behavioral ways rather than via verbal expression
4. When caregivers report "non-compliance" as a problem, consider the presence of avoidance
5. Hyperarousal may present as irritability and/or aggression

Trauma-Informed Care and Psychotherapeutic Interventions

It can be difficult to accurately diagnose PTSD in individuals with IDD and studies to guide appropriate treatment of individuals with IDD and co-occurring PTSD are limited. Characteristics of therapies for treating PTSD include increased caregiver support, psychoeducation and training, along with availability of 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).

One therapeutic approach postulated as effective for all people with IDD is a ***trauma-informed care approach***. Many people with IDD at various cognitive levels respond well to adapted TF-CBT or EMDR. However, in some cases, such as when an individual is unable to process the traumatic events abstractly, approaching trauma directly could lead to worsening symptomatology and unnecessary and inadvertent re-traumatization. Trauma therapy is also contraindicated when acute psychiatric instability, severe suicidality or self-injury are present.

TRAUMA-INFORMED CARE[4] 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 • Choice and empowerment, utilizing strengths • Preventing re-traumatization • Interdisciplinary
Key components	• Emphasis on the environment, educating caregivers on trauma effects and how to support patients in a positive way • Removal of potential environmental triggers in the patient's immediate environment • Educate caregivers on removing triggers and learning appropriate interventions to deal with challenges • Structured activities revolving around strengths, preferences, and choices • 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, self-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 Table 3.

[4] Substance Abuse and Mental Health Services Administration. *SAMHSA's Concept of Trauma and Guidance for a Trauma-Informed Approach.* Rockville, MD: Substance Abuse Mental Health Services Administration, 2014.

Table 3: Psychopharmacological treatment approaches for PTSD in patients with IDD

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 individuals 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 individual. Other considerations in patients with ID 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.**

Case 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 class teacher's assistant, was not coming back to school for a month because she was having surgery. Linda had been the teacher 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 as way to get out of his work.

What school personnel did not 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 very sudden and records about what actually 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. He 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 three 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[5], 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

[5] Rumball, F. A systematic review of the assessment and treatment of post-traumatic stress disorder in individuals with autism spectrum. *Rev J Autism Dev Disabil.* 2019; 6:294-324.

- Recognition that John had a fear response instead of labeling him 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

References

American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders (5th ed.).* Washington, DC: American Psychiatric Association, 2013.

Fletcher RJ, Barnhill J, Cooper S-A (Eds). *Diagnostic Manual-Intellectual Disability 2: A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability.* Kingston, NY: NADD Press; 2017.

Gilderthorp R. Is EMDR an effective treatment for people diagnosed with both intellectual disability and post-traumatic stress disorder? *J Intellect Disabil*. 2015; 19(1): 58-68.

Hales T, Kusmaul N, Nochajski T. Exploring the dimensionality of trauma-informed care: Implications for theory and practice. *Hum Serv Org Manag Leaders Gov*. 2017; 41(3):317-325,

Harris M, Fallot R. (Eds). *Using Trauma Theory to Design Service Systems: New Directions for Mental Health Services.* San Francisco, CA: Jossey-Bass; 2001

Hindsburger, D. Healthy sexuality: Attitudes, systems and policies. Research and practice for persons with severe disability. *Res Pract Pers Serv Disability.* 2002; 27(1): 8-17.

Hopper EK, Bassuk EL, Olivet J. Shelter from the storm: Trauma-informed care in homelessness services settings. *Open Health Serv Pol J.* 2010; 3(2):80-100.

Keesler J. A call for the integration of trauma-informed care among intellectual and developmental disability organizations. *J Pol Pract Intellect Dis*. 2014; 11(1): 34-42.

Mansell S, Sobsey D, Moskal R. Clinical findings among sexually abused children with and without developmental disabilities. *Amer J Ment Def.* 1998; 36(1):12-22.

Mevissen L, De Jongh A. PTSD and its treatment in people with intellectual disabilities: a review of the literature. *Clin Psychol Rev*. 30(3): 2010; 308-316.

Mevissen L, Lievegoed R, Seubert A, De Jongh A. Treatment of PTSD in people with severe intellectual disabilities: A case series. *J Dev Neuorehabil*. 2012; 15(3):223-232.

Rumball, F. A systematic review of the assessment and treatment of post-traumatic stress disorder in individuals with autism spectrum. *Rev J Autism Dev Disabil.* 2019; 6:294-324.

Shapiro, J. All things considered: She can't tell us what's wrong. NPR. Accessed January, 2018: https://www.kunc.org/post/she-cant-tell-us-whats-wrong#stream/0.

Shapiro, F. *Eye Movement Desensitization and Reprocessing.* New York: Guilford Press. 2018.

Substance Abuse and Mental Health Services Administration. *SAMHSA's Concept of Trauma and Guidance for a Trauma-Informed APproach.* Rockville, MD: Substance Abuse Mental Health Services Administration, 2014.

Van der kolk, B. *The Body Keeps the Score*. New York: Random House; 2014.

Anxiety and Anxiety Disorders

L. Jarrett Barnhill, MD, DFAPA, FAACAP

This section provides a brief overview of the adjunctive role for psychotropic drugs in the treatment of Anxiety Disorders in individuals with Intellectual and Developmental Disabilities (IDD) and Autism Spectrum Disorders (ASD). In this context, pharmacotherapy is part of a comprehensive treatment plan, not a stand-alone intervention.

From Anxiety to Anxiety Disorders

Anxiety represents a spectrum of emotional, somatic, and cognitive responses to both external and internal threats. The core features of anxiety arise from the basic neurobiology of fear (flight, fight, or freeze reactions) and fear-conditioned process that include generalization, sensitization, and resistance to extinction. At higher cortical levels, more complex neurocognitive processes generate anticipatory anxiety, agoraphobia, avoidance in response to perceived social disapproval, skill deficits in problem solving, intolerance of uncertainty, and anticipation of future threats.

Pathological anxiety is a step beyond developmental anxiety. It is anxiety that morphs out of the effects of trauma experiences, early loss, family chaos, and significant skill/problem solving deficits. Pathological anxiety usually presents as both internalizing and externalizing signs and symptoms that do not meet the full criteria for anxiety disorders. In at risk children, it may be a marker for prodromal or subsyndromal forms of anxiety disorders. An imbalance between genetic risk, life stressors and compromised resilience contribute to its progress towards full syndrome anxiety disorder.

The diagnosis of Anxiety Disorders (AD) requires meeting current diagnostic criteria. The DSM-5[1] and DM-ID-2[2] include Specific Phobias, Separation Anxiety, Selective Mutism, Panic, Social Anxiety, Agoraphobia, Generalized Anxiety, Specified and Unspecified Anxiety Disorders, as well as Anxiety Disorder due to Another Medical Disorder. Specific ADs are frequently comorbid multiple psychiatric disorders in which they accentuate their negative impact on quality of life, intensify emotional distress and suffering, contribute to secondary depression and complicate treatment outcomes.

ADs are the most common psychiatric disorders among individuals with IDD. The higher prevalence rates for anxiety reflect an imbalance between resilience, negative life experiences (including trauma) and other susceptibility factors. The prevalence rates for ADs are influenced by diagnostic uncertainty secondary to cognitive and communication deficits, misinterpretation of baseline exaggeration data, and diagnostic overshadowing. Severe/profound disabilities can also interfere with our ability to distinguish AD subtypes. For many with severe/profound IDD, Unspecified AD (overlapping trauma or adjustment disorder), AD due to Another Medical Disorder, and Generalized Anxiety Disorders are about as specific as can be determined.

Case Vignette

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

AK was four at our initial contact. His parents were concerned about school avoidance in AK's first two weeks of pre-kindergarten. AK was described as a shy child with slow to warm up temperament, who rarely spoke outside the family setting. His past medical history revealed: 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. AK's 10-year old twin sisters were shy but doing well. On examination, AK revealed mild delays in most motor milestones, mild spastic left hemiplegia, mutism, and mild separation anxiety.

[1] American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders (5th ed.). Washington*, DC: American Psychiatric Association, 2013.

[2] Fletcher RJ, Barnhill J, Cooper S-A (Eds). *Diagnostic Manual-Intellectual Disability 2: A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability.* Kingston, NY: NADD Press; 2017.

AK's presentation illustrates the importance of an adaptive and stable family ecosystem in matching temperament, attachment needs, and enhanced resilience in early childhood disorders. It is also crucial to understanding the complex roles genetic risk, behavioral inhibition, articulation disorders, and neurodevelopmental problems 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.

AK responded to a brief exposure-graduated desensitization program and did not require pharmacotherapy. Pharmacotherapies are frequently required for children with severe anxiety, parental mental illness, disruptive family life, and chronic trauma and/or abuse. Older children and adolescents with Separation Anxiety may require intensive services for comorbid depressive-anxiety and/or externalizing 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. AK lost his "best buddy." Then in rapid succession, AK had his first panic attack, an intensification of worries about dying and "not keeping up" at school.

During his assessment, AK described worries about his mother's sadness, his father's constant worrying, and missing his sisters, who entered college. His parents shared concern about AK reaching an academic ceiling secondary to his cognitive and learning disabilities and about his increased risk for depression.

A second issue arose from parental concerns about a recent onset of "night terrors." Their description was more consistent with nocturnal panic attacks (may affect 40% of individuals with Panic Disorder). His medical and neurological workups were negative. His neurologist ordered a polysomnography that did not support night terrors.

The mental status exam revealed relative anhedonia in conjunction with grief and growing anticipatory anxiety about another panic attack. The patient's therapist noted similar findings. Neither of us detected suicidal ideation or intent. CBT with modifications was started, but his symptoms persisted. At that point, his therapist, family and AK requested a trial of sertraline (his mother responded to it). Within eight weeks, he appeared euthymic and less anxious, but his sporadic nocturnal panic attacks persisted. We discussed adding clonazepam for night terrors but did not pursue it. AK did well. After two years on sertraline and CBT, we slowly tapered and discontinued his SSRI while continuing his modified CBT.

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

AK did well off sertraline until the beginning of his senior year. In May, his father called to report an intensification of his panic attacks and sleep episodes. When I saw AK, he described his anxiety in different terms. He described a "funny feeling" in his belly that "felt like a mouse running up chest" before 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 resembled "complex partial seizures" intertwined with worsening anxiety. Valproic acid (VPA) was started and titrated up to a serum level of 85 mcg/d. Three months later, his neurologist concurred with the diagnosis of complex partial seizures and maintained VPA. He also wondered if his sleep disturbances also improved, suggesting nocturnal seizures. We increased his VPA and his seizures improved, but his panic attacks and depressed mood persisted. We restarted out-patient CBT and titrated his sertraline to 200 mg/d. His mood improved over the next 2 months.

Treatment: How Do We Help the Fly Get out of the Bottle?

This vignette reinforces two issues. First, the diagnosis and treatment of Anxiety Disorders requires a longitudinal, systemic/ecological perspective as clinical status may change over time. Secondly, the potential for diagnostic overshadowing of disorders can represent a two-way street, and that AD, neurodevelopmental, medical, and/or neurological disorders are not an either/or problem. Focusing exclusively on one or the other can backfire. These caveats support the concept that diagnoses are working hypotheses, not written in stone.

Current best practices trend toward Cognitive Behavior Therapy (CBT), Dialectical Behavior Therapy (DBT), Positive Psychology/Interactive Behavior Therapy (PP/IBT), exposure therapy, and other psychological interventions as preferred frontline treatments. Meta-analytic studies report similar response rates with frontline psychotropic medications (SSRIs and SNRIs). Combining therapies is a practical solution, but the evidence related to managing treatment non-responders suggests that this may be case-by-case decision. Despite this caveat, psycho/ecological 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.

Meta-analytic studies also suggest that psychotropic drugs can be organized into algorithmic hierarchies (see Table 1). Most pharmacotherapy algorithms begin with SSRI's and SNRI's as frontline treatments. Predictors of moving onto second, third and augmentation strategies usually boil down to a lack of response or intolerance. If the drug is not effective 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. If a drug is not tolerated, then switching to alternative classes of medications is prudent.

The second and third treatment tiers are frequently older treatments or those without sufficient research support. As outlined in the table, there is a variety of drug classes and possible mechanisms of action in treatments; for example, older treatments (tricyclics, benzodiazepines) as a replacement for ineffective SSRI/SNRIs. The third-tier treatments are consistent with a high degree of variability within AD drugs like pregabalin, buspirone, beta blockers, multiple anticonvulsants and second-generation antipsychotics. They are usually Tier 3 interventions but can be preferentially 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.

Table 1. Categories of Anxiety Disorders

Category	**Anxiety Disorder**
Fear related	Panic disorder; Social Anxiety (performance); Specific Phobias; Separation Anxiety
Anxious anticipation of threat	Agoraphobia; Selective Mutism
Excessive worry and misery	Generalized Anxiety Disorders; Mood-Anxiety Disorders
Anxiety Disorder due to another medical condition, unspecified and anxiety/trauma anxieties may fall in each of the categories above.	

Table 2. Consensus Treatment Algorithm-Anxiety Disorders

Tier 1	• 1st and 2nd generation SSRIs and SNRIs • Short term benzodiazepines • Beta-blockers (social anxiety-performance related) ***Treatment non-responders:*** review diagnoses and current team-based treatment plan
Tier 2	• Pregabalin • Benzodiazepine and other GABA-Calcium channel mediating treatments • 3rd generation SSRI (Votioxine is most popular) • Tricyclic Antidepressants ***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 once.
Tier 3	• Reversible and standard MAO-A and B Inhibitors • Valproic acid and other anticonvulsants • 2nd and 3rd generation antipsychotic augmentation • Buspirone (Generalized anxiety) • Beta-blockers • TMS and somatic therapies • Alternative treatments

Summary

This review provided an overview of the role of pharmacotherapies as adjuncts in the treatment of AD in the context of IDD. SSRI's, 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).

However, there are exceptions. 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 drugs are adjunctive treatments, and that their true values lies in ecologically-based interventions.

References

Addington AM, Rapoport JL. Annual research review: Impact of advances in genetics in understanding developmental psychopathology. *J Child Psychol and Psychiatry.* 2012; 53: 510-518.

Allgulander C. Generalized anxiety disorder: Between now and the DSM-5. *Psychiatric Clin N Amer.* 2009; 32: 611-628.

American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders (5th ed.).* Washington, DC: American Psychiatric Association, 2013.

Barnhill J, McNelis D. Overview of intellectual/developmental disabilities. *Focus.* 2012; X(3):300-307.

Barnhill J. Integrated pharmacological management. In Rubin IL, Merrick J, Greydanus DE, Patel DR. *Health Care for People with Intellectual and Developmental Disabilities Across the Lifespan.* Dordrecht, NY: Springer; 2016:601-1606.

Beesdo K, Knappe S, Pine DS. Anxiety and anxiety disorders in children and adolescents: Developmental issues and implications for the DSM-5. *Psychiatric Clin N Amer.* 2009; 32: 483-540.

Caspi A, Moffitt TE. All for one and one for all: Mental disorders in one dimension. *Amer J Psychiatry.* 2018; 175(9):831-844.

Conn M (Ed). *Conn's Translational Neuroscience.* New York: Academic Press; 2017.

Cooper SA, Smiley E, Morrison J, Williamson A, Allan L. Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. *Br J Psychiatry*. 2007; 190:27-37.

Cooper N, Feder A, Southwick SM, et al. Resilience and vulnerability to trauma: Psychobiological mechanisms. In Romer D and Walker EF (Eds). *Adolescent Psychopathology and the Developing Brain***.** New York: Oxford Univ Press: 2007; 347-372.

Davis E, Saeed SA, Antonacci DJ. Anxiety disorders in persons with developmental disorders: Empirically informed diagnosis and treatment. *Psychiatric Quarterly.* 2008; 79: 249-264.

Deutz MHF, Woltering S, Vossen HGM, Devotic M, van Baar AL, Orinzie P. Underlying psychophysiology of dysregulation: resting heart rate and heart rate reactivity in relation to childhood dysregulation. *J Amer Acad Child Adolescent Psychiatry.* 2019; 58(6):589-599.

Dilbanz N, Encz A, Cavus S. Social anxiety disorder. In Salek, S (Ed). *Different Views of Anxiety Disorders.* Rijeka Croatia: InTech: 2011.

Fletcher RJ, Barnhill J, Cooper S-A (Eds). *Diagnostic Manual-Intellectual Disability 2: A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability.* Kingston, NY: NADD Press; 2017.

Foa E. Commission on anxiety disorders. In Evans DL, Foa EB, Gur RE, et al (Eds). *Treating and Preventing Adolescent Mental Health Disorders: What we Know and What we Don't Know.* New York: Oxford Press; 2005.

Gonzalez P, Martinez KG. The role of stress and fear in the development of mental disorders. *Psychiatric Clin N Amer.* 2014; 37:535-546.

Harris JC. Advances in understanding behavioral phenotypes in neurogenetic syndromes. *Amer Med J Part C Sem Med Gen***.** 2010; 154(C):389-99.

Jorstad-Stein EC, Heimberg RG. Social phobia: An update on treatment. *Psychiatric Clin N Amer.* 2009; 32:641-664.

Kagan J, Snidman N. Temperament and biology. In Coch D, Fischer KW, Dawson G et al (Eds). *Learning and the Developing Brain.* New York: Guilford Press; 2007.

Katzman MA, Bleau P, Blier P, Chokka P, Amerigan MV. Canadian anxiety guidelines group. *BMC Psychiatry.* 2014; 14(suppl 1).

Kheirbek MA, Klemenhagen KC, Sahay A, Hen R. Neurogenesis and generalization: A new approach to stratify and treat anxiety disorders. *Nat Neuroscience.* 2012; 15:1613-1620.

Kreiser NL and White SW. Autism spectrum traits and recurring psychopathology: The moderating role of gender. *J Autism Dev Disab.* 2015; 45(12):3932-3938.

Kwok H, Cheung PWH. Co-morbidity of psychiatric disorder and medical illness in people with intellectual disability. *Curr Opin Psychiatry.* 2007; 20(5):443-447.

Lanouette NM, Stein MB. Advances in the management of treatment–resistant anxiety disorders. *Focus.* 2010; 8:501-524.

Lissek MA, Rabin S, Heller TE, Lukenbaugh D, Geraci M, Pine DS, et al. Overgeneralization of conditioned fear as a pathogenic marker for panic disorder. *Amer J Psychiatry.* 2010; 67:47-55.

Martin EI, Ressler KJ, Binder E, et al. The neurobiology of anxiety disorders: Brain imaging, genetics and psycho-endocrinology. *Psychiatric Clin N Amer.* 2009; 32:549-576.

Mangolini VI, Andrade LH, Latufo-Neto F, Wang Y-P. Treatment of anxiety disorders in clinical practice: A critical overview of recent systemic evidence. *Clinics.* 2019; 10:60-61

Matthew SJ, Price RB, Charney DS. Recent advances in the neurobiology of anxiety disorders: Implications for novel therapeutics. *Amer J Med Genetics.* 2008; 89-98.

Perez-Edgar K, Fox NA. Temperament and anxiety disorders. *Ch Adol Psychiatric Clin N Amer.* 2005; 14:681-706.

Reiss S. *The Concept of Anxiety Sensitivity: Possible Implications for Research on Dual Diagnosis.* Kingston NY: NADD Press; 2000.

Royall College of Psychiatrists. *Diagnostic Criteria for Psychiatric Disorders for Use in Adults with Learning Disabilities/Mental Retardation.* London: Gaskell; 2001.

Rutter M. The interplay of nature, nurture and developmental influences: The challenge ahead for mental health. *Arch Gen Psychiatry.* 2002; 59(11):996-1001.

Obsessive Compulsive and Related Disorders

L. Jarrett Barnhill, MD, DFAPA, FAACAP

Obsessive Compulsive Disorder (OCD) was once considered to be a rare disorder. The current combined prevalence rates for community and clinic-based sampling remain around 1-3%[1] of the general population. The prevalence rates have not changed dramatically since nomenclature and inclusion criteria were clarified with the adoption of the DSM-5[2] or DM-ID-2[3]. Only a minority of affected people seek treatment unless there are co-occurring mood, anxiety, OC related behaviors, or comorbid neurodevelopmental disorders (including ADHD and tic disorders).

Assessment

Diagnostic criteria 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, and an extensive list of rule outs and co-occurring disorders. Specifiers in level of insight and co-occurring tic disorders are principal signifiers. Factor analytic studies focused on limiting heterogeneity in Obsessive Compulsive and Related Disorders (OC-RD) suggest four subtypes: 1) primary obsessives; 2) hoarding; 3) classical contamination, doubting and associated passive avoidance behaviors along with a cluster of intrusive violent/sexual images; 4) counting, arranging, touching symmetries and some asocial behaviors. Classic OCD appears related to high harm avoidance/low novelty seeking temperament that may underlie the obsessions, and a relatively narrow range of compulsions that permit a transitory respite from the distressing obsessions. Hoarding associated with OCD seems the most closely linked to Autism Spectrum Disorder (ASD) but this is still under study. Touching, need for symmetry, and counting tend to co-occur with tic disorders. Primary obsessions include intrusive images, or sensory urges (overlapping sensory and premonitory tics) that lack a significant cognitive component. Several related disorders seem to share features with other forms of OC-like disorders, and impulse control disorders (internet shopping addiction for example).

Among individuals with intellectual and developmental disabilities (IDD), including ASD, prevalence rates are biased by a limited capacity to attain self-reported symptoms, diagnostic overshadowing by other related disorders, and difficulty distinguishing OC behaviors from the core features of ASD (stereotypic, restrictive and repetitive behaviors) or ritualistic behaviors in individuals with severe ID. Referrals for people with IDD involve high levels of co-occurring disruptive stereotypies and complex ritualistic behaviors, self-injury and aggression. 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.

Treatment Strategies

OC-RD is a heterogeneous group of repetitive behaviors with multiple etiologies and comorbidities. For many individuals, treatments begin with generalized strategies, which may be effective in two-thirds of patients. Each decision step beyond this point requires a 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 individuals with ASD and ID, ADHD and externalizing behaviors, OC-related symptoms and tic disorders are common co-occurring conditions. Combined therapies are common, but it is important to avoid unnecessary polypharmacy and apply ecological interventions and psychotherapies in each subsequent treatment tier.

Generalized Strategies for OC-RD:

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

Common psychopharmacological treatment strategies for OC-RD:

- SSRIs/Clomipramine

[1] National Institute of Mental Health. *Obsessive compulsive disorder (OCD).* https://www.nimh.nih.gov/health/topics/obsessive-compulsive-disorder-ocd/index.shtml. Updated October 2019. Accessed August 27, 2020.

[2] American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders (5th ed.)*. Washington, DC: American Psychiatric Association, 2013.

[3] Fletcher RJ, Barnhill J, Cooper S-A (Eds). *Diagnostic Manual-Intellectual Disability 2: A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability*. Kingston, NY: NADD Press; 2017.

Treatment is Associated with Four Basic Approaches

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.

Perhaps 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:

1. Patients with OC-RD generally require a prolonged latency of response, longer duration of treatment, and higher doses of SSRI/SNRIs.

2. Most treatment strategies contribute to improvement but fewer remissions, and rarely complete recovery from OC-RDs.

3. 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).

4. Many individuals 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.

5. 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 | OC-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:

1. ERP/CBT/HRT, SSRI's augmented with alpha-agonists, SGAs and in exceptional cases clonazepam.
2. Treating OC symptoms and tics first means overcoming concerns about the adverse effects of treating psychiatric co-morbidities that can increase irritability, SIB and aggression; and increase repetitive behaviors associated with OC-RD. For example, stimulants used to treat ADHD might, in some cases, increase repetitive behaviors. Current evidence suggests that this is unlikely but there are exceptions.
3. 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.
4. Clinical judgment and consultation or referral to peers and experts may be useful. These complex co-occurring conditions suggest more neuropharmacological heterogeneity. In reality, OC-RD is not a single neuro-transmitter condition and NE, DA, GABA, glutamate, and neuropeptide/opioid are players in its pathophysiology.
5. Consider the presence of genetic disorders associated with SIB (e.g. Lesch-Nyhan syndrome), neurodegenerative disorders, and cerebrovascular 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

Co-morbidities might include: ADHD, mood disorders, anxiety, TBI, impulse control disorders, trauma/PTSD, schizophrenia, substance use, and fronto-temporal dementias.
In this situation, treat the primary condition first. See other sections of this guide for treatment recommendations for these conditions.

Tier 4 | OC-RD, ID and ASD

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

Summary

In general, 60% respond to treatment, fewer go into remission, and some are treatment resistant. Most individuals with IDD and OCD require augmentation, or in combination with pharmacotherapy/ manualized psychotherapies. This group may also require an extensive review of previous diagnoses and treatment, especially reassessment, including associated neurological or degenerative disorders.

Case Vignette

RB is a 26-year-old male with ASD, borderline ID, Tourette's disorder, and compulsive handwashing. 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 fed his compulsive handwashing rituals.

A combination of increased structured activities outside the home and a very slow successive program of exposure and limiting time he could wash (decreasing from three hrs. to under 30 minutes/day) was more effective than standard ERP and HRT techniques. Even with modified ERP/HRT intervention, RB continues 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 Transcranial Magnetic Stimulation (TMS), Direct Current Stimulation and more invasive somatic procedures were under investigation.

Conclusion

OC-RD is a heterogeneous group of repetitive behaviors with multiple etiologies and comorbidities. For many individuals, treatment begins with generalized strategies (CBT/ERP/HRT and SSRIs/clomipramine). These may be effective in two-thirds or patients. Each decision step beyond this point requires a 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.

References

American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders (5th ed.)*. Washington, DC: American Psychiatric Association, 2013.

Bais M, Figee M and Denys D. Neuromodulation in obsessive-compulsive disorder. *Psychiatric Clin N Amer*. 2014; 37(3):393-414.

Barnhill J. Obsessive-compulsive disorders or not: Differential diagnosis of repetitive behaviors among individuals with intellectual and developmental disorders. In Selik S (ed). *Different Views of Anxiety Disorders.* InTech; 2011.

Barnhill J. Integrated pharmacological management. In Rubin IL, Merrick J, Greydanus DE, Patel DR. *Health Care for People with Intellectual and Developmental Disabilities Across the Lifespan.* Dordrecht, NY: Springer; 2016:601-1606.

Beauilieu AM, Tabasky E, Osser DN. The psychopharmacology algorithm project as the Harvard South Shore Program: An algorithm for adults with obsessive-compulsive disorder. *Psychiatric Res.* 2019; 281112583:1-9.

Denys D. Pharmacotherapy of obsessive-compulsive disorder and obsessive-compulsive spectrum disorders. *Psychiatric Clin N Amer*. 2006; 29(2):553-584.

Fletcher RJ, Barnhill J, Cooper S-A (Eds). *Diagnostic Manual-Intellectual Disability 2: A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability.* NADD Press: Kingston, NY; 2017.

Golembeck AA, King B. Pharmacotherapy. In Dryden-Edwards RC, Combrick-Graham L (Eds). *Developmental Disabilities from Childhood to Adulthood.* Baltimore, MD: Johnson Hopkins Press; 2014: 270-295.

Katzman MA, Bleau P, Blier P, Chokka P, Amerigan MV. Canadian anxiety guidelines group. *BMC Psychiatry* 2014:14 (suppl 1).

Kennedy CH. Behavioral interventions. In Dryden-Edwards RC, Combrick-Graham L (Eds). *Developmental Disabilities from Childhood to Adulthood*. Baltimore, MD: Johns Hopkins Press; 2014:296-311.

Lewin AB, Wu MS, McGuire JF, Storch EA. Cognitive behavioral therapy for obsessive-compulsive and related disorders. *Psychiatric Clin North Amer*. 2014; 37(3): 415-446.

Mangolini VI, Andrade LH, Latufo-Neto F, Wang Y-P. Treatment of anxiety disorders in clinical practice: A critical overview of recent systemic evidence. *Clinics*. 2019; 10:60-61

March JS. The expert consensus guideline series: treatment of obsessive-compulsive disorder. J. *Clin. Psychiatry*. 1997; 58 (Suppl):1–72.

National Institute of Mental Health. *Obsessive compulsive disorder (OCD)*. https://www.nimh.nih.gov/health/topics/obsessive-compulsive-disorder-ocd/index.shtml. Updated October 2019. Accessed August 27, 2020.

Oesterheld J, Osser DN. Drug interactions in augmentation strategies for pharmacotherapy of OCD. *J. Pract. Psychiatry Behav. Health*. 1999; 5(3):179–13.

Pettinger C, Bloch MH. Pharmacological treatment of obsessive-compulsive disorder. *Psychiatric Clin N Amer*. 2014; 37(3):375-392.

Scrieber , Odlaug BL, Grant JE. Impulse control disorders: updated review of clinical characteristics and pharmacological management. *Front Psychiatry*. 2011; 2(1): DOI: 10.3389/fpst2011.00001.

Depressive Disorders

Jennifer McLaren, MD

This section provides a brief overview of Depressive Disorders in individuals with Intellectual and Developmental Disabilities (IDD) and Autism Spectrum Disorders (ASD). Depressive Disorders are common among individuals with IDD, with lifetime prevalence rates of 37%.[1] Common antecedents for depression in individuals with IDD include personal loss (e.g., caregiver, friend, staff), isolation, marginalization, meaninglessness, lack of autonomy, trauma, bullying, victimization, or other adverse experiences. It is important to ask about these losses as it 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 an individual's baseline and impairment in functioning. The severity of an individual's ID impacts the presentation of depression. Individuals with mild to moderate ID may report feeling sad or depressed, making depression easier to recognize. Individuals with a more significant intellectual impairment may not be able to verbalize their internal feelings, making a depression diagnosis more nuanced. For all individuals, 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. These disorders are frequently comorbid with anxiety disorders. Consider utilizing a standardized rating scale when assessing and treating depression such as the PHQ-9. Adaptations to the PHQ-9[2] have been made for individuals with IDD.

For moderate to severe depression consider a combination of therapy plus antidepressants. There is a lack of research on psychopharmacologic treatments for individuals with depression and IDD. The psychotropic medications used to treat depression in typically developing individuals are utilized for individuals with IDD. 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). If an SSRI is not appropriate, then consider serotonin-norepinephrine reuptake inhibitors, atypical antidepressants, and serotonin modulators (Figure 1). 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.

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

- Citalopram: increase in irritability for individuals 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

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 individual is not improving and tolerating the antidepressant, then titrate the antidepressant in stepwise increments as tolerated up to lowest effective dose.

[1] American Psychiatric Association. Practice Guidelines for the Treatment of Patients with Major Depressive Disorder. Washington DC: American Psychiatric Association, 2010.

[2] Breen J. Adapting the GAD-7 and PHQ-9 Clinical Measures for People with Learning Disabilities [PhD thesis]. Royal Holloway, University of London; 2017.

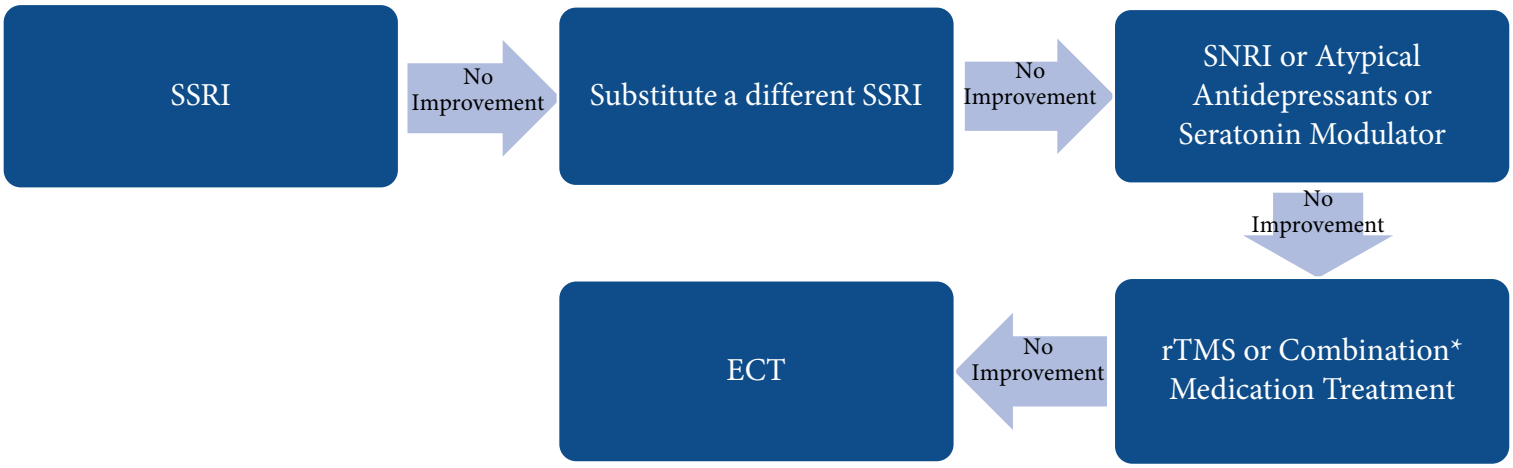
Table 1. Key Components in Assessing Depression in Individuals with IDD

- Comprehensive history with collateral information, including behavioral observations from caregivers, residential staff, day staff, etc.
o 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?*
o Symptoms of depression include four 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 (individuals 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
o 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
o Assess for episodes of mania or hypomania to rule out bipolar disorder
o Comorbid substance use/abuse/dependence
o Assess for psychosocial stressors and abuse
o 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.
o Ask about complementary and alternative medications.
o 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

For individuals not showing improvement with antidepressant treatment, consider re-evaluating their diagnosis and compliance with treatment. 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, consider augmenting the initial antidepressant with second-generation antipsychotics (aripiprazole, quetiapine, and risperidone), lithium, or other antidepressants. **Risks and harms of adding additional medications must be carefully considered.** After three adequate trials of antidepressants, if the individual continues to have significant symptoms of depression, consider neurostimulation such as repetitive transcranial magnetic stimulation (rTMS) and then electroconvulsive therapy (ECT). ECT should only be utilized when symptoms are severe, refractory to medication treatment, or when medication options run out.

Figure 1. Consensus Treatment Psychotropic Algorithm – Depressive Disorders



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

Comorbid Treatment

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

Case 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 interview it was reported that Mr. F is pacing more than unusual, 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 was dead or not here. While you did not 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 of losing a preferred staff members. He remains on his SSRI for 1 year, and it is slowly tapered with no re-emergence of depressive symptoms.

References

American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders (5th ed.).* Washington, DC: American Psychiatric Association, 2013.

American Psychiatric Association. *Practice Guideline for the Treatment of Patients with Major Depressive Disorder*. Washington DC: American Psychiatric Association, 2010.

Breen J. *Adapting the GAD-7 and PHQ-9 Clinical Measures for People with Learning Disabilities [PhD Thesis]*. Royal Holloway, University of London; 2017.

Constantino JN, Strom S, Bunis M, et al. Toward actionable practice parameters for "dual diagnosis": Principles of assessment and management for co-occurring psychiatric and intellectual/developmental disability. *Curr Psychiatry Rep*. 2020; 22(9).

Cooper SA, Smiley E, Allan L, et al. Incidence of unipolar and bipolar depression, and mania in adults with intellectual disabilities: prospective cohort study. *Br J Psychiatry*. 2018; 212:295-300.

Cooper SA, Smiley E, Morrison J, et al. Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. *Br J Psychiatry*. 2007; 190:27-35.

National Collaborating Centre for Mental Health (UK). *Depression: The Treatment and Management of Depression in Adults (Updated Edition)*. Leicester, UK: British Psychological Society; 2010.

Fletcher RJ, Barnhill J, Cooper S-A (Eds). *Diagnostic Manual-Intellectual Disability 2: A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability*. Kingston, NY: NADD Press; 2017.

Gartlehner G, Hansen RA, Morgan LC, et al. Comparative benefits and harms of second-generation antidepressants for treating major depressive disorder: an updated meta-analysis. *Ann Intern Med*. 2011; 155:772-85.

Hamers PCM, Festen DAM, Hermans H. Non-pharmacological interventions for adults with intellectual disabilities and depression: a systematic review. *J Intellect Disabil Res*. 2018; 62:684-700.

Jahoda A, Hastings R, Hatton C, et al. Comparison of behavioural activation with guided self-help for treatment of depression in adults with intellectual disabilities: a randomised controlled trial. *The Lancet*. 2017; 4:909-919.

Kennedy SH, Lam RW, McIntyre RS, et al.: Canadian network for mood and anxiety treatments (CANMAT) 2016 clinical guidelines for the management of adults with major depressive disorder: Section 3. Pharmacological treatments. *Can J Psychiat*. 2016; 61:540-606.

King BH, Hollander E, Sikich L, et al. Lack of efficacy of citalopram in children with autism spectrum disorders and high levels of repetitive behavior: citalopram ineffective in children with autism. *Arch Gen Psychiatry*. 2019; 66:583-90.

Magnuson KM, Constantino JN. Characterization of depression in children with autism spectrum disorders. *J Dev Behav Pediatr*. 2011; 32:332-400.

Milev RV, Giacobbe P, Kennedy SH, et al. Canadian network for mood and anxiety treatments (CANMAT) 2016 clinical guidelines for the management of adults with major depressive disorder: Section 4. Neurostimulation treatments. *Can J Psychiat*. 2016; 61:561-75.

Muir W: The use of ECT in people with learning disability. In Scott AIF (ed). *The ECT Handbook (Second Edition)*. Gaskell. 2005; 57-67.

Rai D, Heuvelman H, Dalman C, et al. Association between autism spectrum disorders with or without intellectual disability and depression in young adulthood. *JAMA Netw Open*. 2018; 1(4):e181465.

Simon GE, Perlis RH. Personalized medicine for depression: can we match patients with treatments? The *Amer J Psychiatry*. 2010; 167(1): 445-55.

Spijker J, Nolen WA. The algorithm for the biological treatment of depression in the Dutch multidisciplinary guideline on depression. *Tijdschr Psychiatr*. 2011; 53(4):223-33.

White SW, Simmons GL, Gotham KO, et al. Psychosocial treatments targeting anxiety and depression in adolescents and adults on the autism spectrum: Review of the latest research and recommended future directions. *Curr Psychiat Rep*. 2018; 20(10):82.

Bipolar and Related Disorders

Jennifer McLaren, MD

This section provides a brief guide to Bipolar Disorder in individuals 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 an individual's baseline. The severity of an individual's intellectual disability will influence the presentation of symptoms for Bipolar Disorder. Individuals with mild to moderate intellectual disability may report their internal feelings and observations of their own behavior. Individuals with a more significant intellectual impairment may not be able to verbalize their feelings and observations. For all individuals, 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 is required in order to prescribe effectively.

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.

Case Vignette

Nancy is a 23-year-old female with mild Intellectual Disability. She had a chaotic childhood. Her parents experienced significant mental health issues, and Nancy also had multiple psychiatric hospitalizations though these records are not available. 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 appears irritable, withdrawn, has low energy and nothing seems to give her pleasure.

Nancy begins Lithium and it is titrated to a therapeutic blood level. She does well for six months then begins to frequently miss her Lithium as she does not like how she feels on it. She experiences another manic episode and during this episode, 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 appears to be 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.

Case Summary

This vignette highlights several important points:

- Potential family history of Bipolar Disorder
- Grandiosity in someone with ID or ASD may be exaggerated claims of skills or accomplishments.
- Individuals 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)

Table 1. Key Components in Assessing Bipolar and Related Disorders in Individuals with IDD

- Comprehensive history with collateral information, including behavioral 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 mania or hypomania include a persistently elevated, expansive or irritable mood with the following symptoms
        - Mania: symptoms lasting at least 1 week and that cause 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 individual'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 individuals with Bipolar Disorder and IDD. The psychotropic medications to treat Bipolar Disorder in typically developing individuals are utilized for individuals with IDD.

Treatment of Mania

It is important to provide psychoeducation about the chronicity and course of Bipolar Disorder, treatment, and the importance of adherence to treatment. Manic and hypomanic episodes are treated with the same psychotropic medication. A variety of medication shows comparable efficacy in treating mania and are considered first line medications including lithium, quetiapine, divalproex, asenapine, aripiprazole, paliperidone, risperidone and cariprazine. Among these medications, lithium, valproate, aripiprazole, risperidone and quetiapine have a favorable safety and tolerability profile and a stronger evidence base in patients with ID and ASD. These medications should be considered first to treat mania in individuals with ID and ASD. Table 2 shows how to choose medication to treat mania.

Table 2. Which medication to choose?

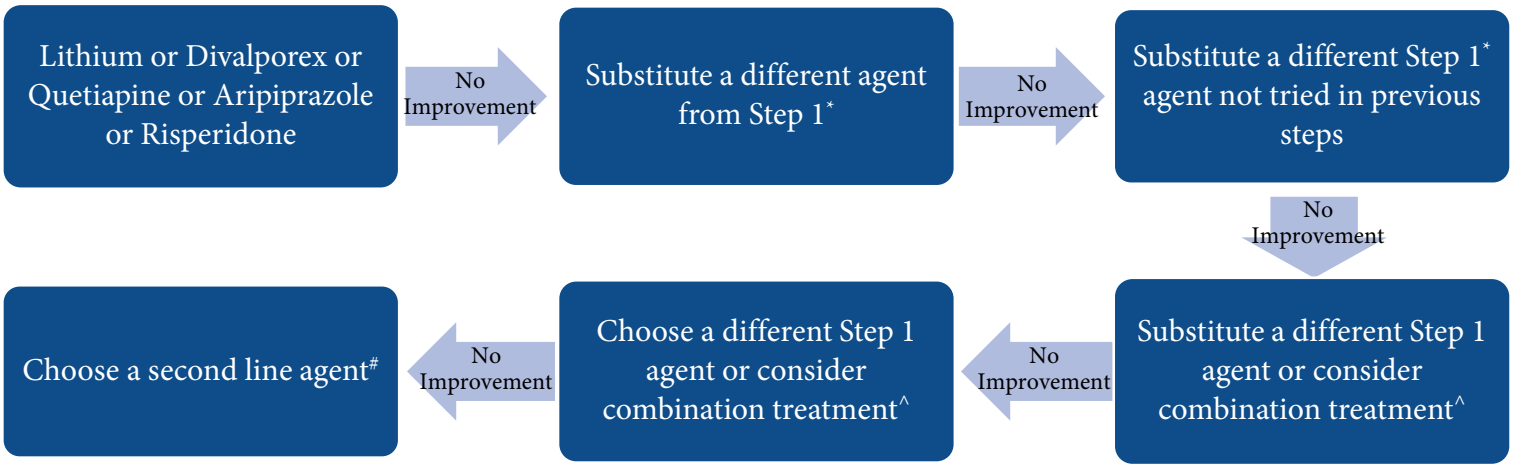
- The choice between lithium and valproate, and the choice of the antipsychotic should be based upon the following:
○ Individual's past response to medications ○ Past response to medications of family members with Bipolar Disorder
○ Symptoms
○ Comorbid general medical illnesses ▪ If patient has epilepsy 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 an individual does not respond to a first line agent, substitute a different first line agent before preceding 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 individuals with IDD.

Treatment of Depression

Consider Positive Cognitive Behavioral Therapy to help the individual learn coping strategies to manage depression. First line psychotropic medications to treat depression in Bipolar Disorder include the following: quetiapine, lithium, lamictal, lurasidone, or lurasidone with lithium or divalproex. Second line agents include the following: Divalproex, SSRI or bupropion, ECT, cariprazine, and olanzapine-fluoxetine. Maintenance treatment is important in Bipolar Disorder to prevent future episodes of mania and depression.

Figure 1. Consensus Treatment Psychotropic Algorithm – Manic Episode Mild-Moderate Severity

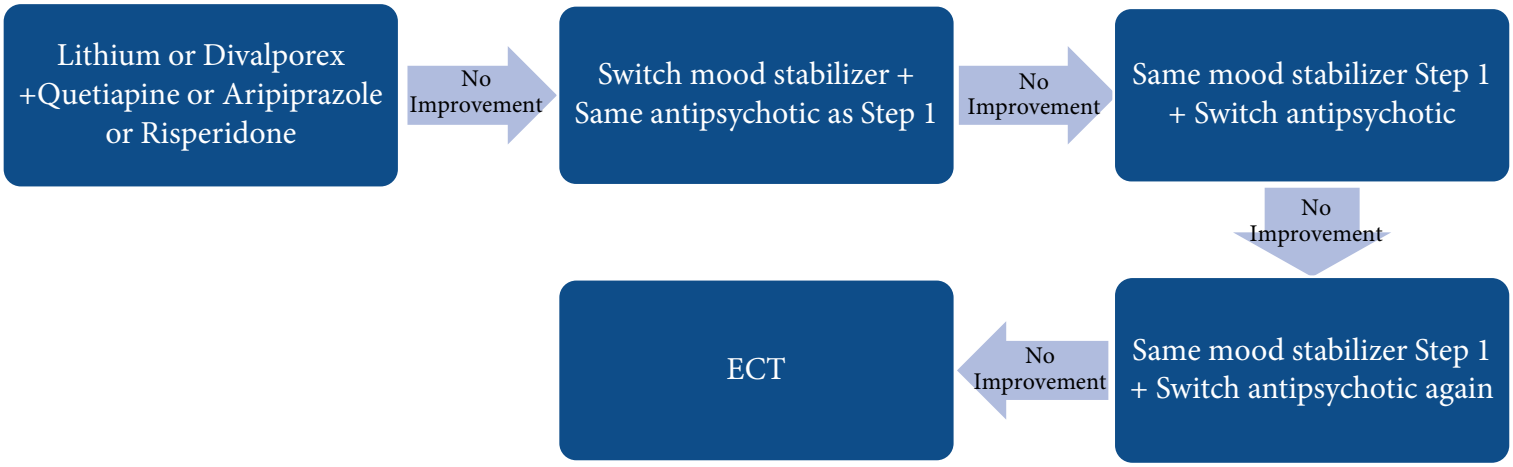


* Step 1 agents: lithium, valproate, aripiprazole, risperidone, and quetiapine
^Combination treatment if symptoms becoming more severe: lithium or valproate plus quetiapine, aripiprazole or risperidone
#Second line agents: olanzapine, carbamazepine, ziprasidone, haloperidol, lithium plus valproate, olanzapine plus valproate or lithium, and ECT

Severe Mania

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 no response, then switch to a different antipsychotic or try ECT. ECT should only be utilized when symptoms are severe, refractory to medication treatment or when medication options run out. Figure 2 illustrates an algorithm for treatment of severe mania in individuals with ID or ASD.

Figure 2. Consensus Treatment Psychotropic Algorithm – Severe Manic Episode



References

American Psychiatric Association: *Diagnostic and Statistical Manual of Mental Disorders (5th ed.).* Washington, DC: American Psychiatric Association, 2013.

Deb S, Chaplin R, Sohanpal S, Unwin G, Soni R, Lenotre L. The effectiveness of mood stabilizers and antiepileptic medication for the management of behaviour problems in adults with intellectual disability: A systematic review. *J Intellect Disabil Res.* 2008; 52(2):107-113.

Deb S, Farmah BK, Arshad E, Deb T, Roy M, & Unwin GL. The effectiveness of aripiprazole in the management of problem behaviour in people with intellectual disabilities, developmental disabilities and/or autistic spectrum disorder–a systematic review. *Res Dev Disabil.* 2014; 35(3):711-725.

Fitzpatrick SE, Srivorakiat L, Wink LK, Pedapati EV, & Erickson CA. Aggression in autism spectrum disorder: presentation and treatment options. *Neuropsychiatr Dis Treat.* 2016; 12:1525-1538.

Fletcher RJ, Barnhill J, Cooper S-A (Eds). *Diagnostic Manual-Intellectual Disability 2: A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability.* Kingston, NY: NADD Press; 2017.

Goodwin GM, Haddad PM, Ferrier IN, et al. Evidence-based guidelines for treating bipolar disorder: revised third edition recommendations from the British Association for Psychopharmacology. *J Psychopharm.* 2016; 30(6):495-553.

Grunze H, Vieta E, Goodwin GM, Bowden C, Licht RW, Azorin JM, WFSBP Task Force on Bipolar Affective Disorders. The World Federation of Societies of Biological Psychiatry (WFSBP) Guidelines for the biological treatment of bipolar disorders: Acute and long-term treatment of mixed states in bipolar disorder. *World J Bio Psychiatry,* 2018; 19(1):2-58.

Ji NY, Findling RL. Pharmacotherapy for mental health problems in people with intellectual disability. *Curr Opin Psychiatry.* 2016; 29(2):103-125.

Malhi GS, Gessler D, Outhred T. The use of lithium for the treatment of bipolar disorder: recommendations from clinical practice guidelines. *J Affect Disorders.* 2017; 217:266-280.

Maneeton N, Maneeton B, Putthisri S, et al. Risperidone for children and adolescents with autism spectrum disorder: A systematic review. *Neuropsychiatr Dis Treat.* 2018; 14:1811.

Muir W: The use of ECT in people with learning disability. In Scott AIF (ed). *The ECT Handbook (Second Edition).* Gaskell. 2005.

National Collaborating Centre for Mental Health (UK). *Bipolar Disorder: The NICE Guideline on the Assessment and Management of Bipolar Disorder in Adults, Children and Young People in Primary and Secondary Care.* London: The British Psychological Society and Royal Collect of Psychiatrists; 2014.

Perugi G, Medda P, Toni C, et al. The role of electroconvulsive therapy (ECT) in bipolar disorder: effectiveness in 522 patients with bipolar depression, mixed-state, mania and catatonic features. *Curr Neuropharm.* 2017; 15(3):359-371.

Scherk H, Pajonk FG, Leucht S. Second-generation antipsychotic agents in the treatment of acute mania: a systematic review and meta-analysis of randomized controlled trials. *Arch Gen Psychiatry.* 2007; 64(4):442-455.

Williamson E, Sathe NA, Andrews JC, et al. *Medical Therapies for Children with Autism Spectrum Disorder—An Update.* Rockville, MD: Agency for Healthcare Research and Quality; 2017.

Yatham LN, Kennedy SH, Parikh SV, et al. Canadian Network for Mood and Anxiety Treatments (CANMAT) and International Society for Bipolar Disorders (ISBD) collaborative update of CANMAT guidelines for the management of patients with bipolar disorder. *Bipolar Disord.* 2018; 20(2):97-170.

Grief and Loss

Katy Stratigos, MD, Lauren Charlot, PhD, LICSW, and Andrea Caoili, LCSW

There is an extensive body of research that focuses on the relationship among grief, bereavement and mood disorders. Unfortunately, many clinicians assessing and treating individuals with Intellectual and Developmental Disabilities (IDD) and Autism Spectrum Disorder (ASD) may not be familiar with this body of work. In addition, few studies focus on grief and grief work in people with IDD. This section will investigate the many faces of grief and outline appropriate treatment techniques and resources.

DSM-5[1] Changes to Assessment and Diagnosis of Bereavement

The authors of the DSM-5 eliminated the longstanding concepts that defined the boundaries between bereavement and Major Depressive Disorders (MDD). In previous editions of the DSM, the diagnosis of bereavement, rather than MDD, required that depressive symptoms occurred in the context of significant losses, regardless of whether the depressive symptoms met the criteria for major depression.

The DSM-5 requires clinical judgment as to whether the severity and symptoms in response to loss rise to the level of a major depressive episode. The issue involves discriminating between the factors that increase the likelihood that significant loss triggers MDD and not other DSM-5 disorders. Persistent Complex Bereavement Disorder in the DSM-5 presents as an intense, turbulent, intrusive, prolonged, and maladaptive process.

Criteria for Persistent Complex Bereavement Disorder

- Lasts at least 6 months for children and 12 months for adults
- Manifestations of separation distress, traumatic distress
- Significant functional impairment

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[2] developed a five-stage model of grief to describe the different stages and experiences of a person when bereaved. Later, Kessler[3] 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.

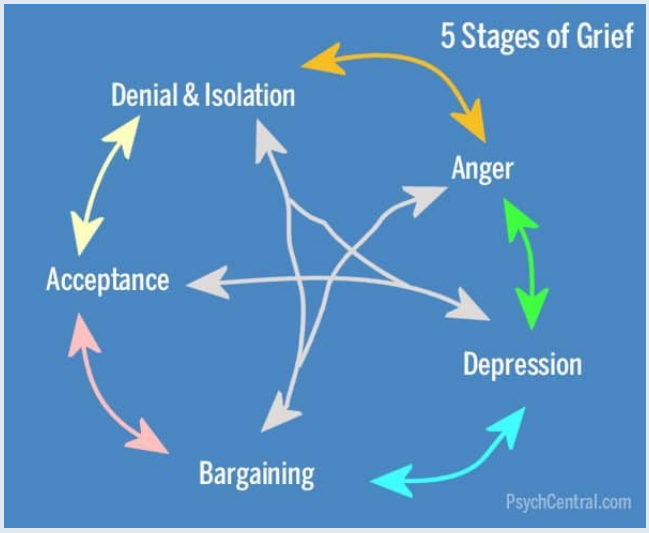


Image source: https://psychcentral.com/lib/the-5-stages-of-loss-and-grief/

Table 1. Six Stage Model of Grief (Kubler-Ross, Kessler)

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

[1] American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders (5th ed.).* Washington, DC: American Psychiatric Association, 2013.

[2] Kubler-Ross, E. *On Death and Dying.* New York, NY: Collier Books/Macmillian, 1969.

[3] Kessler D. *Finding Meaning: The Sixth Stage of Grief.* New York, NY: Scribner, 2019.

Considerations for Patients with IDD

As with other stressful life events, the impact of personal loss may be underestimated in individuals with IDD. 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." As a result of these biases, people with IDD may not be permitted to grieve with their family, attend funerals or memorial services, or provided psychological supports to cope with the loss. A poignant example involves the person waiting or searching for the deceased, not fully understanding that death is irreversible. Such responses, when an individual is not involved in family rituals, may create more distress for other grieving family members and have systemic effects on the survivors.

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 considered symptoms of another condition. This mischaracterization can result in the person receiving treatment (including medications to treat different conditions) that is not indicated for grief.

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. 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, becoming "the straw that breaks the camel's back." Unrecognized or undiagnosed grief may result in inadequate grief resolution and put the person at greater risk of Persistent Complex Bereavement Disorder. In this sense, grief resembles untreated trauma in terms of its transformation into a disorder that is more complex and difficult to treat.

The grief response for people with IDD can be a prolonged 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.

Table 2: Emotional and Behavioral Symptoms of Grief in IDD

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

Grief responses related to crises other than death may also be significant and require clinical attention. Individuals with IDD, and particularly some with ASD, experience significant health, emotional and behavioral challenges secondary to loss other than death. Many people with IDD lack control and ability to make choices regarding their living arrangements, jobs, social opportunities and even their medical and psychiatric care. Lack of control and choice likely amplifies anxiety in many contexts. The 2019-2020 advent of the COVID-19 virus and related restrictions such as needing to shelter in place provide an extreme example of this form of loss and its impact on the lives of people with IDD.

Effective Psychosocial Treatment Options for People with IDD Who are Grieving

The few large-scale scientific studies available 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. For example, preventative or proactive interventions may take advantage of frequent, less extreme situations to help the individual 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. At the formal level, it has been reported that attachment work, addressing coping mechanisms, and guidance and education of home staff, as well as coordination with home staff, have been successful." Group supports and planned activities may also be effective, including visits to funeral homes, making memory tables, and "comfort bags."

Bereavement counseling can benefit individuals 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.

When does bereavement require psychopharmacological intervention?

Psychopharmacological intervention may be beneficial for some people with IDD in conjunction with individual and/or group psychotherapy. When the bereaved person with IDD meets the criteria for clinical depression, has significant impairment in daily functioning and/or is experiencing suicidal ideation, antidepressant therapy may be appropriate.

Case Vignette

George is a 60-year-old man with mild ID and autism. Record review indicated poorly supported diagnoses of bipolar disorder and schizophrenia diagnosed in 2017. George lived at home with his younger brother and parents for his entire childhood. His mother homeschooled him although his brother went to public school. George's entire immediate family has always been very 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 turned 18 and went to college. This left only George and his mother living in the family home for many years until his mother passed in 2016. At that time, George moved to a group home. Although he still has some support from his brother, his brother does not live in the same state and travels a lot for work.

Before moving to the group home, George attended a day program five days per week. He also received occasional weekend respite and was involved in his church. His primary care manager was a long-time family friend, but he retired shortly before the passing of George's mother. Upon moving to the group home, new primary care services needed to be established.

George was referred for psychiatric assessment at an IDD specialty clinic in 2018 due to "aggressive behaviors," limiting his day program to only twice/week. His sleep was disrupted, with awakening often in the middle of the night. 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.

Taking symptom trends into consideration, it was determined that a diagnosis of complex bereavement disorder should be considered. In-home supports were coordinated with the group home to provide additional assistance to titrate George off ineffective medications and begin a trial on an SSRI. In addition to psychopharmacological treatment, George was screened and then enrolled in bereavement-focused psychotherapy.

References

American Psychiatric Association: *Diagnostic and Statistical Manual of Mental Disorders (5th ed.).* Washington, DC: American Psychiatric Association, 2013.

Bonell-Pascual, E, Huline-Dickens, S, Hollins, S. Bereavement and grief in adults with learning disabilities: A follow-up study. *Br J Psychiatry*. 1999; 175(4):348–350.

Brickell C, Munir K. Grief and its complications in individuals with intellectual disability. *Harv Rev Psychiatry.* 2008; 16(1):10-12.

Clements P, Focht-New, G, Faulkner, M. Grief in the shadows: Exploring loss and bereavement in people with developmental disabilities. *Iss Ment Health Nurs*. 2004; 25:799-808.

Clute, MA. Bereavement interventions for adults with intellectual disabilities: What works? *Omega*. 2010; 61(2):163-77.

Clute, M. *A Grounded Theory Study of the Bereavement Experience for Adults with Developmental Disabilities Following the Death of a Parent or Loved One: Perceptions of Bereavement Counselors [PhD Dissertation].* Cleveland, OH: Case Western Reserve University; 2017.

Dowling S, Hubert J, White S, Hollins S. Bereaved adults with intellectual disabilities: A combined randomized controlled trial and qualitative study of two community-based interventions. *J Intellect Disabil Res*. 2006; 50(4):277-287.

Fletcher RJ, Barnhill J, Cooper S-A (Eds). *Diagnostic Manual-Intellectual Disability 2: A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability.* Kingston, NY: NADD Press; 2017.

Hume K, Regan T, Megronigle L, Rhinehalt C. Supporting students with autism spectrum disorder through grief and loss. *Autism Glance.* 2015; 48(3):128-136.

Kessler D. *Finding Meaning: The Sixth Stage of Grief.* New York, NY: Scribner, 2019.

Kubler-Ross, E. *On Death and Dying.* New York, NY: Collier Books/Macmillian, 1969.

MacHale R, Carey S. An investigation of the effects of bereavement on mental health and challenging behavior in adults with learning disability. *J Learn Disabil.* 2002; 30(3):113–117.

Mosher PJ. Everywhere and nowhere: Grief in child and adolescent psychiatry and pediatric clinical populations. *Child Adolesc Psychiatr Clin N Am.* 2018; 27(1):109-124.

Shear MK, Bloom CG. Complicated grief treatment: An evidence-based approach to grief therapy. *J Ration Emot Cogn Behav Ther*. 2017; *35*(1): 6-25.

Van Dyke L. *Lessons in Grief & Death: Supporting People with Developmental Disabilities in the Healing Process.* Homewood, IL: High Tide Press; 2013.

Treatment of Schizophrenia and Other Psychotic Disorders

L. Jarrett Barnhill, MD, DFAPA, FAACAP

Psychoses are brain disorders associated with significant impairments in perception, attention, memory, social–emotional processing, thought processes, social communication and a group of executive functions that underlie "reality testing." Psychoses lie on a continuum that ranges from clearly defined physiological abnormalities (delirium, post-ictal states, traumatic brain injury etc.) to those associated with severe trauma and psychosocial stressors (PTSD, brief reactive psychosis). The level of functional impairment varies based on severity, duration of psychotic experiences, comprehensive systemic treatments, and psychosocial factors. Some disorders, like delirium and untreated schizophrenia, can contribute to a shortened life span as well as persistent deficits in cognitive, social, and occupational functioning.

Psychotic experiences without obvious psychopathology occur in nearly 4%[1] of healthy children and adults. For other at-risk individuals, psychotic experiences become a risk factor for other nonpsychotic mental disorders. Psychotic experiences take on a different meaning for individuals affected by severe trauma or co-occurring psychiatric disorders such as mood and anxiety disorders. For example, the expression of psychotic experiences in major depressive disorder can include recurring auditory hallucinations and delusions of worthlessness. In this context, psychotic experiences may result in a more severe disorder (Depressive psychosis) that will require modifications in treatment.

Psychotic experiences have a different meaning for adolescents or young adults who are genetically at high-risk for schizophrenia. Recent studies suggest that these individuals are at increased risk for brief or attenuated psychotic experiences. The stakes are even higher for those at-risk young adults who display not only psychotic experiences but who are also struggling with increasing social isolation, academic decline, and disorganized thoughts. Around 40%[2] of those with psychotic experiences will progress to Schizophrenia Spectrum Disorders (SSDs). The rest may develop a variety of personality, internalizing disorders and chronic functional impairments.

In this section, we define risk level in terms of polygenic risk scores (multiple genes with small effect size) combined with other genetic changes (copy number variants) discussed in the vignette of a young woman with Velo-Cardio-Facial Syndrome (VCFS). But even in the contexts of behavioral phenotypes like VCFS, gene-effects do not occur in isolation. All too often, multiple premorbid insults (trauma, TBI) combine with multiple gene-environmental interactions to produce severe mental illness. The presence of ID and ASD contribute to risk scores.

Schizophrenia Spectrum Disorders

The prevalence of Schizophrenia Spectrum Disorders (SSD) in people with IDD is unknown. Some years ago, the idea was proposed that negative symptoms and cognitive changes represented the core features of SSD as a neurodevelopmental psychotic disorder. Positive symptoms reflected a different neurophysiology and gene expression. The positive symptoms represented trans-diagnostic features that co-occurred in other major psychiatric disorders. SSDs are a complex subset of the psychotic disorders. Current DSM-5[3] and DM-ID-2[4] diagnostic criteria require the presence of positive symptoms (hallucinations, delusions, thought and behavioral disorganization, catatonia) and negative symptoms. Nevertheless, there is a wide range of variability in gene-expression underlying SSDs (genotype to phenotype uncertainties). For example, genomic scans reveal the presence of genes that influence the development of SSD, ASD, ID, epilepsy, ADHD, and specific learning disabilities. Those abnormalities that influence early brain organization (early brain structures, synaptic stability, and integrated networks of neurotransmitter activity) are likely to present among the spectrum of neurodevelopmental disorders. The risk for primary psychiatric disorders may include similar genes, but in general at-risk genes modulate their expression. As a rule, the insults that occur later during gestation impact later developing skills. These modulations seem active in a different set of neurodevelopmental disorders, and yet even these aberrations

[1] Moreno-Küstner B, Martín C, Pastor L. Prevalence of psychotic disorders and its association with methodological issues. A systematic review and meta-analyses. PLoS One. 2018;13(4):e0195687.

[2] Renard, SB, Rafaele JC, Huntjens, Lysaker, PH, et al. Unique and overlapping symptoms in schizophrenia spectrum and dissociative disorders in relation to models of psychopathology: A systematic review. *Schizophr Bull.* 2017; 43(1): 108–121.

[3] American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders (5th ed.).* Washington, DC: American Psychiatric Association, 2013.

[4] Fletcher RJ, Barnhill J, Cooper S-A (Eds). *Diagnostic Manual-Intellectual Disability 2: A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability.* Kingston, NY: NADD Press; 2017.

do not determine outcome. In short, genetic risk factors resemble setting events or risk factors that are subject to modifications by life experiences. This leaves room for both positive (resilience) and negative (trauma, TBI) life influences.

Unfortunately, many clinicians overlook the role of ID and ASD in altering predisposition, nature of precipitating factors, clinical presentation, symptomatic course, and treatment response of psychotic experiences. Fortunately, most individuals with SSD and IDD respond to common treatment options. *But what about those who do not?* This challenges us to explore the "uncertainties" of our knowledge base. For example, why do only 40% of very high-risk individuals go on to develop a full-blown SSD? Likewise, why do we find nearly 50% discordance rates among high-risk monozygotic twins?

Dividing psychotic disorders and SSDs into primary and secondary subtypes can be helpful. The primary disorders represent the major psychiatric disorders in the DSM-5[3] and DM-ID-2[4]. The secondary disorders represent phenocopies associated with the presence of acute or chronic medical/neurological disorders, and those associated with genetic, metabolic, neurodegenerative, traumatic brain injury, or substance use disorders. This dichotomy demonstrates that there are many pathways to psychotic disorders or SSDs. For example, SSDs may have a different developmental trajectory (mosaic rather than linear progression) that moves from premorbid, prodromal, attenuated psychotic experiences, and full-syndrome schizophrenia. The developmental trajectory for secondary disorders may follow the course of a metabolic disorder or an improved level of seizure control. Primary and secondary disorders share in their vulnerability to gene-environmental interactions and systemic response to multiple psychosocial and ecological forces. They also represent final common pathways that suddenly grow more complicated when we add IDD/ASD to the mix.

Table 1. Spectrum of Psychotic Disorders

Core Features of Psychosis	**Schizophrenia Spectrum Disorders**	**Psychosis Due to Other Medical Disorders**	**Borderline-Mild IDD**	**Severe-profound IDD**
Hallucinations	Core psychotic symptoms	Core psychotic symptoms	Core psychotic features	Core features present
Delusions	Cognitive impairments	Visual and tactile hallucinations noted	SSD recognizable, Complexity of delusions modified by cognitive limitations and life experiences	Cognitive impairments may overshadow verbal expression of delusional states
Disorganized thinking or speaking	Negative symptoms	Brain disorders and prefrontal lesions associated with content specific delusions	High Polygenic Risk Score may link risk for ID and Schizophrenia	Limitations in language, but behavioral reactions, level of fear and avoidance may be clues
Abnormal motor behaviors- catatonia	Specifiers and Differential diagnosis	Dementias- e.g. Lewy Body- visual hallucinations, Later onset in Alzheimer's disease	Confusion with EPS secondary to overuse and antipsychotic Rx for no psychotic disorders	Difficult to recognize, rule out APD side effects.
Differential diagnosis- R/O medical neurological disorders, delirium	Duration of psychotic features	Neurodegenerative disorders- psychosis may precede or occur during the trajectory	Milder forms of some neurodegenerative disorders may present with psychotic symptoms	R/O medical, neurological and metabolic disorders before finalizing psychotic dx. Prudent label as Psychotic Disorders due to Other Medical Conditions
Age of onset- relationship to autoimmune, inflammatory disorders	Functional impairment	Delirium- "acute brain failure"	Age of recognition may be delayed Relationship to trauma	Age of recognition rather than onset, timeline relationship to major life events and traumatic experiences
Pattern of onset- related to etiology, judgment call when medical and/or neurological disorders are present	early onset is related to worse prognosis	Onset linked to medical condition	Overshadowed by comorbid behavioral disturbances. For SSD, insidious onset with early negative symptoms may delay recognition based on positive symptoms	Positive symptoms related to medical/neurological disorders may overshadow negative symptoms

Case Vignette

Part 1: 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 working diagnosis by her local psychiatrist was treatment-resistant Psychosis Due to Other Medical Condition. She also had a poorly controlled mixed seizure disorder that required multiple anticonvulsants. There is 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 a 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 is 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. At this point, there is documentation of failed trials of olanzapine, quetiapine, lucosamide and multiple mood stabilizers. Extensive interviews with family, group home staff, vocational staff and reviews of past psychological, medical and neurological history suggest "visual hallucinations in early childhood" that waxed and waned over time. Her "psychotic symptoms" markedly intensified during her early twenties.

Part 2: Current treatments

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 a low serum calcium and mild blood abnormalities, low Vitamin 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 deletion 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 a late-onset schizophrenia-like syndrome. This behavioral phenotype has generated a lot of excitement as a rare CNV that, although it makes up only a small part of the pool of schizophrenia CNV and single nucleotide polymorphisms, nearly 30% of individuals with VCFS develop SSD. There are genes involved that affect early brain development and regulation of neurotransmitter, 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) and a range of psychosocial factors.

An Overview of Treatment Options

Treatment relies upon assessment, differential diagnosis and a careful review of all treatment options. The selection of modified Cognitive Behavioral Therapies (CBT) depends on four factors:

1. The individual's position in the developmental trajectory of emerging psychosis
2. The severity of psychotic symptoms (including comorbidities)
3. The individual's place in the treatment cycle (goal attainment)
4. The reasonableness of individual preferences, availability of good therapists, and time availability

These factors suggest that modifications to CBT are helpful during premorbid, and prodromal (attenuated psychosis) periods and during maintenance treatment and medication reduction or elimination protocols. In addition to CBTs, family involvement in treatment for younger patients, social supports, community services, and employment opportunities are part of the process.

Pharmacotherapies are important but adjunctive to treatment. Since introduced in the 1950's, antipsychotic drugs (APDs) have greatly improved SSD treatment options. There were many advances in APD technology based on a broader understanding of the 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.

- The recovery rates are better for acute, first episode schizophrenia if the duration until treatment (DUP) is short, positive symptoms are present, and a rapid response to antipsychotic treatments occurs (improvement by six weeks).
- This calculus changes when the onset is insidious, there is a long DUP of psychotic symptoms before beginning adequate treatment, compliance issues, significant EPS without improvement, negative symptoms dominate, and there are comorbid psychiatric, personality and substance use disorders.
- The definition of treatment resistance is two or three treatment failures. Some treatment failures are due to poor medication adherenace generated by weight gain, Type 2 Diabetes, and cardiovascular side effects.
- In addition to inconsistent follow-through with medications, 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.
- The use of appropriate doses of long-acting injectable APDs can reduce concerns related to missed pills.
- Diet and exercise education and programs, access to enjoyable wellness activities, primary care and occasionally metformin can be very helpful in reducing health care risks associated with APD treatment.
- We are under-utilizing Clozapine but still need to remain vigilant to ongoing research findings about cardiovascular toxicity (myopathy), weight gain, GI complaints, hematological/stem cell suppression, and adverse effects on some forms of epilepsy.
- All APDs are best initiated at low doses. Go slow, and keep in mind drug-drug interactions during its use. Maintain a keen eye on drug-drug interactions (managing polypharmacy), and the disruptive effects of EPS on measures of treatment response.
- Application of nonpharmaceutical supports, variants of CBT, and well-structured but flexible dose reduction schedules are helpful. The decisions about which drugs to begin with, determining reductions in small decrements, close follow-up, and enhanced recognition of the difference between clinical relapse and extinction spurts need to be made carefully and not in isolation. Clinicians should expect variants of tardive dyskinesia and "withdrawal symptoms" and not panic with "knee jerk" re-instatement of antipsychotics.
- Lastly, there are alternatives to polypharmacy that underscore the weakness in the dopamine hypothesis. Positive and negative symptoms, as well as cognitive symptoms may involve different neuronal networks and nodal-point neuropharmacologies. For example, treatment failure with dopamine/5-HTa antagonists force us to consider other factors. Recent treatment ideas involve networks associated with GABA, glycine, glutamine, nicotinic receptors, numerous peptide and hormonal neuromodulators, probiotics/omega-3 fatty acids, NAC and other novel interventions, focus on cognitive enhancement and transcranial magnetic stimulation.

Conclusions

The development of treatments for SSD/psychoses in people with IDD is still a work in progress. This section 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.

McGrath et. al.[5] described the spectrum of "psychotic experiences" in terms of severity factors- mood-congruent hallucnations and delusions in psychotic depressive disorder. These observations segue into the use of APDs to alleviate the "psychotic experiences" in patients who failed to respond to antidepressant regimens. ECT and other biological therapies may be more effective for psychotic mood disorders than negative symptoms in chronic SSD. These observations may also point us towards other trans-diagnostic treatment approaches for psychotic symptoms in ASD, anxiety disorders and PTSD.

Given all of the information currently available, it may be the case that clinicians need to rethink psychotic disorders in individuals with ID and ASD. The conceptual model of "psychotic experiences" is a better fit for many people with ID who present with psychotic experiences but do not meet the criteria for a specific underlying psychiatric or neurological disorder. This approach might help us avoid labeling individuals with a psychotic disorder or schizophrenia, while supporting the idea that many of our current APD treatments can reduce psychotic experiences but be less effective in reducing the intense distress and suffering that require major ecological therapies.

References

American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders (5th ed.).* Washington, DC: American Psychiatric Association, 2013.

Barnhill J. Can the DSM-IV-TR be salvaged for individuals with severe intellectual disability? *Ment Health Aspects Dev Disabil.* 2003; 6(3):85-98.

Barnhill J. Integrated psychopharmacological management. In Rubin IL, Merrick J, Greydanus DE, Patel DR. *Health Care for People with Intellectual and Developmental Disabilities Across the Lifespan*. Dordrecht NY: Springer; 2016.

Buckley PF and Messias EL (Eds). Schizophrenia: A aomplex disease necessitating complex care. *Psychiatric Clin N Amer.* 2007; 30(3).

Cannon TD, Changhong Ms, Addington J, Bearden CE, et al. An individualized risk calculator for research in prodromal psychiatry. *Am J Psychiatry.* 2016; 173(10):980-988.

Carpenter WT. Early detection of psychosis vulnerability: Progress, opportunity, and caution. *Am J Psychiatry.* 2016; 173(10):949-950.

Cubells JF. 22q11.2 deletion dyndrome: A aaradigmatic copy number variant (CNV) disorder. In Fletcher RJ, Barnhill J, Cooper S-A (Eds). *Diagnostic Manual-Intellectual Disability 2: A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability.* Kingston, NY: NADD Press; 2017:773-730

Fletcher RJ, Barnhill J, Cooper S-A (Eds). *Diagnostic Manual-Intellectual Disability 2: A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability.*, NY: NADD Press; 2017.

Friedlander RI, Klancnik JM. Psychoses. In Rubin IL, Merrick J, Greydanus DE, Patel DR. *Health Care for People with Intellectual and Developmental Disabilities Across the Lifespan*. Dordrecht NY: Springer; 2016:1617-1628.

Fusar-Poli P, McGorry PD, Kane J. Improving outcomes of first-episode psychosis: An overview. *World Psychiatry.* 2017; 16:251-265.

[5] McGrath JJ, Saha S, Al-Harmzawi A, Andrade L, Benjet C, et al. The bidirectional associations between psychotic experiences and DS-IV diagnosis. *Am J Psychiatry.* 2016; 173(10):997-1006.

Goff DC, Falkai P, Fleischehacker W, Giris RR, Kahn RM, Uchida H, Zhao J, Liebereman JA. The long-term effects of antipsychotic medication on clinical course in schizophrenia. *Am J Psychiatry* 2017; 174 (9): 840-849.

Gothelf D. Velo-cardio-facial syndrome. *Child and Adolesc Psychiatric Clinics of North Amer*. 2007; 13:677-94.

Harris JC. Advances in understanding behavioral phenotypes in neurogenetic syndromes. *Amer Medical J Part C Semin Med Genet.* 2010; 154C: 389-99.

Hassiotis A, Fodor-Wynne L, Fleisher MH, Hurley AD. Schizophrenia and other psychotic disorders. In Fletcher RJ, Barnhill J, Cooper S-A (Eds). *Diagnostic Manual-Intellectual Disability 2: A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability.* Kingston, NY: NADD Press; 2017:231-244.

Kelleher A, Cannon M. Putting psychosis in its place. *Am J Psychiatry*. 2016; 173(10):951-952.

Keshavan MS, Kaneko Y. Secondary psychoses: An update. *World Psychiatry.* 2013*;* 12(1):4-15.

Kuniyoshi JS, MsClellan JM. Early onset schizophrenia. In Dulcan M (Ed). *Textbook of Child and Adolescent Psychiatry.* Washington DC: APA Press; 2009:367-379.

Lieberman JA, Small SA, Giris RR. Early detection and preventive interventions in schizophrenia: From fantasy to reality. *Am J Psychiatry.* 2019; 176(10):794-810.

Lowther C, Boot E, Boyd K, Bassett AS. 22Q deletion syndrome. In Watson SL, Griffiths D (EDs) *Demystifying Syndromes 2*. Kingston NY: NADD Press: 2016:159-177.

McGrath JJ, Saha S, Al-Harmzawi A, Andrade L, Benjet C, et al. The bidirectional associations between psychotic experiences and DS-IV diagnosis. *Am J Psychiatry.* 2016; 173(10):997-1006.

Moreno-Küstner B, Martín C, Pastor L. Prevalence of psychotic disorders and its association with methodological issues. A systematic review and meta-analyses. PLoS One. 2018;13(4):e0195687.

O'Dwyer C, McCallion P, Henman M, McCarron M, et al. Prevalence and patterns of antipsychotic use and their associations with mental health and problem behaviors among older adults with intellectual disabilities. *J Appl Research Intellect Disabil.* 2019; DOI: 10.1111/jar.1259.

Renard, SB, Rafaele JC, Huntjens, Lysaker, PH, et al. Unique and Overlapping Symptoms in Schizophrenia Spectrum and Dissociative Disorders in Relation to Models of Psychopathology: A Systematic Review. *Schizophr Bull.* 2017; 43(1): 108–121.

Thom RP, Levi-Carrick NC, Bui M, Sibersweig D. Delirium. *Am J Psychiatry.* 2019; 176(10):785-793.

Yang AC, Tsai J-S. New targets for schizophrenia treatment beyond the dopamine hypothesis. *Int J Molecular Sciences.* 2017; doi:10.3390/ijms18081689.

Prescribing in Mental Health Crises

Jen McLaren, MD and L. Jarrett Barnhill, MD, DFAPA, FAACAP

This section provides an overview of emergency and crisis care for individuals with Intellectual and Developmental Disability (IDD) and Autism Spectrum Disorders (ASD). Acute crises are likely to occur when the intensity of stressors overwhelms the individual's limited social, cognitive, emotional regulation and adaptive skills. For individuals with co-occurring behavioral 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 the adverse events.

What is a Crisis and Who is Vulnerable?

Crises can be singular or recurring events that lead to difficulties for the individual in adapting or resolving the situation, significant changes in emotional states (internalizing), expressed behaviors (externalizing) or relapses in pre-existing mental disorders. Individuals with IDD, ASD and ASD + IDD constitute a heterogeneous population that vary relative to the severity, etio-pathogenesis, genetic/metabolic/medical and behavioral comorbidities, temperamental traits, and patterns of attachment. Events become crises in the context of the transactions among a multitude of ecological and biopsychosocial forces. In vulnerable individuals, crises can trigger the relapse of pre-existing conditions, or the onset of new disorders. Left unresolved, some crises can lead to life-threatening circumstance or worsening in baseline levels from a wide range of physical or mental health conditions.

How and for Whom Do We Evaluate?

It is important first to rapidly triage based on a quick assessment of nature, severity, and ecological context of the presenting symptom. Depending on the severity, medical evaluations help with the triage by ruling out potentially life-threatening illness or injury. The next step is to provide a protective environment to minimize any further physical or emotional trauma as the team provides a more focused assessment, gathers collateral information, completes a more detailed history, and performs medical/mental status examinations. The medical decision-making moves quickly towards rapid treatment at the expense of more detailed behavioral health decision-making.

Where Is the Best Place to Evaluate?

Unfortunately, for many behavioral health crises, there is pressure to jump to a rapid screening and referral to behavioral health specialists. The first step in the triage process is to decide whether to refer the individual to the ED or for community-based assessment. Community providers need to understand the strengths and weaknesses of ED referrals and, when possible, reserve ED consultations for complex, severe crises that require a higher level of care. The nature and structure of most emergency departments (ED) can intensify challenging presentations for individuals with IDD.

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]

This approach is also helpful when combined with the template outlined in the DM-ID-2- addressing predisposing, precipitating factors leading to persistence, and protective/resilience factors.[3]

Any template or timeline strategies remain incomplete without addressing both previous trauma history and the imbalance between protective/resilience and vulnerability factors. In short, the assessment is an ongoing process that may take time and flexibility. Table 1 outlines a useful mnemonic and key methodology in assessing individuals in crisis.

Table 1. Key Components in Assessing Individuals with IDD, ASD or IDD + ASD in Crisis

- Assess for medical/neurologic disorders (use the HEAD TO TOESS acronym as a guide) [1,2,4]
o Headache and other pain (ingrown toenails, calluses)
o Epilepsy
o Aspiration Pneumonia or dysphagia
o Drugs: Assess for adverse medication effects or interactions; ask about complementary and alternative medications; understand recent changes
o Teeth: Examine the individual's teeth for dental pain, infection, abscesses, or impacted teeth
o Ocular and Otolaryngology Issues: Earache, hearing issues, sinusitis, vision problems, and obstructive sleep apnea
o Tummy: GERD, Constipation, Bowel obstruction and volvulus
▪ Osteoporosis and atypical fractures, pressure sores, spasticity
▪ Etiology/cause of IDD: Genetic syndromes can have acute presentations
• Eg. 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 individual 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 (eg. Abdominal imaging for constipation, etc.)

Psychotropic Drugs

The use of psychotropic drugs in crisis stabilization is a balancing act. In some contexts, the individual's expressed emotional state and/or signs of stress requires a thorough assessment, but they cannot tolerate the ED. Unfortunately, an over sedated person can provide limited information but an agitated one may interfere with a comprehensive evaluation. Non-pharmacological strategies (Table 2) can be extremely helpful.

Table 2. Non-Pharmacologic Strategies to Utilize in Emergencies and Crisis

- Attempt to verbally de-escalate the individual
- Find out what thing are comforting, soothing or enjoyable to the individual- consider utilizing positive psychology interventions
- Quiet room, minimize non-essential monitoring equipment, dim fluorescent lighting
- Ensure safety, consult with or have available individuals familiar with the patient's history
- Consistent staff, minimize intrusive or nonessential contacts
- Explain or demonstrate when possible what is about to be done
- Minimize physical restraints or prn injections if possible [5-7]
- See chapter on Sensory Recommendations for Medication Prescribers in this guide for further recommendations.

When Do We Prescribe?

The decision to use psychotropic drugs in crisis intervention is a complex topic that cannot be reviewed in depth here. Many of the basic decision-making steps are outlined in this guide. Each section in this guide provides guidelines for medication selection for psychiatric disorders.

Who Should Get Psychotropic Drugs?

Externalizing behaviors like aggression, self-injury, agitation and loud vocalizations are heterogeneous and arise from many sources. There is no one-size-fits-all for behavioral or pharmacological treatment. 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.

The evidence-based treatments available for irritability provide a problem. Irritability is a transdiagnostic pattern of behavior (occurs 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 behavior, 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 pattern 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 individuals with IDD, ASD and IDD + ASD 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 individual 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 individual is in need of medications 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 individuals with IDD or ASD may have a paradoxical reaction to benzodiazepines and become more agitated instead of more calm/sedated.

While medications may calm the individual, it is important to recognize that they are not diagnostic and the cause for the emergency/crisis should be pursued, fully evaluated, and treated appropriately.

References

1. Sullivan WF, Diepstra H, Heng J, et al. Primary care of adults with intellectual and developmental disabilities: 2018 Canadian consensus guidelines. *Canadian family physician Medecin de famille canadien.* 2018;64(4):254-279.
2. Grier L. Commonly missed diagnoses: Head-to-toe assessment. 2015; Accessed February 2, 2021. https://www.porticonetwork.ca/documents/38160/893368/PC_Commonly+missed+diagnoses.pdf/54669007-88c5-49d3-86a1-981ed6853250
3. Fletcher RJ Barnhill J, Cooper S-A (Eds). *Diagnostic Manual-Intellectual Disability 2: A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability.* Kingston, NY.
4. Lunsky Y PA, Lake J, Lee J. Improving emergency are for adults with developmental disabilities: A toolkit for providers. 2016;. Accessed February 2, 2021. www.hcardd.ca. https://www.porticonetwork.ca/documents/38160/99698/Emergency+Dept+Toolkit+FINAL.pdf.
5. Sullivan WFaJ, D. Rapid tranquilization for adults with crisis behaviors. 2011;. Accessed February 2, 2021. http://ddprimarycare.surreyplace.ca/wp-content/uploads/2018/03/Rapid_Tranquillization-1.pdf
6. Zun LW, M. and Nordstrom, K. . Treatment Goal for Agitation: Sedation or Calming. *Annals of Emergency Medicine.* 2017;70:751-752.
7. Gottlieb M, Long B, Koyfman A. Approach to the Agitated Emergency Department Patient. *The Journal of emergency medicine.* 2018;54(4):447-457.

Acknowledgements

Thank you to all who contributed to the development of *Integrated Mental Health Treatment Guidelines for Prescribers in Intellectual and Developmental Disabilities*, and prescribers who served as volunteer reviewers.

Our primary aim is to provide accessible best practice resources with a focus on integrated health and positive medicine for prescribers of persons with intellectual and developmental disabilities and mental health needs.

The *IDD-MH Prescribing Guidelines* were published by the Center for START Services at the University of New Hampshire Institute on Disability/UCED with funding from the WITH Foundation. For more information about the Center for START Services, visit www.centerforstartservices.org.

Senior Editors
- Joan B. Beasley, PhD, LMHC
- Jarrett Barnhill, MD, DFAPA, FAACAP
- Andrea Caoili, LCSW

Editors
- Melanie Hecker, MPA, Self-Advocate
- Susan Klick, Family Member
- Leslie Rubin, MD
- Laurie Charlot, PhD, LICSW
- Diane Jacobstein, PhD