A Louisiana Guide to Providing Behavioral Health Services for Individuals with an Intellectual or Developmental Disability (I/DD): A Guide for the General Clinician

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Executive Summary

A "well" life is more than a good life. Wellness is a conscious, self-directed, and evolving process of achieving one's full potential. Health is "a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity." (World Health Organization 2022). The breadth of this definition is relevant to everyone and how we think about wellness/health. Considering this full definition, it becomes clear that the absence of problematic issues cannot be sufficient. Health cannot be fully present, nor are "problems" absent if there is no focus on the larger wellness picture for each individual. It is an active process in which each individual becomes 'aware of' and makes 'choices toward' a more successful existence. Recognizing the behavioral health care needs of individuals with intellectual/developmental disabilities (I/DD) is fundamental to the overall "wellness" of these individuals.

The presence of behavioral health conditions for individuals who experience I/DD is now well established, with significant research amassed since the 1960s. While the specific incidence and prevalence statistics will vary from study to study depending upon methods, sample, etc., there is data to support the presence of conditions occurring at a higher frequency than for those individuals who do not experience I/DD. Common co-occurring psychiatric disorders include major depressive disorder, bipolar disorder, anxiety disorders, impulse control disorders, personality disorders, and oppositional defiant disorder. Sadly, the behavioral health needs of people with I/DD often go unrecognized, and these individuals are defined by their behavior. If the behavior is attributed to their disability, the co-occurring behavioral health condition goes undiagnosed. The undiagnosed condition can and will significantly affect their overall "wellness" and greatly reduce their quality of life.

In Louisiana, Individuals who experience I/DD (and their families) must navigate three different systems, at the minimum, if they experience behavioral health needs. The Developmental Disability System, managed by the Office of Citizens with Developmental Disabilities, Medicaid for their everyday health care needs, and the Behavioral Health System, managed by the Office of Behavioral Health for their behavioral health needs. Youth with I/DD (and their families) may also navigate the school system or other child-serving systems. Understanding and navigating these systems often confuses and frustrates individuals and their families. Parents often report feeling overwhelmed trying to find the right supports and services from the right system.

The Louisiana Guide's stance is that behavioral health care services for people with an I/DD must be underpinned by a Civil Rights framework that promotes full inclusion and independence of people with an I/DD. The most fundamental component of meeting one's needs is access to support and services. Any lack of access to supports and services is the foundational barrier to improved outcomes, healthier lives, and overall wellness for individuals who experience an I/DD and co-occurring behavioral health

conditions. According to Substance Abuse and Mental Health Services Administration (SAMSHA), in 2015, over half of the parishes throughout Louisiana did not have a psychologist practicing in that area, and even among the most populous profession in this group, licensed social workers, caseloads would need to be quite large and likely unmanageable to meet the needs in that area. For youth who have a Serious Mental Illness (SMI) that the National Institute of Mental Health defines as "a mental, emotional, and behavioral disorder resulting in serious functional impairment, which interferes with or limits one or more major life activities" (National Institute of Mental Health, 2021) access to intensive residential treatment is also extremely limited when looking at comparable metrics across states. According to a recent study, Louisiana ranks 23rd out of 31 states with licensed Psychiatric Residential Treatment Facilities (PRTFs).

Individuals who experience an I/DD are frequently systematically excluded from accessing non-developmental disability systems and their services when their I/DD is viewed through a traditional lens of "primary" diagnosis and thus belongs to the "primary" system. Unfortunately, most training programs do not include information on understanding the disability experience and assuring access to treatment within that understanding. We must guard against any view or trend toward an approach that is, at best, "separate but equal" systems and, at worst, "separate but unequal." Additionally, the cost of proceeding in this manner is prohibitive.

The vast majority of individuals who experience an I/DD and co-occurring behavioral health conditions benefit from the same treatments as people who do not experience an I/DD. The research overwhelmingly dispels any myths about the lack of efficacy of traditional treatments and supports. There are no grounds for the existing systems not serving this population, at least persons with I/DDs who have mild and moderate challenges, and these individuals make up over 85% of individuals served. Helping individuals who experience I/DD is often framed via the lens of professional competence, meaning that a clinician does not feel competent to provide the service and, therefore, is acting responsibly by not providing it. However, disability should be viewed within an obligation to provide culturally and linguistically competent treatment and support. [NCCC | Distance Learning (georgetown.edu)]

Louisiana has experienced significant shifts in its public health system within the last decade and continues to strive toward a comprehensive continuum of behavioral health services. Individuals who experience an I/DD and co-occurring behavioral health conditions must be considered in this development and implementation. With an already limited network of clinical providers, assuming specially trained clinicians and a separate set of options is not possible or practical. It is also not consistent with supporting individuals who experience an I/DD to live meaningful lives connected to the same community and social systems/networks as individuals who do not experience an I/DD.

We all recognize that locally and nationally, there is much to be done at a policy, resource, and provider level before behavioral health services are fully accessible for

people with an I/DD. However, we know that change begins at the grassroots level and community organizations, faith-based organizations, and educational programs must be critical partners in assuring the ability to meet the needs of all members of our communities regardless of disability status.

The Guide presents a framework for assuring individuals who experience an I/DD and co-occurring behavioral health conditions can access needed services, participate, and achieve the benefits of those supports and services. The Guide is rooted in a human rights perspective. It asserts the rights of individuals who experience an I/DD and co-occurring behavioral health conditions to receive the same benefits and treatments as individuals who do not experience an I/DD.

The human stakes of helping individuals who experience an I/DD and co-occurring behavioral health conditions is the ability to support countless people to live happier and more productive lives. In many cases, access to treatment results in substantial remediation of conditions that hold the person back from living a full life. It is the difference between happiness and a life plagued by distress, misery, or dysfunction. And from a cost standpoint, failure to treat with effective therapies cost the individual and society much more.

How to Use This Guide

This Guide will highlight the adjustments and accommodations a clinician can make to ensure that needed behavioral health services are accessible to individuals with I/DD. The Guide will begin with the most general recommendations for office and clinic practices and preparing for assessment and treatment interactions. This will be followed by available communication adjustments and considerations relevant throughout clinical interactions with the individual and their family. Modifications for assessment practices, including adjusted diagnostic considerations and guidelines, will be provided, followed by modified considerations in treatment and therapy approaches. The appendices of this Guide include clinician tools that aid in implementing the adjustments and accommodations covered in this Guide.

Introduction

What is an Intellectual/Developmental Disability (I/DD)?

An I/DD is a severe, chronic disability of an individual that is attributable to an intellectual or physical impairment or a combination of intellectual and physical impairments. It manifested before the individual reached age 22 and is likely to continue indefinitely. It results in substantial functional limitations in three or more of the following areas of significant life activity:

1. Self-care
2. Receptive and expressive language
3. Learning
4. Mobility
5. Self-direction
6. Capacity for independent living
7. Economic self-sufficiency

The severity of an I/DD can be mild, moderate, severe, or profound. People with an I/DD are a diverse group with highly varied support needs depending on their level of disability. In addition, having an I/DD is associated with a high rate of co-occurring medical and behavioral health conditions. The behavioral health support needs of people with mild I/DD can often be met within mainstream behavioral health services with slight modifications and accommodations. However, people with communication deficits, more severe ID, and comorbid health problems often require a more specialized approach to behavioral health care.

Behavioral Health Needs in People with an I/DD

It is important to know that the presence of mental health conditions for I/DD is now well established with significant research amassed since the 1960s. In reality, persons with an I/DD are at increased risk of developing behavioral health disorders due to a complex interaction of multiple factors:

- Biological
- Psychological
- Social
- Developmental

A recent CDC study found that adults with an I/DD report experiencing more behavioral distress than those without disabilities. In 2018, an estimated 17.4 million (32.9%) adults with I/DD experienced frequent Behavioral distress, defined as 14 or more reported behaviorally unhealthy days in the past 30 days. Frequent Behavioral distress is associated with poor health behaviors, increased use of health services, chronic disease, and limitations in daily life.

According to data collected by The National Core Indicators in Louisiana in 2018-19:

- **Adult survey**: 25% reported psychiatric disorder; 50% reported supports for self-injurious, disruptive, or destructive behavior
- **Adult family/guardian survey**: 35% reported psychiatric disorder; 68% reported supports for self-injurious, disruptive, or destructive behavior
- **Child family survey**: 11% reported psychiatric disorder; 43% reported supports for self-injurious, disruptive, or destructive behavior

Per references highlighted by the Substance Abuse and Mental Health Services Administration (SAMSHA) and recognized by other national groups, this population represents approximately one-third (32.9%) of adults served in the I/DD system, and children and adolescents in this population represent closer to 50% of the overall served population.

Per references highlighted by the National Association on Dual Diagnosis (NADD) within its Diagnostic Manual – Intellectual Disabilities II (2016), prevalence ranges from 15.7% to 40.9% depending upon the study and classification used and children and young adults with I/DD are four times as likely to present with a co-occurring behavioral health condition.

While the specific incidence and prevalence statistics will vary from study to study depending upon methods, sample, etc., there is clear data to support that these conditions occur and, in some cases, more frequently than for those without I/DD. Some clear trends to think about include the following:

1. Individuals who reside or spend time in institutional settings are more likely to have a co-occurring mental health need. When individuals leave institutional settings after either a short- or long-term stay, the importance of identifying and planning for addressing these co-occurring mental health needs increases.
2. While diagnosing a co-occurring condition may become more complex as an individual's I/DD symptoms become more severe, the likelihood of a co-occurring mental health need increases.
3. When assessment and treatment methods or techniques, including diagnostic criteria considerations, are adjusted, co-occurring conditions are more likely to be identified.
4. Some individuals with I/DD will have emotional or behavioral problems or significant trauma impacts even when a formal co-occurring diagnosis is not given. It is important to remember that these individuals may still need professional assessment and treatment to address these symptoms. The earlier this occurs, the better the outcome.

Barriers to Access

Despite clear evidence that individuals who experience I/DD also experience behavioral health conditions, people with an I/DD experience significant barriers accessing community and residential-based behavioral health services. Some of those barriers are:

1. Inadequate training and awareness among behavioral health professionals
2. Diagnostic overshadowing
3. Lack of coordination between agencies
4. Inaccessibility of existing behavioral health services
5. Other social determinants of health

Inadequate Training and Awareness of behavioral health professionals
Most professional training programs do not include education, training, or experience geared toward providing services and treatment to individuals with I/DD who also have co-occurring behavioral health needs (Schwartz et al., 2005; US Department of Health and Human Services, 2005; US Public Health Services, 2002; Viecili et al., 2010).

Providing treatment and services to individuals with I/DD who also have co-occurring behavioral health needs should be seen as a core competency rather than viewing these individuals as a specialty population (NADD, 2013; NCCC | Distance Learning georgetown.edu.) However, surveys of professionals reveal that most believe that individuals with I/DD are a specialty population requiring specialized support (Jacobstein et al., 2007; Smith, 2014; Viecili et al. 2010). Conversely, research suggests that by providing education, training, and experience, professionals become more open to serving individuals with I/DD and co-occurring behavioral health needs. For example, Viecili and colleagues found the following:
- Professionals with experience during graduate training are almost three times as likely to indicate intent to work with individuals with I/DD.
- Professionals who took a course in I/DD were six times more likely to indicate intent to provide services to individuals with I/DD.

Lack of access to training during professional graduate education significantly impacts later access to services. While some persons require specialized services, the vast majority with a co-occurring behavioral health condition(s) and an I/DD **DO** benefit from the same behavioral health treatments as persons without an I/DD. A wellness approach embedded in behavioral health services, which focuses on crafting healthy lives, relationships, and experiences, is equally valid. Pharmacological interventions for mood disorders, anxiety disorders, thought disorders, etc., have comparable benefits. While there may need to be slight modifications in evidence-based therapies (simplifying language, slowing the pace of therapy, etc.), psychotherapeutic and behavioral approaches, cognitive-behavior therapy, teaching coping skills, trauma-based therapies, anger management, all have been evaluated in persons with an I/DD, and were found to be effective.

Diagnostic Overshadowing

Diagnostic Overshadowing occurs when there is an assumption that any emotional or behavioral presentations are due to the person's I/DD. It is important to know that aside from some genetic conditions with documented behavioral phenotypes that will be reviewed later, neither behavioral challenges nor mental health symptoms can be linked explicitly to I/DD. There can at times be an impact on presentation when the individual has some communication and cognitive challenges. Additionally, individuals with IDD may experience a poor match between supports provided and desired life outcomes or an absence of wellness related supports. When this mismatch occurs, the person may experience significant emotional/behavioral distress. However, there must be thorough assessment of these issues prior to any assumed connection.

Because of the diagnostic overshadowing that often occurs, any behavioral/emotional presentation is often labeled a "problem/challenging" behavior, and the person needs some behavior plan/program without considering possible co-occurring behavioral health conditions that may be present. This approach is often driven by what others identify as a problem that needs "fixing."

Several challenges have occurred with this approach:
- An over-focus on consequences/punishment approaches until the advent of the "positive behavior supports" movement.
- Misuse of reinforcement strategies, including the idea that an individual with I/DD has to "earn" all good or positive things in their life.
- A mismatch between actual assessed needs and treatment since every mental health need is not treated using the same approach.
- A loss of choice and control in their lives and daily power struggles that get set up with those present to support the individual.

Because of many of the biases and assumptions about the underlying causes of behavioral/emotional symptoms and the ability of individuals with I/DD to participate in and benefit from traditional mental health treatment, many individuals have experienced an overuse of psychotropic agents and their associated side effects.

Lack of Coordination between agencies

Individuals with I/DD (and their families) often have to access services across multiple systems in Louisiana. Individuals with I/DD, the recipient (family) must access services across at least the following methods:
- Education: for both head start school/academic needs and accommodations
- Louisiana Rehabilitation Services: for vocational supports
- OCDD: for Early Steps, in home, community and vocational supports via waiver options and access to residential supports within Intermediate Care Facilities for individuals with Intellectual disability (ICF/IID) programs
- Medicaid: for both health and behavioral health services

Other systems may also be relevant for some individuals depending upon the individual and family's needs. Each system has options for support in coordinating

needs/services; however, there is not always a clear linkage between systems for coordinating and this often falls to the individual or family.

Inaccessibility of Existing Behavioral Health Services
Workforce capacity within the behavioral health sector is a huge barrier to access. Individuals, their families, and advocates state that clinicians providing behavioral health services do not have the knowledge, expertise, or willingness to truly meet the needs of individuals with an I/DD. In addition, they note a large gap between the need for treatment, the active provisions for treatment, and the poor quality of care for those who receive treatment. These factors should encourage the state to develop an adequate continuum of behavioral health services, including residential services, when needed.

Social Determinants of Health
Some of the most significant barriers to accessing behavioral health treatment have to do with what is termed Social Determinants of Health (SDOH). Social, environmental, and lifestyle choices make up approximately 60% of the determinants of health, while genetics and health access account for 40% (Social Determinants of Health – Aligning for Health).
A breakdown of social determinants of health is noted below:

Economic Stability & Food	Neighborhood & Physical Environment	Education	Community & Social Context
Employment Income Expenses Debt Medical bills Hunger & Access to healthy food options	Housing Transportation Safety Parks Playgrounds Walkability Interests & Access	Literacy Language Early childhood Education vocational Training Higher education	Social integration Support systems Community engagement Discrimination Relationships

A quick review of the information in the table reveals that many of these determinants are areas with which individuals who experience I/DD routinely struggle.

Many individuals with co-occurring I/DD and behavioral health conditions live in poverty. This population may also live far from their most needed resources, making affording transportation, or getting to appointments difficult. Mental health services are often costly, especially if you fall outside poverty levels and have insurance deductibles. Medications often have a copay, which can be a barrier to those living paycheck to paycheck and are outside the federal income limits to make them eligible for Medicaid. The conventional practice of most mental health agencies also contributes to disparities in access to mental health care. Clinic hours, which are more often during the day, do not accommodate people working in low-wage shift positions, who may not have the flexibility to consistently attend weekly mental health appointments held during business

hours. Clinics often have long wait times for appointments and require multiple intake visits before treatment is rendered. The effects of these barriers are exacerbated by the daily stressors and demands of living in poverty that can keep families from prioritizing mental health needs." - [Improving Mental Health Access for Low-Income Children and Families in the Primary Care Setting (nih.gov)](#)

Family Experience and Impacts

The experience of individuals, their families, and advocates are that mainstream behavioral health providers do not have the knowledge, expertise, or willingness to truly meet the needs of people with an I/DD. This lack of access, and with the closing of the only two inpatient treatment centers dedicated to the treatment of people with an I/DD and co-occurring behavioral health conditions in Louisiana, and having no crisis therapeutic services has led families to rely on Emergency Departments (ED), or even Intermediate Care Facilities (ICF) for help when it becomes too difficult at home. Families report that the while Louisiana offers other community-based behavioral health, most families are unaware of the services available. They also report that when access is attempted, clinicians are often not comfortable serving people with an I/DD and co-occurring behavioral health. Finding Medicaid providers who serve those with I/DD and co-occurring behavioral health needs is also very difficult.

The literature indicates that caregivers of a loved one with an I/DD often experience impaired mental health, including anxiety and depression. They also report a poorer quality of life and well-being and higher stress levels than caregivers of a loved one without an I/DD. Previous studies revealed that mothers of children with an I/DD reported elevated psychological distress and caregiving burden, health-related problems, lower levels of resilience, and problems in various areas of family life, including marital and sibling relationships and family socialization. A study published in the Journal of Child and Family Studies (Mazur, 2017) highlights common frustrations expressed by mothers and fathers parenting a child with mental illness. "Helplessness, needing [parenting support groups](#) and advice about coping with their child's behaviors and emotions, struggling to deal with unwanted input from strangers, and the safety and effectiveness of medication plus getting their child to take it".

Families are also burdened with navigating multiple systems from which their child/young adult receives services. For example, Medicaid, Early Steps, the school system, the Office of Behavioral Health, and the Office for Citizens with Developmental Disabilities. Often, these systems do not talk to one another, making things more difficult for the individuals and families trying to navigate their services.

> "I have spent years researching and searching for professionals who could help my son with his mental health issues. He has Down syndrome, but his issues are more related to his mental health. Over the years, we worked with psychiatrists and psychologists, as well as board certified behavioral analysts, to find what would work with my son. He was in his early teenage years when it became necessary to have ABA

therapy daily. His behaviors had gotten so challenging that this was the only way to keep him from going into an inpatient facility in another state. We were able to get the school to also provide him with some ABA support in the classrooms from home, and everyone would communicate, but the services did not necessarily look the same. It was very frustrating and took a lot longer for ABA to work. After approximately three years, he was finally found in the rearview mirror and put on the everyday ABA therapy behind him. But his mental health treatment was not over. The ABA helped to teach him how to verbalize his needs and how to handle his anger and aggression when he went into his fight or flight mode. However, his anxiety and OCD were still present. So, the new task was to find a therapist or counselor to help him. That was a daunting task. But, because we had the Resource Center involved, his psychologist could help us find a Medicaid provider and a therapist that his psychologist could work alongside to help her understand what he needed to succeed. It has been over 13 years since we first saw issues with his mental health. We finally see the benefits of the weekly therapy session for our son. He and his therapist have connected, and she can help him through times that can be anxiety provoking for him. She knew nothing about working with people with an I/DD and co-occurring behavioral health when she started working with him almost four years ago. But she was willing to learn, and for that, we are grateful." – Liz Gary.

Louisiana System Resources Advancements and Changes that May Positively Impact Access

In recent years, Louisiana has undertaken some efforts toward improving services for individuals with behavioral health needs, including service options that individuals with I/DD can and should access when needed. These include:
1. The Coordinated System of Care (CSoC) is now available for individuals with I/DD and behavioral health needs even when an Office for Citizens with Developmental Disabilities (OCDD) waiver option is being accessed
2. The crisis system currently being implemented statewide, including the new 988 crisis line and access to a broader spectrum of crisis services
3. Expansion of evidenced-based practices for behavioral health treatment

Louisiana's OCDD continues to operate a Resource Center to offer expertise in supporting individuals with complex needs. Within the Resource Center, clinicians from across a spectrum of disciplines, including behavioral health, provide education/training and consultation to expand the capacity of community providers and clinicians to provide treatment and services to individuals with I/DD and complex needs. The Resource Center clinicians are available to community behavioral health clinicians and providers for the following:
- Education and training, including sharing resources and tools
- Clinical consultation to adapt assessment and treatment practices

The OCDD Resource Center is available for clinical consultation to any clinician or behavioral health care provider to support their ability to engage effectively with an individual with co-occurring needs through any assessment or treatment activities. Anyone can initiate a Resource Center referral. If a clinician or behavioral health provider is initiating the referral for clinical consultation, it is important to note that a clinician/provider is engaged and is requesting collegial consultation. The Referral form can be found at [OCDD Resource Center | La Dept. of Health](). The form should be sent to [Resource.Center@la.gov]() .

This Guide is designed to support access to services within the existing systems and to provide tools/aids for needed communication across services/programs when clinical treatment is engaged. The Guide is intended to be an additional component available within Louisiana to support continued improvement in service access for individuals with IDD and co-occurring behavioral health needs.

Guidelines for Accessible Behavioral Health Services

General Guidelines and Considerations

Assuring that behavioral health services are accessible for individuals who experience an I/DD starts with evaluating and adjusting general clinical and office processes. Understanding available services, getting an appointment, and feeling comfortable in the clinic area are essential to consider. The Americans with Disabilities Act (ADA) (www.ada.gov) prohibits discrimination based on disability. To meet the ADA requirements, the provider/clinician must assure full and equal access for people with disabilities, including individuals with I/DD. Per the ADA, healthcare entities must assure a) reasonable modifications of policies, practices, and procedures, b) effective communication, and c) accessible facilities (including websites/online access). The guidelines offered here will assist providers/clinicians in meeting these requirements.

Clinic/Office Correspondence

1. Assure all correspondence and instructions use easy-to-understand language
2. Where possible, use versions that also include visual cues/pictures

Scheduling and Waiting for Appointments

1. Simplify the process of making an appointment
   a. Consider how to accomplish this when someone other than the individual needs to do this or be a significant support
   b. Make sure there is not a need for frequently leaving a message or having to wait to hear back from someone
   c. Assure staff with whom person/caregiver must interact are prepared to communicate with individuals who may have differences in understanding, communication, and interaction styles

2. Book longer appointments to allow for more time with the person to accommodate any communication differences, the need for more observations during the session, the inclusion of the person and others in the session, and any physical issues that may result in slower movement through the session activities.
    a. Ask about needed accommodations and considerations.
    b. When a more extended time block cannot occur, more appointments/more frequent appointments may be needed.
    c. Consider the best times to book appointments so that a long wait is unnecessary.
    d. Consider adding earlier or later appointment times for individuals needing a less crowded and less stimulating waiting and clinic experience. While Iit is important that there is not a presumption that all individuals with I/DD need to be seen at times outside of other typical office hours, for some individuals this option should be considered.
3. Consider the arrangement of the waiting area.
    a. Be sure that the waiting area allows for some seating away from others or in a manner to assure all seating is not in potentially crowded areas.
    b. Have access onsite to sensory items.
    c. Consider having an area/room where individuals who may need more space for decreased interaction/stimulation can wait.

Preparing for an Appointment
1. Make sure you know the person's communication style/approach/needs and be prepared to accommodate.
    a. Arrange an interpreter if needed.
    b. Assure that needed cues/equipment will be present with the person.
2. Ask about and provide accommodations for any sensory or physical need.
3. Ask questions about and be prepared for who will be with the person at the appointment.

Communication Strategies

Individuals with I/DD may have differences or challenges in communication compared to their same-age peers. However, everyone communicates in some manner. Therefore, supporting individuals with I/DD may mean adjusting some communication strategies and understanding that each individual may have their own methods and preferences related to communication. These issues and considerations may also frame our understanding of how we may support the individual to learn best and should be considered in any strategies geared at independence or self-initiated activities related to mental health therapies and strategies.

Tips for Communicating/Sharing Information
1. Allow sufficient time for the individual to hear, process, and respond which may mean waiting a minute or two before prompting or speaking again.
2. Consider the use of visual cues or pictures in communication to aid in understanding.
3. Share information in smaller bits; focus on one issue at a time.
4. Use examples from the person's experience.
5. Avoid using abstract concepts until/unless it is determined that the individual understands the terms.
6. Look for individual specific options for keeping info/prompts (journal/notebook, pictures, and other visual cues).
7. Use a balance of open and closed-ended questions.

Tips for Supporting the Individual in Communicating Ideas/Thoughts/Preferences
1. Listen and reflect back to the individual in small bits of information to confirm if your understanding is consistent with their intent.
2. Provide time for the individual to communicate as individual differences in the rate of speech, processing time, and other variables will be present.
3. Do not rush to respond to the person in the manner you think he/she is trying to communicate, and be careful about others doing so (other report has places in assessment and treatment for some people, but this should not overshadow the individual's ability to participate as fully as possible and to express themselves).
4. Remember that some discrepancies in detail may not reflect the total inaccuracy of a particular event or feeling about an event; this may require patience and diligence to parse out, respond to, and assimilate relevance into assessment and therapy.
5. Observe for any inconsistencies in facial expression, body language, and verbal expressions; ask questions to try to clarify and remain curious about what these may mean even when the person may not readily clarify.

Supporting Communication that is not verbal
1. Verbal communication is not the only method that will be effective.
2. Picture cues/books/etc. may already be in use for some individuals and can be quite effective.
3. Technology such as smartphones and tablets now exist with both texting and communication apps available.
4. Ask if the person has any individual-specific communication strategies/signs.
5. During assessment and treatment, learn and document communication unique to the individual to assist them and those they rely on now and in the future for support.

Appendix A provides a communication log that can be helpful if the individual does not already have one.

Consent for Assessment and Treatment

Services that acknowledge the importance of person-centeredness must be concerned with the issue of individual consent. Obtaining consent can become complicated as an individual's ability to make their wishes known and genuinely understand their options become more challenged. Nevertheless, at its most basic element, consent and an organization's/service provider's values and mindful attempts to obtain consent to the fullest degree possible constitutes the chief protection of an individual's rights and personal freedom. It is central to the right to self-determination of individuals with developmental disabilities. This section is intended to offer thoughtful consideration of issues relevant to consent and to offer guidelines that, if followed, take substantial steps toward promoting personal choice and consent to treatment services.

Guidelines for Obtaining Consent of Persons with Developmental Disabilities

Behavioral health treatment is a collaborative partnership between the clinician and the patient. This partnership is guided by a dialogue that ensures all treatment decisions are made with the consent of the patient. All patients are presumed competent unless adjudicated otherwise by a court. If the patient carries a legal status of competent major AND demonstrates the capacity to understand the "purposes, consequences, risks, and benefits of the decision and any available alternatives," the patient can make an unassisted decision. However, a default legal status of a competent major does not relieve the clinician of assessing the capacity to consent at each decision point. In all instances, when it is apparent that significant capacity issues are operative, arrangements for assisted decision-making are made before proceeding. The fullest possible efforts should be made to understand the individual's wishes and obtain consent for services that constitute the treatment plan. This effort begins by assuring the person is present when decisions are being made, and decisions are consistent with age-appropriate standards that would be used for someone without an I/DD. Making "the fullest possible efforts" to understand wishes of the individual also might include, but should not be limited to, the following:
1. Talk to the person rather than to the other people in the room
    a. Greet the person when entering the room and when beginning any discussions, including those focused on consent for any treatment/therapy.
    b. Engage directly with the individual throughout discussions and do not make assumptions about what the person understands.
    c. Find out about the person's communication preferences and adjust accordingly.
    d. Check in with the person throughout the discussion to ensure understanding and address any questions.
2. Use the language commensurate with the individual's preferred language and

level of communication abilities to facilitate understanding to the most significant degree possible.

3. Avoid using terms or medical/professional jargon in any explanation and discussion.
4. Adjust timing and efforts to obtain consent
    a. Make multiple attempts to obtain information from the individual if necessary.
    b. Obtain information under circumstances under which an individual is most likely to be able and willing to provide it.
5. Utilize the assistance of others who know the individual best
    a. Ask about and honor any supported decision-making agreement (see the next section for more information).
    b. Even if there is not a formal supported decision-making agreement, ask about and include those who have typically assisted/supported the person in making decisions.
        i. Louisiana law outlines who may consent to medical decisions (RS 40:1159.4 Louisiana Laws - Louisiana State Legislature. The law allows for family, adult friends, or individuals determined by someone's support team with certain considerations.)
        ii. Choice of the person who is supporting decision-making is a make-or-break decision. Some characteristics facilitate the effectiveness of the supporter(s). The supporter(s) should be someone that the patient agrees to, with ample direct observational contact with the patient, and someone who will be available on an ongoing basis. In addition, the supporter(s) must be consistently present in the lives of the individual.
6. Even in instances where the individual has a legally established decision maker (i.e., interdiction, guardianship, tutorship, custody), the patient should still be involved in the discussion and be given an opportunity to register any questions or concerns to the degree they are able. It is also important to remember that some legally established relationships are limited and do NOT constitute a full removal/revocation of someone's rights to make all of their decisions. It is always important to ask about the legal status in these instances and any limitations/considerations. And, it is recommended to obtain a copy of the document for clarification of expectations and limitations.

In consent discussions, the focus on meeting the need for "voluntariness" extends beyond a simple lack of coercion. Coercion can be subtle. Persons working with individuals with developmental disabilities must take power differentials into account. Substantial efforts should be undertaken to ensure that individuals are aware of their choices and are free to disagree with recommendations without fear of retaliation. These issues should be taken into consideration both in terms of the manner in which information is presented and in terms of selecting the individuals best-suited to convey information.

Understanding Supported Decision-Making

Patients should not have their decision-making abilities reflexively questioned because they have an I/DD. The decision-making abilities of individuals with an I/DD are often too quickly questioned or discounted due to their I/DD. Yet, individuals, regardless of an I/D, may make choices deemed good or bad. Supported Decision Making (SDM) is a recognized legal alternative to continuing tutorship and interdiction through which people with an I/DD use friends, family members, and professionals to help them understand the situations and choices they face so they make their own decisions. In Supported Decision Making, individuals can choose supporters to assist them in different areas of their lives - employment, education, services, finances, health, etc.

1. The Supporters and their duties are listed in an agreement shared with all of the individual's medical and service providers to ensure that the Supporters are included in discussions surrounding important decisions.
2. The Supporter does NOT ever make decisions for the individual or discuss matters without the individual present. Instead, the Supporter helps explain information in an understandable way, guides the individual in weighing the courses of action, and advises the individual on the consequences of the decision.

A person with an I/DD can use the SDM supporter to help make or communicate a decision involving any aspect of health care. For example, the person using the supporter may wish to discuss a particular medication's benefits and side effects before deciding to take the medicine. A person with an I/DD disability may ask the supporter to assist in filling out the required paperwork or to explain medical or health insurance terminology. There are many areas within medical care where a person with I/DD can use SDM. The key is that the person with a disability can determine how to use the supporter. Additional information can be found at the link below:

[Using Supported Decision Making in Health Care: Frequently Asked Questions for Medical Professionals - NDRN](#)

Modifications for Assessment and Diagnosis

In an ideal situation, conducting a comprehensive assessment before beginning any treatment approach would be the goal. However, we recognize that this is not always possible to do immediately and quickly at the onset of clinical interactions due to several issues, including:
- All the information needed is not available
- An initial assessment to justify accessing treatment must occur within a set timeframe due to program requirements or to continue billing for services

- The individual and their family are in crisis and taking action cannot wait for all the needed information gathering and assessment

When there are limitations to the initial assessment, remember that assessment can be a process rather than an endpoint and can continue and be updated and refined as you provide treatment and look at progress. When beginning an assessment interaction with an individual with I/DD, the three most important questions to answer up front are:

1. What is the presenting question to be answered regarding the person? What is the stated "problem"
2. Who is asking the question? Determining who is asking for the referral and stating the referral question is important in framing two issues. First, it may tell the clinician who to speak with/address. For example, if another clinician has asked for a consultative evaluation, interactions may be primarily with the clinician in collegial discussions and suggestions. This would be different than if an individual was presenting themselves for evaluation. This information can also help frame the initial interactions with the individual, because you will be aware of if the individual is seeking help or someone else is, on their behalf.
3. Why is this a question or need?

You may need to interact with the individual and others in the initial appointments to clarify these questions and proceed.

General Assessment Considerations

1. The individual should be at the center of the assessment process even when adjustments need to be made.
   a. Considering the communication strategies already covered and information about how the person communicates, engage with the recipient to gather information
   b. Observations may be needed to assess for and use nonverbal cues in the assessment process.
2. Individuals with I/DD often have family and staff who assist them throughout the day. This support aspect, paired with some possible challenges in self-report alone, will necessitate the inclusion of "other" reports in the assessment process more so than might occur when an individual does not have an I/DD.
   a. If an individual with an I/DD who is an older adolescent or adult that has significant independence and can self-report, then the assumption about any inclusion of "other" report should be consistent with what the clinician would do for an individual without an I/DD.
   b. When "other" reports are included, they must be balanced with any self-report that can be provided, and there should not be a presumption that the "other" information is accurate.
   c. When self-report is very limited, the clinician will need to carefully probe during any "other" report and use some additional observational information they gather before interpreting the "other" report as face valid.

d. The general rule for the clinician is to gather information across a variety of sources and look for convergence and gaps that need exploration. Additionally, understanding the importance of consent in involving others is paramount. The individual with I/DD retains the right not to include others unless this is otherwise modified by legal action.

3. Review of available records is important to understand the person's history and what has worked and not worked in the past to guide the following actions/interventions moving forward.

a. Individuals with I/DD often have a long history of seeing various professionals and may have many diagnoses, so reviewing these to see what has been considered in the past is essential.

b. Work to try to clarify/simplify the diagnostic picture. Be careful not to simply add more diagnostic considerations, but to look at what may need to be ruled-out versus added.

c. When possible, obtaining and reviewing records prior to an initial examination of the person is actually advisable. This approach provides the clinician with information that can guide interviews, observations and further testing and can make even the initial appointment more focused and of greater value in the assessment process.

4. Formal Testing should be determined based on each situation and need as well as consideration of previous testing available and the referral question. It may only be necessary in some instances.

a. There are assessment scales that look at behavioral health symptoms for individuals with I/DD, which are noted in the appendix.

5. Use/consider adjusted diagnostic guidance from either the Diagnostic Manual for Intellectual Disabilities-II (DM-ID II; NADD Press) or Diagnostic Criteria – Learning Disabilities (DC-LD; Royal College of Psychiatrists). The DM-ID II is linked to the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition, Text Revision (DSM-5-TR), and the DC-LD is connected to the ICD-10.

Behavioral Consultation & Assessment Questions and Considerations

The following guidelines should be used in initiating an assessment:

1. Obtain a brief history of presenting challenges, i.e., why the person is there to see you, including duration, frequency, and severity.

2. Ask about the following wellness issues and what supports are in place for these [remember that these can be the cause of or may impact intensity of any presenting emotional or behavioral reactions, and any treatment you may provide for a co-occurring behavioral health need will be more limited in impact if these are not known and supported; the appendices include the OCDD Wellness Guide which HCBS waiver providers may use – you can ask if the person has a Wellness Guide and/or use some of these questions to gather information]:

     a. Important relationships and connections
     b. Meaningful school, work, or day activities and opportunities for creativity and learning
     c. Spiritual activities
     d. Physical wellness, including exercise & diet
     e. How the person communicates feelings/emotions, and what the person does to relax and feel good

3. Ask about the following trauma-related issues and what supports are in place for these [remember that these can be the cause of or may impact the intensity of any presenting emotional or behavioral reactions, and any treatment you may provide for a co-occurring behavioral health need will be more limited in impact if these are not known and supported; the appendices include a Review of Trauma History & Risks tool and a Review of Life Stressors tool to assist in gathering this information]:
     a. Any known trauma history and treatment
     b. Any current concerning issues or challenges
     c. Presence/absence of any recent life changes/stressors. Note these and remember that individuals with I/DD may experience these more frequently, and they may be more impactful.

4. Determine if there is any evidence of medical questions/issues and the need for referral (the review of the Health Indicators tool in the appendices can assist with this piece).

5. Are there any recent medication additions or changes? Remember that individuals with I/DD may take multiple medications and that medication side effects may present as emotional/behavioral/cognitive changes so any medication adjustments need to be considered if recent changes in symptoms/presentation are reported.

6. Explore any history of and recent access to substance use/abuse, include illegal substances.

7. Review the person's mental health diagnoses, treatment history, and any current symptoms.

8. Consider if there are there any signs/symptoms of genetic diagnoses (consider any known "syndromal" issue if present).

9. Explore any changes in or problems with sleep or eating patterns.

10. Explore any recent injuries/incidents that could impact the presentation.

Using Observations as part of Assessment

Because many individuals with I/DD may have atypical communication approaches or some limitations in communication, observations may be a necessary part of the assessment process, and the following guidelines should be considered.

1. Observations in the individual's typical environment may be needed. When this is required, it should occur across settings, including:
   a. Home
   b. School
   c. Work
   d. Community
2. When observations can only occur by the clinician in a clinic setting (due to limits of time/billing/etc.), then the clinician should provide the family and staff with guided questions related to their observations across settings to bring to subsequent visits.
   a. These should be guided by the current assessment information, which would lead to possible questions/gaps.
   b. This process may continue throughout the treatment process as needed.
   c. When improvements occur, the clinician will need to pose questions to confirm intervention approaches and consistency (this is to verify that improvements are due to what is covered in the planned approach or to document needed changes).
   d. When improvements are not noted, the clinician will need to pose questions to look for deviations (this is to avoid assuming intervention failure without testing the assumption if the intervention is being done as planned).
3. When observations can only occur in a residential treatment setting, considerable creativity must be used to assess the generalization of issues/concerns from the natural environment to the treatment setting and back. This may involve the following considerations:
   a. Upon admission to the treatment setting, in-depth interviews with the family/staff should occur to obtain as much information as possible about the presenting problems, including any behavioral presentations. This interview should also include questions about the primary issue(s) that could not be supported in the community; Questions should be asked regarding why this became difficult.
   b. Throughout the individual's stay in the treatment setting, additional interviews/queries of the family/staff may be needed as the treatment team discovers possible treatment impacts and areas of intervention. These interviews/queries would pose new questions to test these hypotheses regarding likely relevance in home/school/work rather than being specific to the treatment setting.
   c. Upon some level of improvement/stabilization, the team should work to plan "passes" at home. Initial passes should involve agency staff to assist/support the family/staff in learning treatment and support approaches as needed and to look at any new observational information that may warrant changing the treatment approach to better fit with the home/school/work environment.

Conducting a Mental (Behavioral) Status Exam for a person with I/DD

The need for a mental/behavioral status examination remains important in assessment for individuals with I/DD. Individuals with I/DD can experience mental status changes indicative of other areas of concern just as individuals without I/DD can. Individuals whose cognitive skills are in the borderline range or may be mildly impaired can typically complete a more traditional mental status examination. For individuals whose cognitive challenges may be more significant and concern exists that problems in the mental status examination are more indicative of the impacts of the I/DD rather than a real change or problem with the individual's typical mental status, modification may be necessary. It is also important to remember that aspects of a traditional mental status examination can still reveal observable behavioral indicators, even for someone unable to communicate clearly or using more traditional methods.

1. Appearance
   a. Inquire about independence in this area
   b. Note any significant self-care issues and inquire about cooperation with any assistance
      i. Refusing or other problems in self-care
      ii. Is more disorganized or confused in areas of independence
      iii. Insists on layering or other bizarre dressing/grooming
   c. Observe for any injuries or marks
   d. Observe for any facial or body appearance issues that may warrant genetic referral
   e. Observe for any problems in the manner the person relates to the examiner
      i. Hostile
      ii. Overly familiar
      iii. Guarded/mistrustful
      iv. Overly compliant

2. Intelligence
   a. Avoid stating without formal testing if at all possible
   b. If an individual has a statement of approval from OCDD, seek this information (any comment here should be reserved if not yet available, or should be about consistency with expectation given noted cognitive challenges)
   c. If an individual does not have a statement of approval and no formal testing is available, the examiner should comment on the impression but report the need for formal testing

3. Psychomotor Behavior
   a. Posture
   b. Gait

      c. Activity level
      d. Presence/absence of involuntary movements

(For any noted atypical movement, the clinician should inquire about the history and any changes before commenting on significance)

4. Speech
      a. Focused on the physical production of speech, not content; for any challenges noted, again, history is important before determining current significance, if any
      b. Note any speech impediments/challenges
      c. Note the style, rate, and intensity of speech

5. Emotional expression
      a. Assess understanding of emotions by testing reaction to/naming of facial expressions
      b. Ask the person to use facial expression pictures to show how they feel" today
      c. Observe for consistency in facial expression/mood-related actions and "expressed" feeling
      d. Observe for changes in mood/facial expression as compared to expectations given activities/topics of conversation/interactions with others

6. Thinking and Perception
      a. Look for evidence of thought form/process but remember that this needs to be evaluated against what is typical for the individual and consistent with their I/DD
            i. Concrete vs. Abstract
            ii. Circumstantial/tangential vs. Related
            iii. Thoughts linked in a logical sequence
            iv. Perseveration
      b. Thought content (may need to adjust for developmental expectations and life experiences)
            i. Delusions
            ii. Ideas of reference
            iii. Obsessions
            iv. Illusions
            v. Hallucinations
      c. Suicidal/Homicidal Ideation (this should not be overlooked or assumed to be meaningless for individuals with I/DD)

7. Sensorium
      a. Alertness (note any possible medication impacts if concerning)
      b. Orientation
            i. Remember that individuals with autism spectrum disorder (ASD) may refer to themselves in 3rd person.

        ii. Orientation to place may be general rather than specific (knows at school, not name)
       iii. Orientation to time may need to be tested (may not know the day of the week/month; may know next holiday, etc.)
- c. Concentration (likely cannot do serial 7s or 3s; consider the following modifications)
        i. Ask to count backward from 20 (examiner may begin at 25, asking the individual to count with them and then to continue)
       ii. Naming months or days of the week in order or backward
      iii. Provide an opportunity for a sustained task and observe the ability to focus and complete)
- d. Memory
        i. Recall (present numbers to repeat forward and backward; adjust numbers provided based on response)
       ii. Recent memory
           1. Test if an individual can repeat three word/location/visual stimuli immediately and adjust down if needed
           2. Ask what the individual ate at the last meal or did before entering the office
           3. Hide an item in the office and ask them to locate it later
      iii. Remote memory (ask about events from 2 or more years ago in a person's life)

8. More Complex Cognitive Skills
- a. Fund of Knowledge (ask basic questions about their medicine, supports, job, community)
- b. Reasoning/Insight/Judgment (ask questions related to everyday issues the person may face)
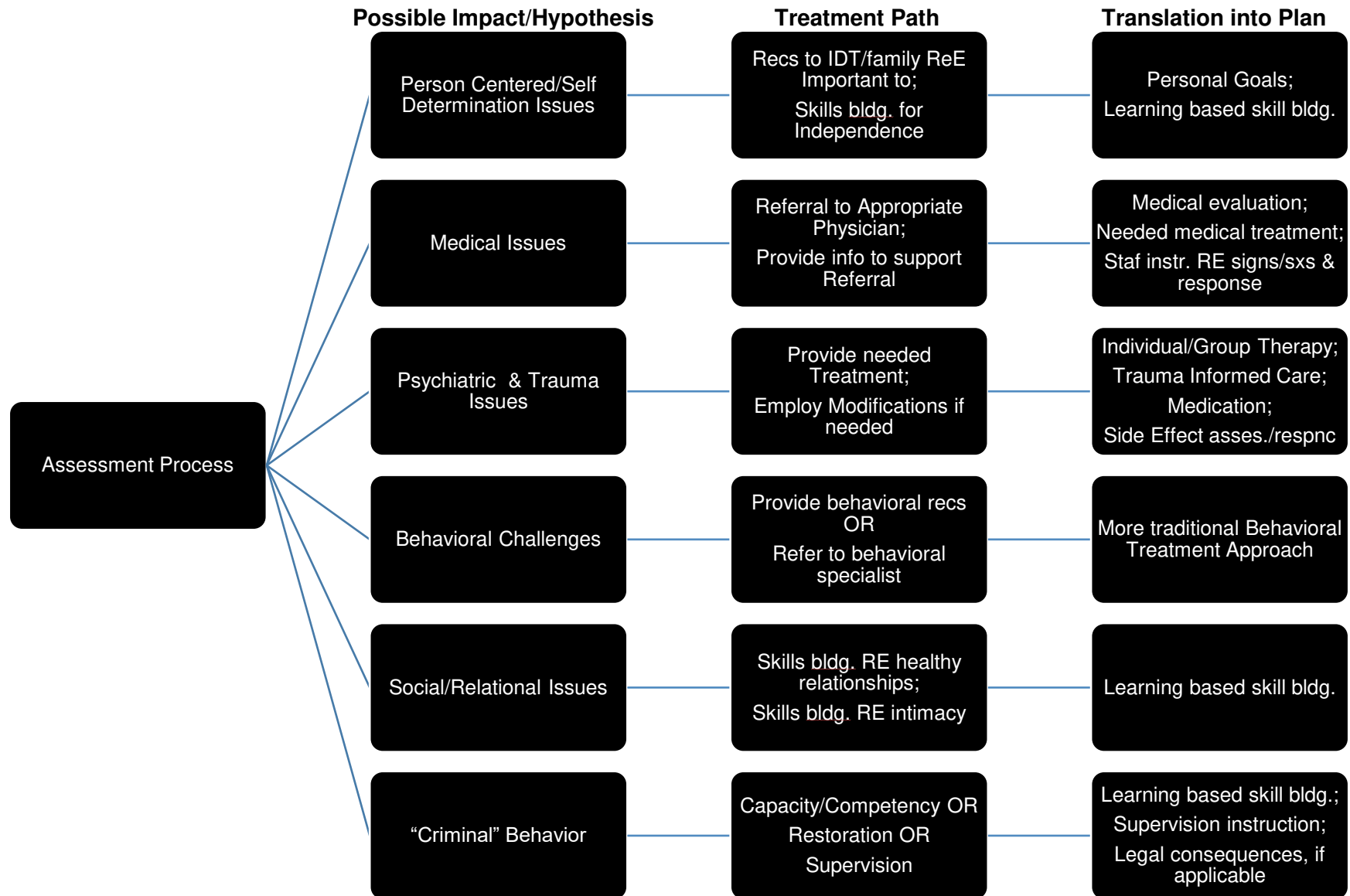
The appendices provide tools to assist the clinician in making many adjustments and gathering information more efficiently for the assessment process.

Behavioral Indicators of Mental Health Needs

Condition/Type of Episode to Consider	Behavioral Indicators to Observe	Other Considerations of Possible Diagnosis	Rule-Out Considerations for Non-Diagnostic Causes
Depression	Crying with no apparent trigger Refusal to get out of bed when previously NOT a problem Refusal to do things the individual once did and enjoyed DECREASE in ADLs from typical	Medical/pain issues ruled out Medication changes/side effects	Recent loss Recent significant life change/transition Chronic medical issue
Mania	Increased activity level (can include increases in existing behavioral challenges) Walking as if "driven" Inability to sit still Sexual acting out (when paired with other symptoms) Sleep will typically be disrupted	Medical/pain/gynecological issues ruled-out Primary sleep disorder ruled out Medication changes/side effects	Siblings/friends achieving milestones – Are these attempts to communicate what they want even if these do not see as possible?
General Anxiety	Avoiding eye contact/looking down when approached Shaking Rubbing/wringing hands Pushing others away Pacing Remaining in the bedroom or area away from others	Medical issues ruled out Medication changes/Side effects	Recent significant life change/transition
OCD	Rituals exist that are typical of OCD presentation: -hand washing -checking behavior -hoarding	Medication changes/Side effects For ASD: Rituals of lining things up, ordering things, etc., may be more characteristic of ASD, AND social features of ASD would be present	Hoarding is not related to the history of things being taken/stolen or "not having enough"
PTSD	Avoiding eye contact/looking away/pushing away specific people OR in the face of specific events/activities Aggression or self-injury in the face of specific events/activities/people Waking up in the middle night crying/screaming (nightmares) Limited response to typical prompts during "behavioral episodes"	Known, suspected, or reported trauma event very recently including: - natural disasters - catastrophic events	Environmental impacts & expectations - What is the "norm" this individual is used to?
Psychosis	Nonsensical comments atypical from a person's norm Picking at skin/clothing Withdrawal atypical from the person's norm Eye and head movements as if hearing something not present	Impact of the suspected delusions/hallucinations: - If symptoms preceded violence of some sort, than consider more likely Seizure or other neurological disorder ruled out Medication changes/Side effects	Sensory impairments Affect typical and no link to violence/behavioral episodes – Is affect more likely developmentally appropriate, if consistent with functional abilities?

Because individuals with I/DD may communicate information and respond to questions differently, observing for potential indicators of diagnostic considerations is essential during the clinical assessment. It is also important to consider medical or medication issues that could present similarly (rule-outs) and life issues that may also need to be checked and addressed. This table is designed to guide the clinician in the assessment process. When any of these behavioral indicators are present there is a clinically significant issue that needs assessment and likely intervention; an appropriate assessment will consider the "pathway" that needs to be taken.

Clinical Pathway Guidance

Possible Impact/Hypothesis	Treatment Path	Translation into Plan
Person Centered/Self Determination Issues	Recs to IDT/family ReE Important to; Skills bldg. for Independence	Personal Goals; Learning based skill bldg.
Medical Issues	Referral to Appropriate Physician; Provide info to support Referral	Medical evaluation; Needed medical treatment; Staf instr. RE signs/sxs & response
Psychiatric & Trauma Issues	Provide needed Treatment; Employ Modifications if needed	Individual/Group Therapy; Trauma Informed Care; Medication; Side Effect asses./respnc
Behavioral Challenges	Provide behavioral recs OR Refer to behavioral specialist	More traditional Behavioral Treatment Approach
Social/Relational Issues	Skills bldg. RE healthy relationships; Skills bldg. RE intimacy	Learning based skill bldg.
"Criminal" Behavior	Capacity/Competency OR Restoration OR Supervision	Learning based skill bldg.; Supervision instruction; Legal consequences, if applicable

Assessment Process

*The overarching goal of any assessment process should be to determine the likely factors impacting the individual's current and historical presentation of any emotional or behavioral symptom. As noted in the graphic above, these possible impacting or causal factors should lead to different approaches to teaching, support, and treatment.

Accessible Therapy & Treatment for Individuals with I/DD

As clinicians, each professional must be aware of the boundaries and limits of their scope of competence. Awareness and consideration of these issues is the ethical and appropriate approach for any clinician to take. However, we must be mindful that any limitations in our own experience, education, and training do not get more broadly interpreted to mean that groups of individuals with needs (for which an individual clinician may be unprepared to respond) do not end up with no access to treatment or worst, deemed as being "unable to benefit." Because many clinicians do not get exposure to the needs of individuals with I/DD and co-occurring mental health (MH) conditions, it is not uncommon for individuals with I/DD who attempt to access treatment to be met with little to no viable options. If each clinician approaches continued education with the acknowledgment and expectation of lifelong learning and growth, then it is less likely that any individual or group of individuals will be approached as simply not needing or not being able to benefit from treatment.

Considerable research does exist supporting the need and efficacy of behavioral health (BH) treatment/therapy for individuals with I/DD. Some modifications to the treatment approach, e.g., length, language/communication, etc., may be needed, but positive outcomes can and do occur. It is also important to remember that there are other individuals and groups for whom cognitive and communication challenges may exist who may also benefit from considering these modifications and developing competence and comfort in making such adjustments.

Factors Impacting Behavioral Health Treatment Needs

Several of the themes reviewed in the assessment and diagnosis section remain important throughout the treatment process. As treatment is developed and implemented with the individual, there will always be a need to ensure an appropriate balance of *important to* and *important for* issues in that individual's life. An imbalance in either direction is never sustainable or productive. Understanding what matters to the person also remains important, as it continually assures motivation to engage in therapeutic activities. And, of course, any needed communication adjustments should be continued throughout the therapeutic interactions.

Trauma and the use of trauma-informed approaches continue to be necessary given the high rate of trauma and the likely impact of "little t" traumas on the lives of the people with I/DD who may present for treatment with you. Therefore, it is particularly important to understand the trauma response and how to best use/pair learning of new coping approaches so that individuals are not being asked to think clearly, learn or practice new skills when anxiety/fear is present to a high degree.

Be aware of the individual's medical issues and status, as well as any known history of impacts of illness, pain, etc., as this can affect symptom presentation over time, even when therapy is engaged and effective. That is, it may look like someone is getting worse when they are simply ill and this has not been accounted for in terms of any information shared or how adjustments in expectations or supports may need to be considered. Remember, the work you do may also aid other professionals and help them to understand better symptoms and treatment approaches that work and others that don't., However, this can only happen if communication about these issues is ongoing.

Finally, remember to always be open to learning — we rarely get it right the first time.

Readiness for Therapy

While there should be a presumption that an individual can participate in and benefit from therapy with appropriate modifications, some effort may need to be devoted to "readiness" for therapy. At the start of therapy, an important consideration will include understanding who made the therapy referral. Often for individuals with I/DD, others are seeking "treatment" for them. While this can often be well intended, it can also feel like others want the individual "fixed" and view the individual as "the problem." Given this context, the therapist may not be viewed positively by the individual, and the individual can be resistant initially. As such, the therapist will need to work with the individual and those who may have sought assistance or supported the individual in doing so to be sure that there is a positive focus on the purpose of therapy and the role of the therapist with each party involved.

The considerations noted below provide some additional areas a therapist may need to consider in looking at the individual's readiness for therapy. Areas of concern do not necessarily translate into any determination that therapy cannot be beneficial but can be used to look at where the therapist may need to begin work with the individual (which could be at much more basic levels of strength spotting and related issues) as well as any modifications that might be needed in emotional language and understanding.

1. Can the individual recognize and identify basic emotions using words/descriptions? Using photos/pictures? In role play?
2. Does the individual have sufficient memory/recall to repeat at least 1 or 2 thoughts/ideas? If not, document limits of recall for use in therapy sessions.
3. Can the individual recognize some link between situations and emotions? NOTE: Present simple scenarios typically tied to specific emotional responses and assess if the person can state or use photos/picture play to show emotional response; Be mindful that history may impact odd responses.
4. Can the individual associate possible thoughts with situation/emotion scenario? NOTE: Using the same scenarios, ask the individual what the person may be "thinking or saying to themselves"; this component will be more relevant in certain types of therapeutic approaches like CBT but may not rule out others such as solution-focused therapy.
5. Can the person reliably communicate for therapeutic conversations using words/descriptions only? Using sign language? Using a combination? Using words with visual cues?
6. Has the individual participated in therapeutic activities before? Is it continuing? Does information suggest adequate participation? What if any barriers were identified? What were the recommendations from a therapist in the last session (if continuing) or at the end of therapy?

As you initiate therapy, several considerations may be somewhat different than how you might approach things with an individual who does not have I/DD.

1. It will be important to consider how the individual's previous experience with professionals may shape their view of you as a therapist. Individuals with I/DD often interface with a large number

of professionals because of not only their disability needs but also the other co-occurring conditions they may experience. Often the experience with professionals will either be a) one in which the professional provides "orders" for certain treatments, and there is little partnership with the individual with I/DD in determining these treatments or b) in a setting where the professionals were among the few individuals who interacted with the individual frequently, and thus they see them as "friends" and have some trouble distinguishing friends from the paid people who help them because they, unfortunately, do not have many people in their life who are not paid for a service. Both can present problems if you, as the therapist, do not take some time in the initial session to set some expectations about your role and the therapeutic relationship you will have with the individual.

2. Because the individual may interact with numerous professionals or others paid for services, you will need to consider who these other people are in the individual's life and with whom it will be necessary to dialogue and coordinate. Lack of discussion and coordination can confuse the individual and their family and can result in less effective treatment outcomes when approaches from different professionals unintentionally conflict.

3. You will likely need to work with the individual to understand that the therapeutic process should be "active" rather than "passive" — you will not be giving "orders" or making the decisions but working with the individual to look for alternative approaches, build skills and address some challenges in the ways that work best for the individual and that can be sustained and used when therapy ends.

As you initiate therapy, it will also be important to build rapport and forge an effective therapeutic alliance — this should be viewed as essential, just as it would for any individual entering therapy. Considering the "goodness of fit" between your approach to therapy and the individual's preferences will be important for the ultimate outcomes to be positive. It is important to remember that the core of therapeutic interactions and the approach you will take remains the same. You are just modifying the approach so that the individual can participate, learn the things they need, and achieve positive therapeutic outcomes. Also, remember that when the individual perceives their relationship with you as the therapist positively, this positively impacts participation and, thus, change in behavior and thoughts/emotions moving forward. As the individual experiences positive changes, this can also boost their sense of self and confidence in their ability to gain independence and feel good about their accomplishments. Recent positive psychology research indicates that the best predictor of improvement in symptoms for people receiving therapy is the belief on the part of the therapist that the person can get better (Tomasulo, 2020)

Individuals with I/DD will often have "others" in their life. These "others" may include family, friends, and support staff. Because the individual may need help at times, it will be important for the therapist to consider how these other individuals will need to be included, communicated with, and consulted throughout the therapeutic process. Part of this begins in the assessment process and some of these tips may remain necessary.

General Therapy Modifications

Some basic modifications apply to most therapeutic programs/approaches. These typically involve:

1. Looking at timing issues that account for how long the person can be in session and how much information can be processed/discussed at any time. It also may mean that therapy will take longer to achieve the same outcome. Often individuals with I/DD, particularly those with specific cognitive and communication challenges, will have more trouble learning and thus will take longer to learn new skills or change ways of responding/behaving.
2. The therapist may need to adjust how much guidance, prompting, questioning, and examples are used in therapy while still assuring that the individual is driving the responses and process.
3. Other modalities, including active role-play, may need to be brought into therapy more often.
4. The use of agendas and modifications to how the agenda is represented in therapy becomes very important.

The appendices provide the clinician tools to assist in implementing key modifications in therapy and treatment. The Table below provides guidelines for modifications depending on specific differences in communication or processing the individual may have.

Adaptations Related to Specific Cognitive Challenges

Cognitive Areas/Domains	Specific Issues/Challenges	Adaptations to Consider
General Cognition	Verbal understanding and reasoning	Adjust language: -simple words -shorter phrases More and more frequent sessions to achieve the same results
	Nonverbal understanding and reasoning	Adjust the use of nonverbal cues/materials: -when challenges exist, rely more on verbal presentation, or assess for and limit use to those clearly understood and used routinely -when a person preferentially uses and understands, incorporate routine use and pairing of nonverbal techniques and materials
Emotional Literacy	Emotional vocabulary	Assess for and only use words/nonverbal the person understands and uses Build in education to expand emotional vocabulary as part of therapy activities
	Understanding the role of thoughts/cognitions	Simplify therapeutic approach: -self-instructional training -solution focused therapy If the challenge is limited to the ability to articulate thoughts clearly -the therapist may provide options/choices
Memory	Assimilation	Repetition (within and between sessions; the assessed need for assistance/support from others) More and more frequent sessions Closer sessions
	Recall	Involve others in portions of sessions

	-of history/past experiences -of homework assignments	Use calendars/picture cues/reminders.
	Prospective Memory	Use of reminders Involve others in portions of sessions
Executive Functioning	Working Memory	Chunking of information: -keep ideas simple and short
	Behavioral Inhibition	Incorporate the following as assessed to be appropriate: -education on self-control techniques -briefer/shorter sessions OR frequent breaks in the session -active sessions (i.e., role play, etc.)
	Initiative	Provision of ideas via guidance/suggestions from the therapist

Common Therapeutic Approaches with demonstrated efficacy with individuals with I/DD

1. Cognitive Behavior Therapy/Trauma-Focused Cognitive Behavior Therapy (CBT)
2. Dialectical Behavior Therapy (DBT)
3. Multi-Systemic Treatment (MST)
4. Assertive Community Treatment (ACT)
5. Eye Movement Desensitization Reprocessing (EMDR)
6. Triple P Parenting
7. Applied Behavioral Analysis (ABA)

Specific Adaptations supported by research are included in Appendix L of this guide for items 1-6. ABA adaptations are not necessary since this therapeutic approach is often implemented for individuals with IDD/ASD.

Prescribing Practices and Considerations

The use of psychotropic medication to treat individuals with developmental disabilities has always been controversial. Much of the controversy is due to the off-label use of psychotropic agents to achieve a general suppression of challenging behavior – a practice that is sometimes referred to as "chemical restraint." Individuals with developmental disabilities have been subject to this general behavioral suppression more often than any other group. As a result, the use of psychotropic medication for individuals with I/DD is subject to heightened scrutiny. Some would contend that this heightened scrutiny has had the unintended consequence of unnecessarily burdening the appropriate use of psychotropics. There is an ongoing need to strike an optimal balance between these concerns.

Standards regarding using psychotropic medication to treat individuals with developmental disabilities are typically presented as aspirational standards, e.g., International Consensus Guidelines. Typical standards also appear to assume that the prescriber is positioned at the outset of establishing the psychotropic regimen, where much more frequently prescribing entails inheriting an existing regimen. Typical standards also appear to assume the availability of ideal resources – an assumption that flies in the face of reality for public behavioral health resources. To address these concerns, pertinent commentary is provided following each standard (these standards are taken directly from the Consensus Guidelines presented in bold italicized type).

1. *A psychotropic medication is any drug prescribed to stabilize or improve mood, mental status, or behavior.*

It's important to ascertain the intent of the prescriber for any agent known to have dual utility, e.g., is valproate being used as a mood stabilizer or as an anticonvulsant? Is propranolol being used to contain acute anxiety or to address hypertension? Etc.

Some agents with dual utility provide a secondary benefit to co-existing conditions, e.g., valproate was prescribed as an anticonvulsant, but it also yields mood stabilization benefits.

Clarity regarding intent of, and primary responsibility for, particular medications is essential to avoiding decisions that impact another clinician's care.

2. *Psychotropic medication shall not be used excessively, as punishment, for staff convenience, as a substitute for meaningful psychosocial services, or in quantities that interfere with a person's quality of life.*

The above prohibitions are largely irrelevant for any clinician operating in good faith to be helpful. However, the piece that refers to as a "substitute for meaningful psychosocial services" can be challenging. Many patients inhabit psychosocial services that are deficient. Remediating that deficiency does not fall to the prescriber. On the other hand, the prescriber is not obligated to attempt to achieve an outcome with medication that requires modification of the infrastructure of the person's support.

3. *Psychotropic medication must be used within a coordinated multidisciplinary case designed to improve the individual's quality of life.*

Prescribers in the community rarely play any role in the development and implementation of the person's overall care plan. The best way to overcome this is to be careful to include, in consultations, a team member well-versed in the overall plan to ensure the plan's most optimal integration possible.

4. *The use of psychotropic medication must be based on a psychiatric diagnosis or a specific behavioral-pharmacological hypothesis resulting from a full diagnostic and functional assessment.*

There is little to no controversy in using psychotropic medications that are FDA-approved for a particular condition, assuming that the condition has been accurately diagnosed. Decisions regarding off-label use with individuals with I/DD are no different from decisions regarding off-label use for individuals without I/DD.

5. *Written informed consent must be obtained from the individual, if competent, or the individual's guardian before the use of any psychotropic medication and consent must be periodically reviewed.*

This is a particularly important standard in working with individuals with I/DD who have communication and cognitive challenges. It is also one of the more challenging standards to meaningfully fulfill.

Formal substitute decision-making is a viable option to consider when the individual carries a default legal status of competent major yet does not demonstrate sufficient competence to make decisions regarding their psychotropic regimen.

6. ***Specific index behaviors and quality of life outcomes must be objectively defined, quantified, and tracked using recognized empirical measurement methods in order to monitor psychotropic medication efficacy.***

This is an ideal standard. It's particularly difficult in a resource-challenged setting - like most in the community. At the very least, dialogue between the prescriber and the patient/team should include specifics about what will need to be monitored as an index of improvement.

7. ***The individual must be monitored for side effects on a regular and systematic basis using an accepted methodology which includes a standardized assessment instrument.***

It is best to develop written protocols regarding content and scheduling of needed labs and other monitors.

The routine use of a "standardized assessment instrument" to monitor for side effects is beyond what can typically be achieved in a community setting. Direct care workers should be encouraged to report any significant changes in the person's status.

8. ***If anti-psychotic medications or other dopamine blockers are prescribed, the individual must be monitored for tardive dyskinesia [an extrapyramidal side effect] on a regular and systematic basis using a standardized assessment instrument.***

The best choice here would be the Dyskinesia Identification System: Condensed User Scale (DISCUS). However, that instrument requires special training that may or may not be available. The more familiar option, the Abnormal Involuntary Movement Scale (AIMS), will suffice if used carefully and flexibly. Note that tardive dyskinesia is only one of several extrapyramidal side effects. If abnormal movements are present then, a referral to a movement specialist may be required to diagnose and arrive at a monitoring system.

9. ***Psychotropic medication must be reviewed on a regular and systematic basis. Clinical reviews must be conducted regularly and frequently by the prescriber. Data reviews must be conducted on a regular and systematic basis by appropriate members of the multidisciplinary team.***

A reasonable minimum standard for the frequency of direct clinical examination is quarterly. In the event of emergent acuity, the frequency of scheduling should be driven solely by clinical values. In the event of modification of the psychotropic regimen, the frequency scheduling is dictated by what is required to evaluate the outcome of the modification.

The multidisciplinary review of psychotropic supports will typically occur without the attendance of the prescriber. However, the outcome of such review should be a routine component of the consultation dialogue and should provide the larger context of the prescriber's rationale.

10. **Psychotropic medication must be reviewed on a periodic and systematic basis to determine whether it is still necessary or, if it is, whether the lowest optimal effective dose is prescribed.**

This standard is accomplished in the review process cited above. Any modification of a psychotropic regimen should be driven solely by what is clinically indicated and not just in reflexive response to a written standard.

11. **Frequent drug and dose changes should be avoided.**

Changes in agents or dosage should be undertaken as clinically indicated, independent of any considerations of pace.

12. **Keep psychotropic medication regimens as simple as possible in order to enhance compliance and minimize side effects.**

This standard speaks for itself. All things being equal, the simpler the regimen, the better. However, achieving simplicity should not come at a cost to effectiveness. Simplicity in scheduling is also an important consideration. Medication compliance is enhanced by scheduling efficiencies such as once-daily dosage or long-acting injectables.

13. **Minimize the following practices to the degree possible:**
     - **Long-term use of PRN (pro re nata)/as needed orders**
     - **Long-term use of benzodiazepine antianxiety medications such as diazepam**
     - **Use of long-acting sedative-hypnotic medications such as chloral hydrate**
     - **Long-term use of shorter-acting sedative-hypnotics such as temazepam**
     - **Anticholinergic use, such as benztropine, without signs of extrapyramidal side effects**
     - **Long-term use of anticholinergic medication**
     - **Use of antipsychotic medication at high doses**
     - **Use of phenytoin, phenobarbital, and primidone as psychotropic medications**

All of the above apply to community providers. This is simply a list of practices to avoid. This standard can be met by NOT using these practices.

But, of course, sometimes, a provider inherits a regimen that includes one of the above. It would be a rare instance that any of the above practices should continue. A heavy burden would fall on the clinician to defend any of the above. Dismantling any of the above practices requires careful attention to discontinuation issues.

14. **Establish a system of peer review of psychotropic medication prescribing that incorporates a mechanism for flagging cases of greatest concern.**

Peer review systems are generally not available in the community. Pharmacies do issue alerts and warnings regarding any feature of the regimen that raises a pharmacologic question. In lieu of peer-review, a systematic self-review system can be achieved. This can be achieved, at a minimum, with a simple checklist of what one considers essential elements of a service.

Another essential review is evaluating the effectiveness and appropriateness of needed accommodation. This can also be achieved, at a minimum, with a checklist. This helps ensure that procedural drift is detected early so as to not allow it to become entrenched.

Treatment/Therapy Progress and Outcome Monitoring

Throughout treatment (medicine and/or therapy), monitoring of any progress, will, of course, occur. Because individuals with I/DD do receive other services and supports and may rely on others to help them with not only day-to-day activities but also a) wellness activities, b) doing things they enjoy, and c) practice for therapy skills/strategies, it will be even more important to consider a variety of issues when looking at progress or in evaluating any potential treatment/therapy change if progress is not occurring. Individuals with I/DD have long been prescribed psychotropic medication more frequently than other behavioral health treatments and, at times, more for the sedating purposes of the medication. While improvements in this area have occurred, it is still common to see assumptions related to a need to change medication in response to either no progress or a worsening of symptoms. Similar assumptions can often occur for any other behavioral health treatment. When changes are needed, this would, of course, be appropriate; however, if the underlying issues are not related to treatment (medication and therapy), then a change will not address the problem. To consider the best options for "change" to address any lack of progress or worsening of symptoms, the following guideline should be followed:

1. Check the following PRIOR to making any treatment (medical and therapy) change and address any issues discovered (this may not be able to be directly addressed by you as the clinician but you would want to talk with the family/supporters or other providers about addressing these)
    a. Check the wellness needs and supports (you can use the same tool(s) to do this as were discussed in the assessment section; Appendix C)
    b. Check for any indicators of any medical/health changes (you can use the same tool to do this as was discussed in the assessment section; Appendix F)
    c. Check for any trauma needs and supports as well as any potential new trauma situation (you can use the same tool(s) to do this as were discussed in the assessment section; Appendix G)
    d. Ask about supports and consistency in any skill practice related to therapy activities
2. If the above are determined not to be a problem, or you can verify that they are addressed, or it is clear there is not an association with the noted symptom changes, then proceed to consider any needed changes to treatment (medication or therapy).
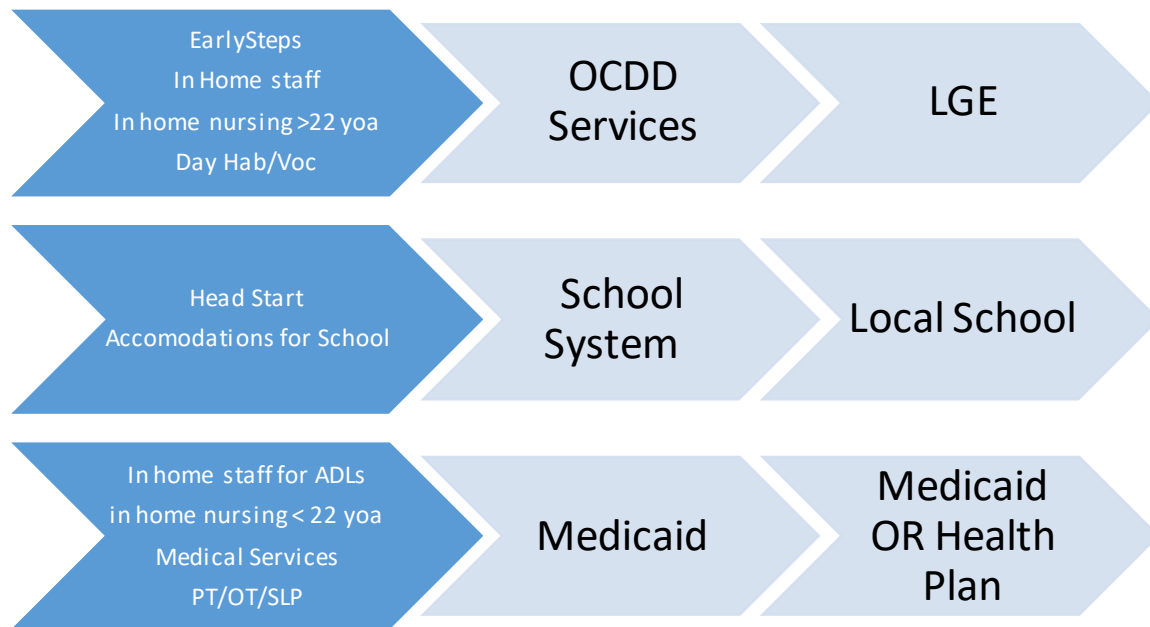
The clinician communication form included in the appendices, Appendix M, along with the tools related to wellness and trauma needs, Appendices C - G, can be helpful in these efforts.
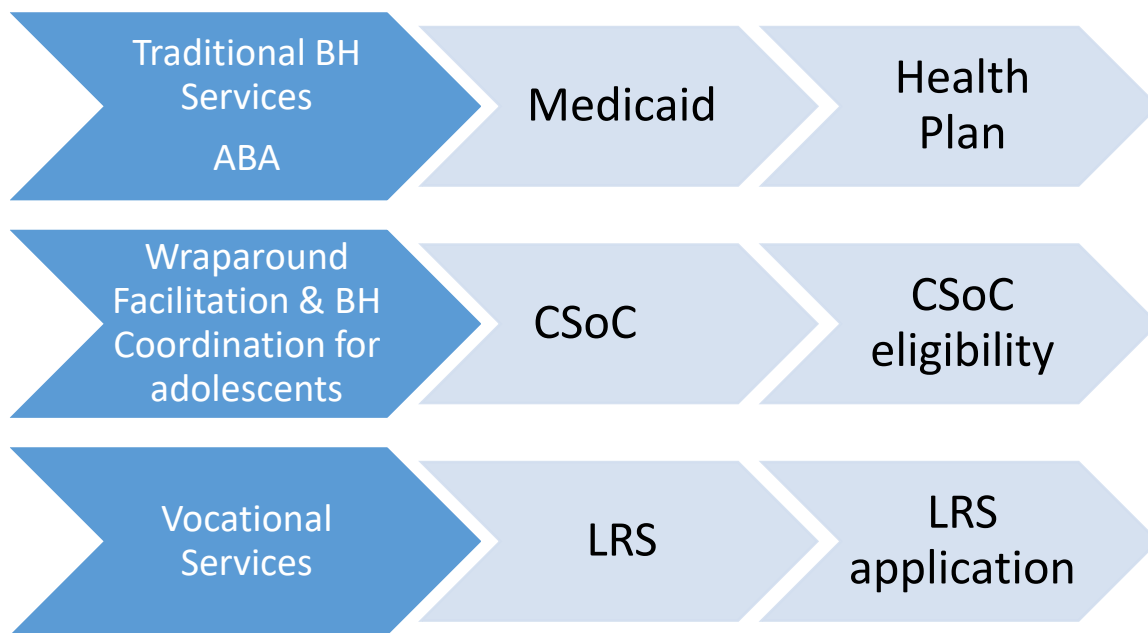
Understanding and Identifying I/DD conditions

Core Components of I/DD Diagnosis and Eligibility
An individual who needs day-to-day supports for developmental disability needs may receive services and supports to meet those needs from several systems in Louisiana:

1. Early Intervention needs from age 0-3→OCDD
2. Head Start/Early Intervention from age 3-5→DOE/Local School Systems
3. Accommodations needed to learn and participate in school activities, nursing supports to attend school, behavioral supports to attend and participate in school→DOE/Local School System
4. In-home supports for typical activities of daily living (ADLs) →Traditional Medicaid or Medicaid Managed Care Plan (Early and Periodic Screening, Diagnostic and Treatment - Personal Care Services, EPSDT PCS, up to age 22; Long Term - Personal Care Services, LT-PCS, after 22)
5. In-home supports for DD needs not covered/authorized via Medicaid or Managed Care Plan→OCDD
6. Medical services, occupational (OT), physical (PT), speech (SLP), or other therapies→Traditional Medicaid or Medicaid Managed Care Plan
7. In-home skilled nursing up to age 22 or Pediatric Day Health Care (PDHC)→ Traditional Medicaid or Medicaid Managed Care Plan
8. In-home skilled nursing after 22→OCDD
9. Traditional BH services, or Applied Behavioral Analysis (ABA) →Medicaid Managed Care Plan
10. Specialized BH services and coordinated wraparound up to age 20→ Coordinated System of Care (CSoC)
11. Vocational Supports→Louisiana Rehabilitation Services (LRS)
12. Day Habilitation and Vocational Supports not provided by LRS→OCDD

EarlySteps In Home staff In home nursing >22 yoa Day Hab/Voc	OCDD Services	LGE
Head Start Accomodations for School	School System	Local School
In home staff for ADLs in home nursing < 22 yoa Medical Services PT/OT/SLP	Medicaid	Medicaid OR Health Plan

Traditional BH Services ABA	Medicaid	Health Plan
Wraparound Facilitation & BH Coordination for adolescents	CSoC	CSoC eligibility
Vocational Services	LRS	LRS application

If you do not have Medicaid eligibility through the typical eligibility process, your child may qualify through Act 421 Children's Medicaid Option/TEFRA passed in the 2019 legislative session and effective January 2022. This program offers alternate eligibility options for youth under age 19 who meet one of 3 possible institutional levels of care options. More information about this program can be accessed at Act 421 Children's Medicaid Option (421-CMO) | La Dept. of Health

Obtaining OCDD eligibility may be important for an individual for whom you suspect I/DD needs may be present; however, it is important to understand where services are accessed to assure the right referral happens for the right person at the right time since all services the individual may need to access will not be via OCDD even if it is related to the individual's I/DD.

To obtain a statement of approval for OCDD services, there are important components of eligibility to consider:

1. A DD diagnosis or condition must be present
    a. "condition" allows for clear evidence of a neurological or physical challenge, even while a clear diagnostic category may be challenging to pinpoint
    b. The diagnosis or condition must be before age 22
2. After age nine there must be a substantial functional limitation across three major life areas
3. The diagnosis or condition must meet the following
    a. Is expected to be lifelong or of extended duration
    b. Is not solely attributable to mental illness

OCDD Eligibility Process
The Human Services Districts and Authorities, often referred to as Local Governing Entities or LGEs, are the single point of entry to the OCDD service system [link to contact information is provided in the appendices]. The first step to receive eligibility is to contact the LGE for the area the person resides. The process involves the following:

1. Contact LGE for an initial eligibility request and a face-to-face interview

2. Assessments and Records will need to be reviewed, so encouraging the individual/family to gather all information for the initial meeting with the LGE will assure the process occurs more smoothly. These records may include the following:
   a. Any medical/clinical assessments that clearly established the diagnosis or condition
      i. A rule-out statement in an evaluation is not sufficient; diagnosis and rationale are needed for establishing a diagnosis
      ii. If the diagnosis in question is an I/DD, there needs to be IQ testing AND adaptive testing.
         1. The LGE may be able to assist in obtaining this if it is not already completed, but presence of an evaluation results in eligibility proceeding more quickly.
         2. If the person is in a hospital/treatment setting at the time of testing, it is important that testing occurs when the individual is stable so that the testing outcome is not likely to be influenced by the impacts of symptoms/illness.
         3. Adaptive evaluations should be done with informants who know the individual well and have provided supports.
      iii. If the diagnosis in question is an ASD, the evaluation should meet standard practice consistent with the expectations for the Medicaid Comprehensive Diagnostic Evaluation.
      iv. If a neurological or physical condition is present, but diagnostic clarity is not yet reached, the evaluation must include clear evidence of the condition.
   b. School records/ Individualized Education Plan (IEP)
   c. Other relevant medical or behavioral health assessments
3. The LGE will review the information from the interview and the assessments/records and make any recommendations for additional needed assessments. The LGE may be able to assist in obtaining certain psychological evaluations, but they are not able to obtain any and all medical and BH evaluations. Some of these will need to be obtained through community clinicians via the person's Medicaid Managed Care Plan or private insurance.
4. For any complicated situations, the LGE has an Entry Review Team that includes clinicians as needed.
5. If a Statement of Approval is provided, the individual can begin the process of accessing needed services. Some Statements of Approval will require redetermination at a set interval.
6. If a Statement of Denial is provided, the individual will be given appeal rights and due process. A request to reconsider eligibility can be made anytime if new information is gathered.

Recognizing and Considering I/DD When BH Conditions are Present

Previous sections discussed challenges an individual with I/DD may have in accessing needed BH services and the difficulty some clinicians may experience in recognizing BH symptoms when present and diagnosed. Unfortunately, there are also instances where an individual may clearly present with BH symptoms and begin receiving BH services, but have DD needs that are missed. Therefore, it is important as clinicians to consider the following:

1. An individual may have a milder disability or delay that is not as noticeable at an early age. If the youth present with BH symptoms, the DD needs can be missed even when/if they begin to have an impact.
2. An individual may not have an I/DD at birth but may sustain an injury or have a medical/neurological event and then present with I/DD needs. If the individual already presented with BH needs, the newer I/DD needs are often overlooked.

The following considerations may assist in identifying the need for assessment for a possible I/DD/neurological condition:

- Dramatic change in academic or adaptive skills with no destabilization of BH symptoms
- Loss of change in awareness/consciousness not attributed to clear psychosis or catatonia
- A known injury or neurological event occurs for someone who has significant BH history and recovery of skills/abilities does not return to baseline
- A decline in skills/abilities that is not associated with BH symptom destabilization and/or does not resolve even when BH symptoms are stable or absent

Closing Statement

The presence of behavioral health conditions for individuals who experience I/DD is now well established with significant research. Individuals who experience an I/DD are frequently systematically excluded from accessing non-developmental disability systems and their services when their I/DD is viewed through a traditional lens of "primary" diagnosis and thus belongs to the "primary" system. The vast majority of individuals who experience an I/DD and co-occurring behavioral health conditions benefit from the same treatments as people who do not experience an I/DD. The research overwhelmingly dispels myths about the lack of efficacy of traditional treatments and supports. There are no grounds for the existing systems not serving this population, at least persons with Mild and Moderate I/DDs who make up over 85% of individuals served.

Our hope for this Guide is to provide Clinicians and Providers with tips and tools to begin to make accommodations and modifications to their practices to ensure equal access and treatment for individuals with I/DD and co-occurring behavioral health conditions.

Appendices

Appendix A: Individual Communication Log

Appendix B: Behavioral Considerations and Assessment Guidelines

Appendix C: Emotional Wellness Guide

Appendix D: Review of Life Stressors & Transitions

Appendix E: Behavioral Assessment Screening

Appendix F: Review of Health Indicators

Appendix A:

Individual Communication Log

The following log can be used to capture what we collectively learn about an individual's communication efforts. This can be particularly important for individuals with limitations in more typical or expected forms of communication. It CAN include behavioral challenges as individuals are learning what they mean; however, it is MOST IMPORTANT that it include more subtle communication signs including those that may be precursors to any behavioral challenges. In this way, we can be sure we are supporting the person to communicate without the frustration that may lead to actually using a behavioral challenge. This type of log can identify opportunities for communication learning, technology, or other alternatives that can then support the individual to communicate more easily with any other individual, not just those who have learned and know their unique methods. This type of log can be started at the beginning of assessment/clinical activities with an individual and can be a dynamic document that grows and changes throughout our interactions with an individual.

When this happens	I do this	It means	I want you to do this
[What is going on in the environment? What is believed to be the identifying trigger?]	*[What behavior expression/action is visible to others? What can they observe/hear/see?]*	*[Meaning of the behavior from the person's perspective.]*	*[What others should do or not do in response.]*

Appendix B:

Behavioral Consultation & Assessment Guidelines

Obtain a brief history of presenting challenges:　☐New　☐Worsening of previous
　　　Frequency:　　　　　　Duration:　　　　　Severity:

Determine the presence/absence of any recent life changes/stressors:　☐Yes　　☐No
(See attached tips for consideration & describe if present)

Conduct abbreviated behaviorally-focused assessment to determine possible impacts:　☐Yes ☐No
(Full functional assessment would be conducted outside of imminent referral situation and/or referral
for one should occur if the clinician is not experienced in this activity; If the current treating
clinician/team does not have experience in behavior analysis, the attached screening may be
completed to determine possible environmental/structural changes that can be tried and/or need for a
functional assessment referral; Referral should also occur if no clear treatment path emerges
following assessment and full consideration of the health and mental health impacts.)

Any evidence of medical questions/issues and need for referral:　☐Yes　　☐No
(See attached areas of consideration & describe if present)

Any recent medication additions or changes:　☐Yes　　☐No

Any history of substance use/abuse and/or recent access to illegal substances:　☐Yes　　☐No

Any existing MH diagnosis and history of treatment and/or any current symptoms:　☐Yes　　☐No

Any genetic diagnosis (consider any known "syndrome" issue if present):　☐Yes　　☐No

Any changes in or problems with sleep patterns:　　　☐Yes　　☐No

Any changes in or problems with eating patterns:　　　☐Yes　　☐No

Any trauma history and/or indication of recent incidents:　　☐Yes　　☐No
(See attached guide & describe if present)

Any recent injuries/incidents that could impact presentation:　☐Yes　　☐No

Appendix C:

Emotional Wellness Guide Template

The purpose of this plan is so that there is a shared understanding about what support I need to make choices toward a healthy and fulfilling life. This is my plan, & just as my needs can change over time, this plan may also need to be updated from time to time to reflect my changing needs.

Name: **Address:**   **Phone #:**

DOB: **Date of Plan:**

Wellness Guide: *Listed below are the activities/things that I need daily to keep myself healthy and to make myself feel better.*

(Note: These questions are good opportunities to identify specific activities related to wellness that are important to the person. Get creative. Use this as an opportunity to explore what's currently important to the person but also activities/things that the person thinks might be enjoyable & wants to try. These activities should be regularly available, as engagement in these activities supports a healthy lifestyle and are important toward preventing negative life events.)		
	Outline answers below & then place 'X' in the box if the person requires support for this:	
Enjoyable activities that I do alone:		
Enjoyable activities that I do with others (please note individual if the action is linked to a specific person):		
Exercise/Fitness:		
Movement (when I get up & move around, this is what I like to do):		
Creative Expression: Journaling/Drawing/Singing/Music/Dance/Etc.		
Relaxation:		
Activities that make me feel good about myself:		
Outdoor activities or activities related to nature:		
Social media, pets, plants, & other important connections:		
These are some goals that I want to accomplish & will make me proud & happy (goals can be short-term & long-term):		
This is the amount of sleep I need each night to feel good the next day:		
Positivity. This is what I love most about me:		
Treating myself – these are the things that I like to do to give myself a boost of positivity when I need it &/or when I want to celebrate an accomplishment:		
Other important wellness tools (this might include any non-negotiables not already noted above):		

Wellness Needs: *Here is my description of myself when I am feeling good and healthy (Note: there is a link between feeling well and using the wellness guide shared above.):*

_____
_____
_____

Appendix D:

Review of Life Stressors & Transitions

Review and indicate any recent (last few months) life stressors the individual has experienced. For any checks, provide in assessment a brief description including details of the stressor/transition, date, and any attempts to adjust supports.

- ☐ Received disability or another new diagnosis
- ☐ Illness
- ☐ Addition of a family member (birth, marriage, pregnancy)
- ☐ Death of a family member
- ☐ The move of a family member
- ☐ Divorce in family
- ☐ Significant illness for a family member
- ☐ Started school
- ☐ Break from school
- ☐ Ending school
- ☐ Marriage
- ☐ Divorce
- ☐ Death of spouse/partner
- ☐ Illness of spouse/partner
- ☐ Starting a new job
- ☐ Changing jobs
- ☐ Loss of job
- ☐ Significant life transition possible (adolescence, school–to–work, retirement/aging)
- ☐ Younger siblings achieving milestones (graduation, marriage, etc., particularly if an individual has not yet achieved the milestone)
- ☐ Move out of home for individual
- ☐ Changing residence (note any history of institutionalization if this is indicated along with historical frequency)
- ☐ Loss of staff/someone providing support
- ☐ New staff/individual providing support
- ☐ Changes in support (could even be positive but brings some anxiety – i.e., more independence)
- ☐ Death of a friend/someone close
- ☐ Loss of friend/important relationship
- ☐ Significant illness of friend/important relationship
- ☐ Failure to achieve important goal (could be no movement on something important – leading to frustration)
- ☐ Natural disasters (flood, hurricane, tornado, fire, etc.)
- ☐ Financial problems
- ☐ Holidays
- ☐ Vacation
- ☐ Change in social or religious activities

Other (specify stressor_____)

Appendix E:

Behavioral Assessment Screening

This is not intended to take the place of a formal/full functional behavioral assessment or analysis when indicated. If indicated, one must be conducted by the treating clinician or a referral made to a professional with expertise in behavior analysis. However, this tool is designed to assist in gaining some basic information that may lead to some support and environmental changes that increase the likelihood of successful behavioral health outcomes for the individual.

Quality of Life/Self-Determination Impacts

- Non-negotiables are identified and listed in the plan
- Non-negotiables are available/accessible/happening routinely
- Important routines and rituals are identified and listed in the plan
- Important routines and rituals are happening consistently
- Important family/friends are identified and listed in the plan
- Visits/Calls/Contact is occurring as listed in the plan
- Preferred activities/interests are identified and listed in the plan
- Preferred activities/interests are available/accessed/happening routinely
- Preferred work activities/schedules are identified and listed in the plan
- Preferred work activities/schedules are available/accessed routinely

Environmental/Structural Impacts

- Consistently occurs at some times of day but not others
- Consistently occurs on some days of the week but not others
- Consistently occurs with some people but not others
- Consistently occurs during some activities/situations but not others
- Occurs differently in crowded situations than in non-crowded
- Occurs differently in noisy situations than in non-noisy

Functional Considerations

- ❑ Activities or requests tend to stop when the behavior occurs
- ❑ Activities tend to start or preferred items are gained when the behavior occurs
- ❑ A good bit of time and attention is provided to the person when the behavior occurs
- ❑ The behavior seems to occur often when the person is alone and/or nothing is happening
- ❑ The individual has limited or atypical communication abilities

Appendix F:

Review of Health Indicators

This is not meant to be a substitute for a formal medical examination; instead, it is a gathering of information from the individual and/or family/staff of areas in which there has been a noted change to assure appropriate referral for ruling out any possible underlying medical contribution to a more overt/observable behavioral presentation. If an individual is able to state a particular complaint, a referral should be made based on this complaint alone.

Review and indicate any recent (last few months) changes the individual has experienced. For any checked, provide a brief description in the assessment including details of changes, dates present vs. absent, and any attempts to adjust supports.

- ☐ Eating habits
- ☐ Sleep patterns
- ☐ Mobility
- ☐ Elimination (bathroom habits)
- ☐ Activity level
- ☐ Alertness
- ☐ Vision
- ☐ Hearing
- ☐ Touch/sensation

Review if any of the following occurs and provide similar information if checked.

- ☐ Moaning/groaning is observed
- ☐ Flinching, crying when moved/touched, or other signs of possible pain
- ☐ Seasonal changes in patterns of behavior
- ☐ Changes in patterns of behavior during the menstrual cycle
- ☐ Vomiting or regurgitation
- ☐ Rashes or other skin changes
- ☐ Recent changes in medications
- ☐ Weight loss/gain
- ☐ Changes in seizure activity
- ☐ Other signs of possible discomfort/pain
- ☐ Behavioral changes specifically associated with mealtime (before, during, immediately after)
- ☐ Change in access to caffeine or nicotine

Appendix G:

Review of Trauma History and Risks

Review and indicate any of the following the individual has experienced. For any checked, provide a brief description in the assessment, including details of trauma, date, and any attempts to adjust supports. (Based on adverse childhood experience identification from CDC and SAMHSA with supported modifications and additions based upon trauma-informed approaches for persons with ID)

- ☐ Physical Abuse
- ☐ Sexual Abuse
- ☐ Emotional Abuse
- ☐ Physical Neglect
- ☐ Emotional Neglect
- ☐ Social trauma (e.g., rejection, teasing, bullying, name-calling, verbal abuse)
- ☐ Violence in the home
- ☐ Substance use/abuse in the home
- ☐ Mental Illness in home
- ☐ Parental separation or divorce (or death of a parent in childhood)
- ☐ History of multiple or failed foster-care placements
- ☐ Loss, death, staff turnover
- ☐ Family member (in-home) in jail
- ☐ History of institutionalization/incarceration
- ☐ History of restraint or significant restrictions used in support plan(s)

Review and indicate any of the following which may be currently present for the individual. For any checked, provide in the assessment a brief description of the situation and any current supports in place to mitigate risk.

- ☐ Individual lives in community with ready access to substance use
- ☐ Personal lives in an area in which violence is prevalent
- ☐ Lack of **needed** support/supervision (could also be a limited number of people providing support)
- ☐ Lack of **required** parental involvement (at school, community, etc.)
- ☐ Little or no social support network
- ☐ Limited or no friends
- ☐ Little individual or family financial resources
- ☐ Little or no job opportunities
- ☐ Individual reports feeling unsafe in their home or neighborhood
- ☐ Family/staff report high levels of stress/frustration

Review and determine if any of the following are present in the individual's community and, if so, are being accessed.

- ☐ After school programs
- ☐ Church/faith-based programs
- ☐ Education/job training programs
- ☐ Other community resources that support positive school/work/community outcomes
- ☐ Access to needed training for any family/staff support
- ☐ Access to respite supports when an individual needs sustained support throughout the day/night

Appendix H:

Formal Assessment and Scales for Individuals with I/DD

Office for Citizens with Developmental Disabilities

Scale	Summary/Purpose
Reiss Screen for Maladaptive Behavior	- Broad screening for dual diagnosis for adolescents or adults - Parent/caregiver report - Internet version is now available
Reiss Scales for Children's Dual Diagnosis	- Broad screening for dual diagnosis for children - Parent/caregiver report - Internet version is now available
Diagnostic Assessment for the Severely Handicapped-II (DASH-II)	- Broad screening for dual diagnosis for individuals with severe to profound cognitive limitations - Parent/caregiver report
Assessment for Dual Diagnosis (ADD)	- Broad screening for dual diagnosis for individuals with mild to moderate cognitive limitations - Parent/caregiver report
Psychiatric Assessment Schedule for Adults with Developmental Disabilities (PAS-DD)	- Broad screening for dual diagnosis for adults (checklist and interview version exist) - Mini version available - Recipient and parent/caregiver report - Can be completed by a "non-professional" - Linked to ICD diagnoses - Allows for assessing progress as it focuses on the last four weeks
Child and Adolescent Psychiatric Assessment Schedule (ChA-PAS)	- Broad screening for dual diagnosis for children and adolescents (checklist and interview version exist) - Recipient and parent/caregiver report - Can be completed by a "non-professional" - Linked to ICD diagnoses - Allows for assessing progress as it focuses on the last four weeks
Anxiety, Depression, and Mood Scale (ADAMS)	- Specific focus on screening for anxiety and mood disorders - Parent/caregiver report
Glasgow Anxiety Scale for People with Intellectual Disabilities	- Recipient report/observation - Completed by a healthcare professional - Focus on anxiety symptoms/conditions
Compulsive Behavior Checklist	- Specific tool to assist in assessing for OCD in individuals with intellectual disabilities - Observational scale - Completed by a healthcare professional
Childhood Autism Rating Scale (2nd edition) – (CARS2)	- Assists in identifying possible symptoms indicative of ASD - Observational rating scale - Completed by a healthcare professional
Gilliam Autism Rating Scale (3rd edition) – (GARS-3)	- Rating by clinician, parent, and/or teachers - Assists in identifying possible symptoms indicative of ASD

Appendix I:

Considerations for Therapeutic Modifications

An individual can recognize and identify basic emotions: ☐Yes ☐No
      Using words/descriptions: ☐Yes ☐No
      Using photos/pictures: ☐Yes ☐No
      In role play: ☐Yes ☐No

Individual has sufficient memory/recall to repeat back at least 1 or 2 thoughts/ideas: ☐Yes ☐No.
[NOTE: document limits of recall for use in therapy sessions: _____]

The individual can recognize some link between situations and emotions: ☐Yes ☐No
[NOTE: Present simple scenarios typically tied to specific emotional responses and assess if the person can state or use photos/pictures or role play to show emotional response; Be mindful that history may impact odd responses.]

The individual can associate possible thoughts with a situation/emotional scenario: ☐Yes ☐No
[NOTE: Using the same scenarios, ask the individual what the person may be "thinking or saying to themselves"; This component will be more relevant in certain types of therapeutic approaches like CBT but may not rule out others such as solution-focused therapy.]

Is the person able to reliably communicate for therapeutic conversations: ☐Yes ☐No
      Using words/descriptions only: ☐Yes ☐No
      Using sign language: ☐Yes ☐No
      Using combination: ☐Yes ☐No
      Using words with visual cues: ☐Yes ☐No

Has the individual participated in therapeutic activities before: ☐Yes ☐No
      Is it continuing: ☐Yes ☐No
      Does information suggest adequate participation: ☐Yes ☐No
      What if any barriers were identified? ☐Yes ☐No
      What were the recommendations from a therapist in the last session (if continuing) or at the end of therapy?

Basic Therapy Agenda Guide

Agenda Item	Written Agenda Item Considerations	Picture Agenda Item Considerations
Monitor current emotional state	• Use language the person understands • Adjust for communication knowledge of the person • Ensure the person is able to read the agenda	• Add visual cues to prompt items if needed • Build in the use of pictures/photos/role plays as needed for person
Review of the Past Week	• Consider if additional prompts about WHAT needs to be reviewed must be included in the agenda or can simply be cued verbally	• Add visual cues for each item if details are included • Consider using a cue/picture that lets the person know this is next on the agenda
Review of Homework	• Consider if we need to specify each week's prompt for EXACTLY what homework was or can simply be cued verbally	• Add visual cues for each item if details are included • Consider using a cue/picture that lets a person know this is next on the agenda
Analysis of one particular incident of cognition, behavior, emotion, or arousal	• Use language the person understands • Adjust for the communication knowledge of the person • Consider if there is a need to include and identify at the outset of therapy with the involved family/staff • Consider the use of a standard process to do this	• Consider use of a cue/picture that lets the person know this is next on the agenda • Use role play and other methods in communication and analysis based on a person's preference/needs
Review implications for future and other settings	• Use language the person understands • Adjust for the communication knowledge of the person • Consider the use of the standard process to do this	• Consider the use of a cue/picture that let's person know this is next on the agenda • Use role play and other methods in communication and analysis based on a person's preference/needs
Exercise for homework	• No specific item on the agenda • Use language a person understands and adjust for communication knowledge in actual exercise	• Consider use of cue, perhaps similar yet just different enough cue for review of homework • Use role play and other methods in communication and analysis based on a person's preference/needs
Setting homework tasks	• No specific item on the agenda • Use language person understands and adjust for communication knowledge in setting exercises • Consider need to bring in involved family/staff for any needed assistance	• Consider use of cue, perhaps similar yet just different enough cue for review of and exercise for homework • Bring in any reminders/calendars/etc. for remembering and completing homework

Example - Format Evaluating Negative Thoughts

(Can be used in session on flip chart/etc.)

Negative Self Thought	Competencies to Beat Negative Self Thought
I am a terrible person.	*Gets along well with co-workers* *Keeps home nice and clean* *Has friends and family who visit*

Appendix L:

Example - In Session Analysis of Emotion

Label of Emotion to be Explored - encourage the person to draw expression if useful	**THINK**
FEEL	**DO**

Appendix M:

CLINICIAN VISIT & COMMUNICATION FORM

Staff/family should complete the information in each section to communicate/share the most important information with the clinician.

Name of Individual:	Date of Visit:
Medicare/Medicaid/Insurance No:	DOB:

Pertinent History / known diagnoses:

Allergies – Medication/Food:

Current Psychotropic (Behavioral health-related) Medications: Other Medications:

REASON FOR THIS VISIT:
What is the reason for today's visit? ☐ Initial visit ☐ Routine follow-up ☐ Requested appointment before routine follow-up
Has anything changed recently?   ☐ Yes   ☐ No
If yes, provide information about what new concerns have been noticed and changes in actions/emotions/symptoms:

Did the clinician ask for any specific information/report/follow-up at the last visit? ☐ Yes   ☐ No
If yes, provide it here, or bring the needed information.

Any of the following changes happened recently:

☐Eating habits   ☐Sleep patterns   ☐Mobility   ☐Bathroom habits   ☐Activity level

☐Alertness reactions   ☐Vision   ☐Hearing   ☐Touch/sensation   ☐Emotional

☐Relationships   ☐Work/School   ☐Routines   ☐Living situation

Appendix N:

CLINICIAN RECOMMENDATIONS AND INSTRUCTIONS

Clinician Name:	**Specialty:**

New Diagnoses/conditions:

Check all that apply:

☐ Wellness needs and supports reviewed

    ☐ No issues noted   ☐ Concerns noted & recommendations to family/provider; If checked, provide concerns/recommendations below:

☐ Trauma concerns and Life stressors/changes were reviewed

    ☐ No concerns noted   ☐ Changes occurred and impact symptoms & recommendations to family/provider; If checked, provide information below:

☐ Coping skills being practiced; If checked, please list below with any tips for staff/family :

☐ Instructions for family/staff if specific signs/symptoms occur; If checked, provide instructions below:

☐ Medication changes; If checked, what are new meds:

☐ Tests ordered; If checked, list tests to complete:

    ☐ Scheduling happened at the office   ☐ Scheduling needs to be done by individual/ provider/family

☐ New/essential signs and symptoms to monitor; Check and list below

    ☐ Signs/symptoms to report immediately to MD:

    ☐ Signs/symptoms to monitor for the next visit:

    ☐ Emergent signs/symptoms = go to ER:

Clinician Signature: _____

Follow-up date:

Appendix O:

Links to Resources

White Papers for [Healthcare - The Arc of Louisiana (thearcla.org)](thearcla.org)

To contact your local LGE: <u>Locate Services | La Dept. of Health</u>

<u>Integrated Mental Health Treatment Guidelines for Prescribers in Intellectual and Developmental Disabilities | Center for START Services</u>

For more information on IDD and BH needs and to access the DM-ID II: <u>Home - The NADD</u>

For more information and to contact CSoC: <u>Magellan of Louisiana</u>

To access wellness tools: http://padlet.com/brandikellyPhD/Wellness_IDD

To access the clinician tools: http://padlet.com/brandikellyPhD/IDD_BehavioralHealth

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