

# 2023 Psychotherapy Practice Guidelines: Working with Adults with Intellectual Disability and Co-occurring Mental Health Conditions



The Ohio State University Nisonger  
Center RRTC on Health and Function

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## **The Ohio State University Nisonger Center RRTC on Health and Function Expert Panel**

These guidelines were informed by the Ohio State University Nisonger Center RRTC on Health and Function collaborators who are listed in alphabetical order by last name, after the Principal Investigator: RRTC Year 5 (2022-2023):

Susan Havercamp, Rebecca Andridge, L. Eugene Arnold, Jarrett Barnhill, Ethan Boerner, Alixe Bonardi, Christine Brown, Andrew Buck, Sarah Burkett, Richard Chapman, Chelsea Cobranchi, Dan Davies, Travis Dresbach, Robert Fletcher, Braden Gertz, Jill Hollway, Gloria Krahn, Rosie Lawrence-Slater, Luc Lecavalier, Alexa Murray, Samantha Perry, Ashley Poling, Paula Rabidoux, Robert Rice, Megan Ryan, Christopher Sanford, Colin Schaeffer, John Seeley, Karrie Shogren, Mary Sowers, Kristy Stepp, Marci Straughter, Marc J. Tassé, Christopher Taylor, Katherine Walton, Andrea Witwer

## **Guidelines Team**

Andrea N Witwer, PhD; Emily Cary, PhD; Richard Chapman, PhD; L. Eugene Arnold, MD; Chelsea Cobranchi; Jastyn Wallace, MA; & Susan Havercamp, PhD. Correspondence or questions about these guidelines should be emailed to Dr. Witwer at: [Andrea.Witwer@osumc.edu](mailto:Andrea.Witwer@osumc.edu).

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*To enhance accessibility for screen readers and those printing the document, hyperlinks are included in-text and URLs are provided at the end of the document and organized by guideline.*

# Executive Summary

These practice guidelines are the result of a 5-year systematic research process funded by the National Institute on Disability, Independent Living, and Rehabilitation Research. Consistent with recommendations from the American Psychological Association and other leading mental health organizations, the development process included a systematic literature review of the state of psychotherapy outcome research for adults with intellectual disability (ID), a scoping review of evidence-based psychotherapy practices for adults with ID, and a series of focus groups with adults who have ID and experience with the mental health service system, and a series of focus groups with clinicians who provide psychotherapy to adults with ID. Adults with lived experience of ID and mental health experience contributed as research participants and as members of the research team to develop these guidelines. A guiding principle of our research center was to elevate the voices and ideas of adults with lived experience to enhance the relevance, authenticity, and the potential to positively impact the mental health and well-being of adults with ID.

The guidelines open with an introduction that describes the research and development process. The guidelines themselves are separated into a section on Person-Centered Practices, Foundational Concepts of Therapy, the Therapeutic Process, Medical Considerations and Future Considerations and Resources. The last section concludes with directions for future research and a list of the URLs included within the document.

The Person-Centered Practices section begins with a discussion of **Cultural and intersectionality considerations**, which includes disability as a component of diversity, intersectionality of disability with other marginalized identities, and resources on diversity equity and inclusion as it intersects with ID. Next is **Ethical Considerations**. Topics discussed include understanding current and previous guardianship status and implications, the importance of obtaining informed consent and permission to release information to other team members, the risk of diagnostic overshadowing, and aspects of ableism and discrimination that clinicians should guard against. Next is a discussion of **Empowering clients to self-advocate and promoting self-determination**. Self-determination and self-advocacy are defined. Strategies to support and promote self-determination in therapy and supporting and promoting self-advocacy, and accompanying resources are provided. **Including Support People** (i.e., parents, guardians, direct support staff, etc.) in therapy closes out the section on person-centered practices.

Included is a definition of individuals who might be considered support people, special considerations prior to the inclusion of support people and ways to include them in the therapeutic process.

Foundational Concepts of Therapy opens with **Assessment**, which covers the many considerations related to assessment with adults with ID in psychotherapy. This includes discussion of who the informant(s) should be, when to conduct assessment, and what should be assessed. A section on available standardized instruments provides information on a number of standardized assessments tools. **Communication** begins with a discussion on the importance of communication assessment, the use of inclusive language, and considerations related to ableist language. It also covers concepts such as identity- or person-first language usage and communication strategies to consider in therapy. This is followed by **Build and Maintain Clinical Relationship** which discusses potential barriers to the therapeutic relationship and considerations on how to build an alliance with clients with ID. **Accommodations and Support within Therapy** includes examples of visual, auditory and multi-sensory supports and accommodations and examples of plain language.

The final Therapeutic Process section provides practical information on how to **Structure Therapy and Goals** and the consideration of **Trauma History**. Finally, **Medical Considerations** such as collaborating with other medical professionals and medication management are discussed.

Throughout this document you will see citations, many of which emerged from two systematic literature reviews [1], [2]. You will also note direct quotes from our focus group participants, consisting of both clinicians and adults with ID who have experience in mental health treatment.

Adults with ID have high rates of co-occurring mental health problems yet face barriers to appropriate mental health care. There are often misconceptions that individuals with ID are somehow protected from mental health problems and that they cannot benefit from psychotherapy. Psychotherapy is effective for many individuals with ID [3]. Mental health professional training programs rarely address the need to adapt psychotherapy for clients with disabilities and there are lack of resources available for clinicians who provide treatment to adults with ID. This guide is intended to be a resource that increases the knowledge, comfort, and confidence for clinicians to provide psychotherapy treatment to the many individuals with ID who need it.

# Important Notes

## **Client Population**

While many of these strategies and recommended resources will be helpful for a range of adults with ID, most research on which they are based has been done with adults with mild and moderate ID. Many of the cognitive and talking-based strategies may not be accessible or applicable to adults with more severe and profound cognitive and communication disabilities. Additional research is needed on this population to inform practice. While some strategies may be helpful for adults with other developmental disabilities, including autism, it is important to note that these guidelines are based on research in those with mostly mild to moderate intellectual disability, as such some strategies may not be applicable.

## **Group Treatment**

While the majority of these considerations may also be applicable to those conducting group therapy, it is important to understand that additional considerations related to groups composition, structure, and content may be required.

## **Behavioral interventions**

Behavioral interventions were only included if they were part of a comprehensive psychotherapy treatment package (e.g., Cognitive Behavior Therapy or Dialectical Behavior Therapy). Because of the distinct goals and techniques used in applied behavioral analysis (ABA), and because of the volume of published ABA research, this body of work was excluded from the reviews and was the subject of a separate systematic review [3].

# Research Background

Individuals with intellectual disability (ID) experience substantial impairment in both cognitive functioning and adaptive functioning, with deficits manifesting during the developmental period [4]. People with ID are at increased risk of psychological distress [5], with one study finding the standardized prevalence of mental health conditions were 26.6% for adults with ID, compared to 14.9% of adults without ID [6]. Accurate assessment, diagnosis, and treatment of mental disorders in adults with ID can be challenging due to associated language and cognitive deficits yet few mental health clinicians are trained to provide care to these clients [7]. This lack of training impacts clinicians' beliefs about the effectiveness of psychotherapy for adults with ID and their confidence in and willingness to treat these patients [8]. Providing clinicians with information about the presentation of mental disorders in this population as well as best practices can increase their self-efficacy in caring for them.

To develop these guidelines, we first conducted a systematic review to understand the state of treatment outcome research related to psychotherapy for adults with ID [2]. This review followed the guidelines of Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA [10]), which is consistent with the Cochrane Collaboration [11]. To be included in this systematic review, published treatment studies were required to meet the following criteria: (a) include only adults 18 years of age or older, (b) be published between 1999 and March 2020, and (c) include only participants with an ID and a co-occurring psychiatric diagnosis or psychiatric symptoms specific to a disorder (e.g., anxiety, depression). Behavioral interventions provided in isolation were excluded, as they were the subject of a separate review. Results yielded several randomized controlled trials of varied modalities, but results were often mixed, or sample populations not adequately characterized (e.g., lack of specific psychiatric diagnoses) that it was determined there is a lack of sufficient evidence for treatment guidelines suggesting specific treatments for specific psychiatric diagnoses in adults with ID. We identified several studies describing approaches to psychotherapy with adults with ID in psychotherapy with promising results in need of further replication.

It is our hypothesis that with appropriate guidance and support through practice guidelines, clinicians can provide therapy to adults with ID using many of the same types of evidence-based strategies used with those without ID. Therefore, a second scoping review [1] was conducted to identify common

practices that appeared in the literature related to the practice of psychotherapy in adults with ID. These included interactive elements of therapy (e.g., games, role-playing, and rehearsal) and materials; use of visual supports in supplemental handouts, workbooks, or to promote generalization; use of caregivers to support and reinforce treatment strategies.

Next, focus groups [2] were conducted to gain stakeholder feedback on appropriate practice, accommodations and supports for adults with ID during psychotherapy. This included 1) adults with ID and experience receiving mental health treatment and 2) clinicians with experience providing mental health treatment to adults with ID. From these focus groups, we extracted themes and quotes that are included throughout this document.

In consultation with our advisory group (i.e., leaders in the ID research and clinical field and adults with disability lived experience) we drafted guidelines that were based on the literature and our own focus group research. We then sought feedback from attendees at several national conferences [12], [13], and peer review from leaders in the field.

The following guidelines are the results of a 5-year project guided by research evidence. All strategies are based on previous peer-reviewed literature, results of focus group, and expert consultation. They reflect this evidence-based and evidence-informed process throughout. As additional research emerges these guidelines will be updated.



# Person Centered Practices

## Cultural Considerations/Intersectionality

Within the body of research in ID on which these guidelines were partially based, there is very little information available on how cultural variability impacts the acceptability and effectiveness of treatment practices. Unfortunately, very few peer-reviewed manuscripts have reported on the race/ethnicity of their participants, and no studies were located that assess relative effectiveness or acceptability of psychotherapy within those with ID with other minoritized identities. While our focus groups and our disability experience panel included a diverse group including individuals with lived experience and other minoritized identities, data were not separated out based on these factors as a part of the thematic coding.

With a lack of existing research in this area clinicians are encouraged to learn about intersectionality and use it to inform their practice. Another valuable tool is to seek out available resources from people that experience intersectional identities.

### **Disability as a Component of Diversity**

Often social factors in conversations of justice, equity, diversity, and inclusion are conceptualized as being related to race, ethnicity, sexual orientation and/or gender identity. Clinicians are encouraged to consider all these aspects and how they relate to the mental and physical health outcomes of the client. It is similarly important to recognize disability as a marginalized social identity that may interact with other marginalized identities.

### **Intersectionality**

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*“The concept of intersectionality describes the ways in which systems of inequality based on gender, race, ethnicity, sexual orientation, gender identity, disability, class and other forms of discrimination ‘intersect’ to create unique dynamics and effects.” -Center for Intersectional Justice [14]*

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A person's life experiences are influenced by many different social factors. In fact, the impact of having more than one marginalized identity (e.g., being Black and having a disability) is not additive but multiplicative, leading to worse physical and mental health outcomes [15], [16]. In addition to understanding how social factors may impact clinical outcomes, clinicians need to consider all the social factors which may be shaping their individual clients' life experiences and how they may impact the therapeutic relationship, involvement of others in therapy, and the course of therapy.

**Resources on Diversity, Equity and Inclusion in ID:**

- [Association of University Centers on Disability \(AUCD\)](#)
- [Mental Health and Developmental Disability Training Center](#)
- [National Center for Cultural Competency](#)
- [AAIDD ID and Intersectionality](#)
- [What is Intersectionality](#)

# Ethical Principles and Considerations

Clinicians are guided by their professional ethical guidelines. The specifics may vary based on the clinician’s specific profession and guideline professional organization but all are guided by themes of respect for people's rights and dignity, including privacy, confidentiality, and self-determination. The following considerations and circumstances will assist clinicians in meeting the needs of their clients with ID.

<p>Understand Current and Previous Guardianship Status and Implications</p>	<p>Ensure that you understand the current status of your client’s autonomy regarding medical and financial decisions.</p> <p>Understand why the client with ID might have a guardian. Regardless of guardianship status, the client should make decisions regarding treatment goals and activities in therapy.</p> <p>Many adults with ID can manage their own affairs with the assistance and support from others such as family and friends [17].</p> <p>If legal limitations on autonomy are necessary, these should be individualized to the person’s support needs. There are many different forms of support; the least restrictive should be used.</p> <p>Be familiar with guardianship <a href="#">laws</a> and <a href="#">levels</a> of guardianship in your state. Your state’s Protection and Advocacy System can provide information about these standards and answer specific questions.</p>
<p>Obtain Appropriate Signed Forms or Verbal Equivalent</p>	<p>Ensure that <b>informed consent</b> is obtained from the client. It is important that the adult with ID is empowered to make decisions about their own mental health care [18]. If an adult has a legal guardian, then the guardian must provide informed consent for treatment and the client should provide informed assent.</p> <p>Obtain appropriate <b>permission to release information</b> before discussing any aspects of the client’s care. Permission should be obtained from the client with ID <b>and</b> guardian (if applicable). This should be done at the onset of therapy, and</p>

revisited in an ongoing manner throughout the therapeutic relationship.

*When asked during a focus group how it felt to have information shared with a guardian (even after the reported they had been informed by their clinician it would be and granted permission), an adult with ID responded it feels “Not okay. I feel like it's invading my space.”*

Guard Against Discrimination

Guard against any discrimination based on an individual’s disability or associated characteristics. It is recommended that clinicians be aware of their own:

- Beliefs and experiences, and increase knowledge on disability terminology and characteristics of [ableism](#) [19], [20].
- Explicit or [implicit biases](#) that may impact how they interact with individuals with ID and their support people. Exposure to counter-stereotypical exemplars can help to reduce bias [21], [22].
- Use of [microaggressions](#) including condescending language (e.g., calling an adult “buddy”) and nonverbals (e.g., patronizing pats).

*A focus group participant with ID shared that their “[group therapist] said I needed to like do something with my hands a lot and I rock a lot so they kicked me out because of that.”*

*A focus group participant with ID shared that their therapist “forced me to do things that I wasn’t able [and] sometimes went to the extent of saying that I was pretending.”*

<p>Be Aware of risk for Diagnostic Overshadowing and its Consequences</p>	<p>Diagnostic overshadowing is a type of negative bias impacting a clinician’s judgment regarding co-occurring disorders in individuals with ID.</p> <ul style="list-style-type: none"> <li>• Diagnostic overshadowing occurs when a clinician assumes that the behavior of a person with ID is part of their disability without exploring other factors such as mental health or biological determinants.</li> <li>• Once a diagnosis is made of intellectual disability there is a tendency to attribute all other problems to that diagnosis, thereby leaving other coexisting conditions undiagnosed.</li> <li>• When psychiatric symptoms are all attributed to the ID diagnosis, this can: <ul style="list-style-type: none"> <li>○ Can impact how case is conceptualized in general</li> <li>○ Can lead to gatekeeping where the adult with ID may not be offered mental health treatment.</li> </ul> </li> </ul>
<p>Treat Adults with ID with Respect, Fairness and Kindness</p>	<ul style="list-style-type: none"> <li>• Treat adults with ID as you would like to be treated, and avoid treating them as if they are inferior simply because they have a disability.</li> <li>• Be sure to take time to understand the adult’s perspective and understand what is important to them.</li> <li>• <a href="#">Using plain language</a> is helpful, but remember that you are talking to an adult and not a child.</li> </ul>

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*“You probably already have ideas about what people with disabilities can do. You might be wrong. Be open to learning what people with disabilities can do.”*  
*-Adult with ID*

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Prioritize the Client	<p>Prioritize and always consider the adult with ID's preferences. The adult with ID is the client and should be centered in treatment decisions.</p> <p>When the client's perspectives, priorities, or values differ from those of his/her support people (e.g., parents, paid staff, or guardian), listen to contradictory information but remember that the adult with ID is your client.</p>
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*"I want my client to know that I'm advocating for them. And yet, I also want to have enough compassion for their support person, whether it's a family member or a staff person to know that I'm not opposing them." -Clinician*

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Choose Appropriate Materials	<p>Choose appropriate materials based not only on the individual's language level and/or cognitive level, but also considering their age [23]. Avoid Infantilizing [24]; that is do not treat an adult with ID like a child. This denies their maturity and experience, which they may find offensive.</p>
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# Promote Self-Determination and Empower Clients to Self-Advocate

A core tenant of interventions for individuals with ID is improving supports to enhance their functioning in and engagement with their environment. This helps them thrive and have meaning and value in interactions. To do this effectively, they should be their own agent of change. Two important concepts that address this in the field of ID are self-advocacy and self-determination. Self-determination is different from self-advocacy, and it is important to support both self-determination skills and self-advocacy skills in therapy and their generalization outside of the therapy session.

Self Determination	<p><b>Self-determination</b> is defined as a dispositional characteristic manifested as acting as the causal agent in one’s life.</p> <ul style="list-style-type: none"><li>• Self-determined people (i.e., causal agents) act in service to freely chosen goals.</li><li>• Self-determined actions enable a person to be the causal agent in his or her life [25].</li></ul> <p>To become self-determined, one’s motivations and needs must be acted upon. [25]</p> <p>In other words, a client is able to set and accomplish their own goals without undue external influence or interference.</p> <p>The literature suggests that when we teach self-determination skills, we increase the quality of life of the individual. This includes individuals with both intellectual and developmental disabilities [26].</p>
Self- Advocacy	<p><b>Self-advocacy</b> is then the next step of having one’s own knowledge of self and what is right, communicating these values, and engaging in leadership [27].</p>

<p><a href="#"><u>Supported decision making</u></a></p>	<p><b>Supported Decision Making</b> a practice that helps individuals with disabilities make decisions that affect their lives.</p> <ul style="list-style-type: none"> <li>• Support the use of a variety of supported decision-making interventions.</li> <li>• Supported decision-making interventions can be used as a way to promote self-determination in the individual even when a guardian is in place [28].</li> </ul>
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Deliberately and concretely teach self-advocacy and self-determination skills, including 1.) understanding one’s own strengths and needs, and 2.) teaching them to use assertive language.

**Strategies**

<p>Supporting and Promoting Self-Determination in Therapy</p>	<p>When working with clients, it is important to:</p> <ol style="list-style-type: none"> <li>1. Empower clients to set and accomplish their own goals; help individuals determine freely chosen goals and giving them strategies to accomplish their goals and set new ones.</li> <li>2. Empower adults with ID to have agency in the therapeutic process by providing choice and control to them whenever possible.</li> <li>3. Empower clients with ID to make decisions regarding confidentiality and disclosure.</li> <li>4. Use modeling and role-playing in sessions.</li> </ol>
<p>Supporting and Promoting Self-Advocacy</p>	<ol style="list-style-type: none"> <li>1. Teach clients with ID to advocate for themselves in their lives, providing tools and practice so that the client is able to speak up for themselves.</li> <li>2. Use modeling and role-playing in sessions</li> <li>3. After practicing via role play, have the client explain something from therapy to their support person at the conclusion of therapy.</li> </ol>



Understand the [multicultural component of self-determination](#) and how culture may impact one's ability to be self-determined. Some questions to consider include:

- In the client's culture, would the client be defined as the individual, family, or community?
- How does an individual's culture impact their values and needs?
- How is autonomy expressed in one's culture (e.g., differences in individualist and collectivist cultures)?

\*\*\*It is helpful for clinicians to reflect on their own beliefs about a person's competence and perhaps unintended manipulation and coercion usurping decisions and choices.

### **Resources on Self-Advocacy and Self-Determination:**

The University of Kansas is a national resource in self-determination intervention and assessment. The University of Kansas has developed a variety of [resources](#) related to self-determination, intervention, and assessment.

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*During a focus group a clinician spoke of the power of the client "...being self-directed and having somebody who is focusing on and facilitating their own problem solving, based on their own perceptions of their own environment."*

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# Involve Support People

Involving support people in therapy can be useful. Support people can help to facilitate communication, putting the client at ease [1]. They can have a key role in helping the client generalize lessons learned in therapy to their wider life. Additionally, the therapist's involvement in the client's life is limited; support people will likely provide support to the individual after the completion of therapy. Additionally, when attending therapy alongside the client, the support person may learn ways of helping the client to cope emotionally.

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*"I have had at least one client where their support person took pictures of all of the stuff we were working on so that they could bring it up on their phone, and they could say, 'hey remember we were talking about this.'" -Clinician*

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Potential Support People	<p>Adults with ID vary in the amount of support they need and on whom they rely to provide support.</p> <ul style="list-style-type: none"><li>• Support people could be a family member such as a parent or sibling, or it may be a close friend.</li><li>• Others may have direct support professionals (DSPs) who assist with various supports.</li><li>• This could range from occasional advice, transportation, or more intensive live-in support. All is based on the individual's support needs.</li></ul>
Special Considerations	<ul style="list-style-type: none"><li>• Be sure that permission to include support people is given by the client and then <b><u>regularly check in to ensure the client has not changed his or her mind.</u></b></li><li>• Empower the client to choose who they involve in therapy, when, and to what extent. For example, it may be necessary to have individual, one-on-one sessions without the support person to check in. <b>This may be especially important if there is a concern for a history of abuse or neglect; certain lines of questioning are best done one-on-one.</b></li></ul>

	<ul style="list-style-type: none"> <li>• Be thoughtful in how and when support people are included in therapy.</li> <li>• Be sensitive to the potential for abuse which may be perpetrated by the support person.</li> </ul>
Consider “pre-session for psychoeducation and planning	<p>If the client chooses to include their support people, consider a “pre-session” with the individual, support people, and referral agency. During this pre-session the clinician can:</p> <ul style="list-style-type: none"> <li>• Provide psychoeducation on mental health and therapy, including exploring what psychotherapy is and describing the role of the clinician.</li> <li>• Enlist support people in promoting mental health rather than “addressing a problem”.</li> <li>• Provide a plain language description of your approach to psychotherapy.</li> <li>• Work with support people and client to set appropriate expectations for therapy.</li> <li>• Work with support people to help increase the client’s <a href="#">self-determination</a> in sessions and in their lives.</li> <li>• Differentiate the client’s needs and goals from those of the support person.</li> </ul>

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*One clinician shared that they explicitly asked about caregiver’s goals so they can differentiate the client’s needs from those of the support person’s: “I distinctly separate. ‘What are your caregiver’s goals for you being in treatment?’ and making sure that those are separate.”*

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Ways to Include Support People	<p>Support people can assume various roles during and between sessions. This can include:</p> <ul style="list-style-type: none"> <li>• Facilitating communication and understanding between the clinician and the client.</li> <li>• Promoting the generalization of skills to home and other settings.</li> </ul>
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	<ul style="list-style-type: none"> <li>• Supporting the client in developing, practicing, and maintaining treatment strategies.</li> <li>• Supporting client to collect data on mood, and/or reporting on successes.</li> </ul>
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<p>Be Mindful of Staff Turnover</p>	<p>While you may have set an expectation to have a consistent support person engage in the client’s therapy, be mindful of the very high rate of support staff turnover.</p> <p>It would be prudent to have plans in place in case a support staff leaves their position abruptly.</p> <p>Abrupt changes in support staff may be perceived as a significant loss or even trauma by the client with ID. Address any subsequent grief, distress, or trauma within the therapeutic process.</p>
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# FOUNDATIONAL CONCEPTS OF THERAPY

## Assessment

Assessment is a key foundational aspect of therapy. Assessment at the start of and throughout therapy can be helpful for clinicians to meet the client where they are. Assessment of client's needs and preferences can help guide planning for the structure of therapy, inclusion of support providers, communication, and adaptations. Measurement of symptoms as well as real life outcomes assist to determine therapeutic change and outcomes.

### Informants

Client self-report is key in the assessment and monitoring processes [29]. This is especially true in mental health assessment because many psychiatric symptoms are internal and can only be understood with direct input from the individual. Additionally, their participation can reinforce self-determination and promote their engagement in the therapeutic process.

Supporters can be allies in measuring and reporting progress towards goals and outcomes. There may be existing data and information that supporters have that could be integral to the therapeutic process. When determining how to interpret information provided by supporters it is important to keep in mind the supporter's role and relationship with the individual.

### When to assess

As Part of the Intake Process	Conducting assessments with clients with ID at the outset of therapy can assist with understanding the client's: <ul data-bbox="492 1602 1323 1864" style="list-style-type: none"><li>• Strengths</li><li>• Areas for growth</li><li>• Support needs</li><li>• Preferences</li><li>• The environments within which they live, work, and socialize</li></ul>
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<p>Progress Monitoring and Goal Attainment</p>	<ul style="list-style-type: none"> <li>• Assessment may also be helpful in determining to what extent the client is meeting goals, or feels they are meeting their goals.</li> <li>• Check in frequently with the client about how they feel therapy is progressing and what can be done differently to continue to inform the structure of therapy.</li> <li>• Continuous progress monitoring has been found to improve psychotherapy outcomes and reduce therapy dropout.</li> </ul>
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## What to assess

<p>Biological-psychological-social history</p>	<p>The biopsychosocial model of care emphasizes conceptualization of the overlap of social, psychological, and physical health in assessment and treatment.</p> <p>One way to assess these factors in care is through use of the ‘five Ps’ [86], [87], which include assessing the individual’s:</p> <ol style="list-style-type: none"> <li>1. Presenting issues or problems</li> <li>2. Predisposing factors that have led to the problem(s)</li> <li>3. Precipitating factors that trigger the problem(s)</li> <li>4. Perpetuating factors that keep the problem(s) going</li> <li>5. Protective factors that prevent the problem(s) from escalating</li> </ol> <p>Another helpful tool is the <b>AAIDD-Informed Cognitive-Behavioral Case Formulation Resource</b> developed Sauter and colleagues [60] which provides a framework to consider:</p> <ul style="list-style-type: none"> <li>• Intellectual functioning,</li> <li>• Adaptive behavior,</li> </ul>
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	<ul style="list-style-type: none"> <li>• Health,</li> <li>• Participation</li> <li>• Context can help to guide this process</li> </ul>
Strengths and areas of needed support	<p>It is key that the clinician have a clear understanding of an individual’s strengths and areas of needed support and/or growth related to:</p> <ul style="list-style-type: none"> <li>• Receptive and expressive language (See <a href="#">Communication Section</a> for more details)</li> <li>• Cognitive and adaptive functioning,</li> <li>• Social skills,</li> <li>• Problem solving, and executive functioning.</li> </ul> <p>This may be achieved via record review or direct assessment.</p>
Individual’s Environment	<p>Assessment of the environment may include:</p> <ul style="list-style-type: none"> <li>• How the individual interacts with those in their life,</li> <li>• Levels of support in place,</li> <li>• Amount of choice and agency individual has at home, work, and other environments.</li> </ul> <p>Assessing the environment of the adult with ID can help clinicians identify:</p> <ul style="list-style-type: none"> <li>• Existing support that could be leveraged to improve therapeutic outcomes,</li> <li>• Opportunities to change the environment to support mental health.</li> <li>• Determine the extent to which support people may be included in therapy.</li> </ul>
Psychiatric Symptoms	<p>To inform diagnosis and monitor symptoms, standardized measures are recommended to assess for psychiatric symptoms presence and severity (see <a href="#">Assessment Tools</a> section below).</p>

	<ul style="list-style-type: none"> <li>• Other key information can assist in diagnostic and treatment planning include: <ul style="list-style-type: none"> <li>○ When was concern in first noted?</li> <li>○ What was behavior of concern? What is frequency and severity of behavior/symptoms?</li> <li>○ Where is it occurring?</li> <li>○ Have there been changes in sleep, eating or activities of daily living?</li> <li>○ Are their patterns?</li> </ul> </li> </ul>
<p>Treatment Goals/Therapeutic process</p>	<p><b>Work collaboratively with the individual to develop goals and monitor progress.</b></p> <ul style="list-style-type: none"> <li>• Monitor therapy progress continuously, using measures that have been developed or adapted and evaluated in individuals with ID [30].</li> <li>• Another option might be to use Goal Attainment Scaling (GAS), a method for writing personalized evaluation scales in order to quantify progress toward goals defined by the client [31]–[33].</li> </ul>
<p>Quality of life, and Overall well-being</p>	<p>Consider measuring positive well-being indicators when considering outcome of therapy. These can include:</p> <ul style="list-style-type: none"> <li>• Adaptive skills,</li> <li>• Self-esteem,</li> <li>• Participation in community and/or home life</li> <li>• Quality of life</li> <li>• Social skills/interpersonal challenges</li> </ul>
<p>Clinician self-assessment</p>	<p>Consider assessment your own utilization of adaptations.</p> <ul style="list-style-type: none"> <li>• Are you consistent?</li> <li>• Do you seek and respond to client’s feedback?</li> <li>• Do you provide adequate opportunity for the client to feel a sense of agency and empowerment in the therapeutic process?</li> </ul> <p>Just doing quick checks in sessions can help to asses this.</p>



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*“My therapist actually always asked me why I was there and always asked me how she could help me more.” -Adult with ID*

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### **Assessment Tools validated in ID Populations**

Whenever possible use instruments developed for/adapted for/validated in the ID population.

Typically, instruments designed for adults with ID use simplified wording and simplified response formats, often with fewer choices and additional pictorial representations to illustrate or clarify response options. Most measures are either read aloud or have the option to be read aloud by the clinician.

There are numerous ID-specific [assessments of psychiatric symptoms](#). The Glasgow Depression (GDS-LD; [34]) and Anxiety Scales (GAS-ID; [35]) were developed for adults with ID and prove sensitive to change [30]. Contact the authors for copies of these scales. An additional measure for assessing anxiety and depression as outcomes of therapy, as well as risk to self and others, is the Clinical Outcome Routine Evaluation-Learning Disabilities 30-Item ([CORE-LD30](#); [36]) [37].

Other instruments include the Psychiatric Assessment Schedule for Adults with Developmental Disabilities ([Mini PAS-ADD](#); [65]), the Brief Symptom Inventory ([BSI](#); [66]) [67], and the Psychological Therapies Outcome Scale for People with ID (PTOS-ID; [68]). These assessments can be used for screening and assessment of broad psychiatric symptoms (anxiety, anger, depression, interpersonal well-being, and psychological well-being). Additionally, more targeted assessments are available. The [Novaco Anger Scale and Provocation Inventory](#) have been adapted to assess for anger responsivity and arousal to a range of situations for those with ID [69].

Though more research is warranted, three promising measures of assessing symptoms of **trauma and PTSD** in adults with ID are The Lancaster and Northgate Trauma Scales (LANTS; [79]) which can be accessed by contacting Sarah Wigham, the International Trauma Questionnaire (ITQ; [80]) and the Impact of Event Scale-Intellectual Disabilities (IES-IDs; [81]), which can both be accessed by contacting Dr. Langdon.

**Quality of life assessments** include the combined WHOQOL-BREF and WHO Quality of Life – for persons with disability ([WHOQOL-Dis-ID](#);[70]), Warwick–Edinburgh Mental Wellbeing Scale-Intellectual Disability version [46], and the measure Personal Wellbeing Index-Intellectual Disability ([PWI-ID](#); [71]).

### **Assessment Adaptations**

When validated scales are not available, clinicians may need to adapt instruments by providing appropriate accommodations to ensure the assessment is cognitively accessible. Assessment accommodations may include reading items out loud, translating items to more simple language (e.g., reducing sentence length, omitting unnecessary words, removing double negatives, and making abstract language more concrete), shortening forms by eliminating items, simplifying and offering fewer response options, giving examples, and using visual aids [72]–[75]. This [adapted version](#) of the PHQ-9 and GAD-7 provide examples of assessment adaptations. See the [accommodation guideline](#) for additional details.

### **Additional sources of information**

In addition to direct assessment, collateral information can be collected to assist with treatment planning and evaluation of progress. This could include previous psychological or other reports, as well as information from support people. However, it is important to consider how well the person providing collateral information knows the client and to consider if they may have differing therapy goals.

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*"It is not always easy, but it is certainly always important to get self-reported information about the wellbeing of individuals with intellectual disability."*

*-Clinician*

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# Communication

Communication is a key aspect of building rapport and the therapeutic process. Being thoughtful in the use of language that is accessible to the client based on their receptive and expressive strengths and areas of needed support is critical.

Clients will likely have varied levels of support and accommodations needs to be considered. Be aware that client receptive (listening skills) and expressive (talking, picture exchange, typing, etc.) communication may not be at the same level [31]. For example, a person may understand more communication than they express through spoken words. Conversely, someone might be quite talkative, but have difficulties comprehending the communication of others.

## Language and Communication Assessment

Use **formal** and **informal** assessments to identify language and communication strengths and areas for support. Knowledge and language ability and preferences can be used to help guide communication accommodations in adults with ID, including language modifications, choice of homework materials, and intervention strategies [53].

Informal Communication Assessments	<p>Consider the individual's communication needs throughout every phase of treatment.</p> <ul style="list-style-type: none"><li>• Ask clients to describe receptive and expressive communication preferences at intake.</li><li>• Ask about current and previous use of <a href="#">augmentative alternative communication (AAC)</a> devices.</li><li>• Observe the client's verbal and non-verbal communication and flexibly adapt to this information by intentionally matching communication complexity and specific words to the client.</li><li>• Involve the support person and client in conversations about current supports used/needed, such as asking about accommodations received in school or work [27].</li><li>• Frequently check with client to ensure understanding</li></ul>
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Formal Communication Assessment	<ul style="list-style-type: none"> <li>• Use a standardized test of language. <ul style="list-style-type: none"> <li>○ For example: The <a href="#">Test for Reception of Grammar</a> (TROG-2 [34]) is an assessment of receptive understanding of grammatical structures</li> </ul> </li> <li>• Ask for previous speech and language assessment reports.</li> <li>• Adaptive Behavior assessments such as the <i>Adaptive Behavior Assessment System -Third Edition [55]</i> have communication sections that can also be used.</li> </ul>
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### Inclusive Communication and Word Usage

Clinicians can promote [inclusive language](#) in professional communication by using appropriate person- or identity-first language as preferred by the client. Recent recommendations on language use for broader audiences include using person-first and identity-first language interchangeably, which may be especially relevant when conducting group therapy [27]. Since language evolves over time, it is most respectful to ask the client their preference.

Determine preference of person-first or identity first language	<p>Clinicians can promote <a href="#">inclusive language</a> in professional communication by asking the client’s preference for person- or identity-first language.</p> <ul style="list-style-type: none"> <li>• Person-first language first (e.g., person with an ID, person with a mental health condition) is said to be used to reduce stigma by putting the person before their disability (e.g., disabled women; autistic man)</li> <li>• Disability- first language (e.g., autistic individual, disabled client) can increase one’s pride and ownership of the disability, recognizing its strengths and emphasizing community membership as a source of empowerment [27]–[29].</li> </ul>
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<p>Other word use considerations</p>	<p>Consider the language around how you refer to the person with whom you are working.</p> <ul style="list-style-type: none"> <li>• The term ‘client’ is often preferred to ‘patient’ in the therapy realm. While widely used, both terms can have negative connotations and can lessen one’s view of the person, mitigating an individual’s agency and autonomy [30].</li> <li>• Consider other terms, such as ‘person’, ‘individual’, ‘person/individual you are serving’, or ‘participant’. The recommended practice is to always ask the client their preference.</li> </ul>
<p>Be mindful of stigmatizing or ableist terminology</p>	<p>Words that and could be considered stigmatizing, ableist, or condescending include terms such as “special needs” “MR” “retarded.”</p> <p>While aligning with the client’s language is typically important for alliance, do not appropriate ‘insider terms’ that a client may use to reflect broad disability pride (e.g., crip, para) [27]. These types of terms tend to be used most by people with mobility or sensory impairments.</p>

**Communication Strategies and Considerations**

Communication should happen in the way that works best for the client. Clinicians are encouraged to understand the person's language skills and modify language that correlates with the level used by the client. Ensure that the adult with ID is in the focus and an included partner in conversations.

<p>Communication Strategies</p>	<ul style="list-style-type: none"> <li>• It can be helpful to break down more complex concepts and make them more concrete when possible.</li> <li>• Give clients with ID adequate, and <b>additional time</b>, if necessary, to formulate an answer when asking questions. Clients with ID value clinicians who allow adequate time for clients to respond to questions.</li> <li>• Take time to actively listen to what the client says. Be patient and do not interrupt.</li> <li>• Techniques such as rephrasing and summarizing what client said to confirm understanding also demonstrates that you are listening and really want to understand.</li> <li>• Limit the proportion of questions/comments directed to the support person.</li> <li>• It is advisable to incorporate any assistive technology that a client has, such as an <a href="#">augmentative alternative communication (AAC)</a> device. AAC includes all communication an individual may use in addition to talking (e.g., writing, drawing, spelling, using an application on an iPad, speech-generating devices). Encourage use of AAC and allow time for responses via AAC.</li> <li>• Additionally, providing materials for the client to review between sessions and prepare for upcoming sessions can help.</li> </ul>
<p>Written communication</p>	<p>Use <a href="#">customized universal design</a> supports, including bolded lists, plain language (clear, short sentences; ask one question at a time, pause for processing), and mobile applications. (See <a href="#">accommodations</a> section for more details).</p> <p>The <a href="#">Books Beyond Words</a> series have a number of helpful print resources.</p>

# Build and Maintain Clinical Relationship

Therapeutic alliance is a powerful predictor of intervention success and long-term outcomes [36], [37]. The alliance is widely understood as a collaborative relationship between therapist and patient that is influenced by the extent to which there is **agreement on treatment goals**, a **defined set of therapeutic tasks or processes to achieve the stated goals**, and the **formation of a positive emotional bond** [62].

Clients with ID share that alliance is important to them, especially having the opportunity to be collaborative in making decisions (e.g., goal-setting), developing trust in a safe relationship, having a strong connection with the clinician, and having the space in therapy to talk through problems [63], [64].

<p>Understand potential barriers to therapeutic relationship</p>	<p>Fostering a strong alliance is especially important when conducting therapy with clients with ID who often face discrimination and ableism.</p> <p>Clients may have difficulties trusting others due to previous negative experiences in relationships [38], [39] and previous experiences with clinicians and other professionals.</p> <p>These experiences can lead to a pattern of deferring to others (e.g., agreeing/saying yes more to others) and being passive in communication [40].</p>
<p>Building Trust</p>	<p>Generally, building trust takes more time with a person who has ID as compared to a person without ID. Non-traditional methods can be therapeutic as a means to establish a trusting relationship.</p> <ul style="list-style-type: none"> <li>Assess the unique needs of each person and employ strategies using their strengths and preferences to guide interactions.</li> </ul>

	<ul style="list-style-type: none"> <li>• Use interests to build the relationship between the clinician and client and incorporate interests when teaching new concepts.</li> <li>• For example: If clients love dogs, consider including dogs as examples of therapy concepts or in therapy worksheets.</li> <li>• You may choose to self-disclose more to connect with client’s interests and build a genuine relationship on shared interests.</li> </ul>
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*“I will take more time on the front end just getting to know somebody, especially doing a lot of listening. Again, this is a population that is talked to a lot and so find out what their personal interests are and listening to them and connecting with them on a personal level—I think is really important before moving on to the personal parts and therapeutic parts of treatment.” -Clinician*

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*“I use a lot of activities to engage people and to be comfortable to have a conversation we play games and we listened to music.” -Clinician*

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<p>Emphasis on trust, integrity, and respect</p>	<p>Treat the person with an ID as an equal with integrity and respect.</p> <ul style="list-style-type: none"> <li>• Create an environment where individuals with ID have a safe place to talk with someone who listens to them and values what they have to say.</li> <li>• Structure therapy to maximize participation and comfort.</li> <li>• Communicate investment in the person as a whole through verbal and nonverbal communication and behavior. <ul style="list-style-type: none"> <li>○ Show your full attention when listening to the adult with ID.</li> <li>○ Rephrasing or summarizing what the client says to confirm you understand can demonstrate to the client that you are listening and want to understand.</li> </ul> </li> </ul>
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*“I would have sessions with therapists and teach them how to treat people with disability on equal grounds.” -Adult with ID*

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*“Modeling for them the way that we would hope they'd be treated in the world.”  
-Clinician*

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Collaboratively  
working to  
achieve goals

Emphasize collaboration and balance in sustaining and contributing to a shared dialogue [41].

Meet clients where they are linguistically and cognitively; structure therapy to maximize their participation and comfort based on this information.

Be responsive to different preferences and be willing to try out different approaches.

Reinforce that they have their own voice and empower them to make their own choices by frequently asking them their perspective on treatment goals, their progress, and their opinions. This helps to communicate to the client that what they think and feel is important.

**\*\*Subsequent sections of this document will also provide additional examples of how to continue to build a therapeutic alliance with clients throughout the therapeutic process.**

# Accommodations and Support within Therapy

***There is very little data on the relative effectiveness of one accommodation over another; therefore, use of accommodations should be evidence-informed AND informed by client assessment and preferences.***

Many accommodations are described in the literature and have some support as a part of larger treatment manuals/packages. Many adults with ID prefer visual supports, but others may have visual impairments or find verbal information or kinesthetic activities more helpful.

Visuals	<ul style="list-style-type: none"><li>• Handouts with plain language (see plain language recommendations below) and adjusting spacing for differences in handwriting sizes [68].</li><li>• Many adults with ID use text to speech technology to assist with reading, which requires specific formats.</li><li>• PowerPoint presentations with pictures illustrating key point of each therapy session [69].</li><li>• Actively creating dynamic supports via white boards, diagrams on paper, event mapping, or flipcharts with visuals [70].</li><li>• Videos (e.g., of individuals with ID) [71].</li><li>• Pictorial representations of emotions and concepts including colored stoplights (red, green), using a colored paper chain to demonstrate behavior chaining, or simple faces depicting emotions (e.g., adapting daily mood diaries by adding emotion faces that the individual can circle) [46].</li><li>• Be creative about adapting workbooks/materials and develop unique visuals according to the preferences of each client (e.g., drawing or photography). For example, you could color-code content with three colors corresponding to past, present, and future, or have photographs and drawings on a page and have the client put their experiences into words next to that [47].</li><li>• Visual reminders to work on a task that the client can take with them (e.g., silicone bracelets to remind the client to practice a skill, rubber balls to remind client of resiliency, notecards, journal).</li></ul>
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*“It’s hard for me to read stuff with lots of words feels like that overwhelmed feeling...I like pictures, you know, that’s what helps me learn.” -Adult with ID*

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Auditory	<ul style="list-style-type: none"><li>• Record audiotapes to be sent home with clients [48] or recording audio on the client’s phone.</li><li>• Read forms aloud to clients [35], [49]–[51].</li></ul>
Multi-Sensory	<ul style="list-style-type: none"><li>• Combine visuals and movement to concretize concepts (e.g., to help clients overcome barriers and achieve goals, write goals on cards and then place them on the ground to represent stepping stones [52].</li><li>• Combine visuals and auditory instruction while doing an activity (e.g., placing a dot on the shoe of the client to encourage them to concentrate mindfully on their feet [53]).</li><li>• Teach CBT concepts through <a href="#">games</a> that include social stories [54].</li></ul>

When using any type of accommodation or visual support, ensure that [plain language](#) is used and that the document is accessible regarding not only content, but also text. Plain language clearly communicates exactly what the client needs to know without using unnecessary words or expressions. Some clients may prefer calling it “clear” or “easy read” language. The [National Institutes of Health](#) and [Center for Plain Language](#) have plain language [checklists](#), resources, and before and after examples for guidance on adapting materials for clients. Additionally, [Easy Health](#) has free [easy read](#) documents explaining different medical procedures and other health related topics.

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### **Plain Language Adaptations for Therapy Handouts and Workbooks**

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Visual formats that provide a combination of text and media or graphical organization of information.

Limit the reading level to or below the 6<sup>th</sup> grade level. [Flesch-Kincaid is a readability statistic available in Microsoft Word.](#)

Avoid/reduce the number of metaphors, avoid difficult words, and use short sentences.

Format text using **emboldened**, underlined, **highlighted**, CAPITALIZED and/or color-coded text to **EMPHASIZE** or enhance information.

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Add alternative text to images, which describes images, icons, charts, and other visual information.

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Use web accessibility features that leverage alternative text, plain text, Word document styles, and other means to be accessible to assistive technology, such as screen readers.

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Use a larger font size (e.g., 16+ point), which supports readers with low vision.

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### **Physical accessibility**

In addition to accessible language and communication, the physical space needs to be accessible. Please refer to the [American Psychological Association Guidelines for Assessment and Interventions for Persons with Disabilities](#) for a more detailed discussion of physical accessibility.

### **Teaching prerequisite skills**

It may be helpful to engage in a preparatory period at the onset of therapy assessing and teaching foundational knowledge and skills that the client will need to appropriately participate in the chosen therapeutic approach. This will increase the likelihood that the individual understands CBT concepts and their ability to engage in treatment. This could include teaching specific skills or breaking some concepts down so they can be understood prior to the individual having to apply them to themselves and the therapeutic process.

<p>Prerequisite Skills to Consider</p>	<p>The client and their support people should have a clear understanding of what therapy is and what it is not. Psychoeducation at the beginning of treatment can be helpful to teach or reinforce:</p> <ul style="list-style-type: none"><li>• The components of therapy,</li><li>• The boundaries of therapy (e.g., how therapy differs from a social relationship),</li><li>• Appropriate and reasonable expectations of the impact of therapy.</li></ul> <p>There are several basic therapy concepts/skills that are often seen as prerequisites to participating in traditional talk therapy [9].</p> <p>This can include:</p> <ul style="list-style-type: none"><li>• Emotion/mood identification,</li><li>• The connection between mood and behavior,</li></ul>
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	<ul style="list-style-type: none"> <li>• Specific terminology.</li> </ul> <p>Allow extended time to teach and model the identification and labeling of emotions.</p>
Special Note	<p><i>It may be possible that some individuals with more significant intellectual disability may not be able to learn all the prerequisite skills to participate in traditional talk therapy.</i></p> <p><i>For example, research has suggested that it is difficult for some adults with ID to connect thoughts, behaviors, and mood; however, the connection between behavior and mood seems to be an easier concept for some [80].</i></p> <p><i>Determining this at the onset will help to guide treatment approach.</i></p>

## Manuals

Using manuals of adapted interventions when available can be helpful (e.g., [CBT for ID](#)). There are a number of helpful tools that exist; however it is important to note that there is limited data on efficacy. We are including some that have some level of research support for therapist reference. For individuals with ID and co-occurring depression, adapted interventions include the behavioral activation intervention [Beat-It](#) [42], a guided self-help intervention [StepUp](#) [43], and Mindfulness Based-Cognitive Behavioral Therapy (MB-CBT; contact [Helen Idusohan-Moizer](#)). Additionally, Trauma Focused- Cognitive Behavioral Therapy (TF-CBT) has been adapted for individuals with mild ID and PTSD (manual available by contacting [Biza Stenfert Kroese](#)). Mindfulness interventions also have some support [78]. While many evidence-based treatment packages follow a CBT orientation, the adaptations and accommodations described below can be used for most types of psychotherapies.

# THERAPEUTIC PROCESS

## Structure of Therapy and Goals

Structuring therapy may require additional considerations of the client's strengths and support needs. It is beneficial to both clinicians and clients to explicitly communicate with clients about the use and type of accommodations which will enable them to participate fully in therapy. Keep in mind barriers due to cognitive limitations, visual impairments, gross or fine motor impairments, etc.

Informed Consent and Authorizations	Therapy should begin with obtaining informed consent. Consideration should be given to how this is approached with the individual and what necessary accommodations might be useful. These can include: <ul style="list-style-type: none"><li>• Providing a clear language version of informed consent</li><li>• Providing consent ahead of time to ensure client has adequate time to understand.</li><li>• Regularly communicate with clients about any changes in their preferences to promote ongoing consent, particularly regarding involvement of support people in therapy.</li></ul>
Psychoeducation on Therapy	Be mindful of taking the time needed to explain the purpose of therapy to clients, which may include concrete discussions of: <ul style="list-style-type: none"><li>• Privacy expectations,</li><li>• boundaries (e.g., how therapy differs from a social relationship), and</li><li>• Types of techniques used in therapy.</li></ul>
Assessing motivation and/or understanding	Understand the client's motivation to participate in therapy and discuss their goals. <ul style="list-style-type: none"><li>• Understanding the client's interest in therapy is key because adults with ID are often referred to therapy by support people or other clinicians.</li></ul>

of reason for referral	<ul style="list-style-type: none"> <li>• It can be helpful to ask them why they think they were referred to therapy to assess their perspective and motivation.</li> </ul>
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**\*\*Processes and questions such as these are essential to building rapport, setting a precedent for clear and open communication, and educating the client about what the therapeutic process is so that both clinician and client are on the same page and able to work together to establish treatment goals and plans.**

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*“I often say, ‘you’re not here because you’re in trouble’, because I think people often feel that way because they did something wrong, so now they’re here...but also...telling them what therapy is and isn’t--how it is different than a social relationship, you know. I’m not going to come to your house for supper, but I’m here to help you and you don’t have to help me, and kind of defining those boundaries more.” -Clinician*

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**Considerations when altering the structure of sessions:**

Therapy Structure Considerations	<ul style="list-style-type: none"> <li>• You may have to allow more time to build trust and rapport with the client before beginning therapeutic content.</li> </ul> <p>Use clinical judgement as to when to take a more directive approach.</p> <ul style="list-style-type: none"> <li>• While for some clients being less directive and more collaborative can benefit rapport, sometimes being more directive can be helpful.</li> <li>• For example, asking open-ended questions (e.g., reflecting on the last week; asking what they want to address today) puts the onus on clients to organize potentially long narratives that might be challenging.</li> <li>• For some clients, this expectation may be overwhelming and unwelcome.</li> <li>• Taking a more directive approach in defining structure can enhance the client’s comfort.</li> </ul>
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Including support people within therapy and planning of therapy can be helpful. Give specific thought as to how and when to include support people (See [support people](#) section)

- Be thoughtful about when it's appropriate to invite support people to sessions and ask the client their permission first.
- It may be helpful to ask support people about the best way to pose questions and structure time.

You may have to be flexible in sessions and make them more individualized. To determine the need for this, go slowly and do discriminative exercises to see which would work best. You may consider:

- Being flexible about types of therapeutic approaches.
- Adapting the length of sessions for optimal session lengths (i.e., shorter or longer).
- Ensure sufficient time in sessions to process questions.
- Consider conducting home visits

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“I don't think I have found one approach that works best. I consider the person and I really have to try to structure it around what I think can be best for them.” -

*Clinician*

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# Trauma History

Adults with ID report experiencing prejudice and stigma [76] and are at increased risk of violence [77], [sexual assault](#), and abuse compared to adults without ID. Up to 75% of adults with ID report a traumatic event in their lifetime [78]. It is advisable to assess for the history of distressing events and symptoms of post-traumatic stress disorder (PTSD). Even if trauma was not the reason for referral, it is important to understand if the client has a history of traumatic stress or other adverse experiences and if those experiences might be contributing to the current concerns.

**There is variability in trauma and what is experienced as traumatic.** It is important to note that many people with ID have experienced distressing events that may impact each of them uniquely and/or differently than expected. It is important for clinicians to understand that what a neurotypical person might experience as a moderate life stressor could be, for an individual with ID, a major traumatic event. For example, if the client has had a break-up with a significant other this could be for them a major life stressor and traumatic loss. Common sources of trauma include accidents, assault, neglect, and abuse. However, other traumatic events in the lives of adults with ID may include losing part of one's support system, medical procedures, or not having access to a support person in a time of stress or natural disasters.

## Assessment

Assessment of very sensitive topics, such as trauma, are best addressed within a secure and trusting therapeutic relationship. Consider informal assessment as well as formal assessment of trauma and PTSD (See [Assessment](#) Section for details). It is important to note that the client may be experiencing significant stress associated with an experience but have difficulty understanding or communicating the connection between the event and their feelings. Informal methods such as observing body language and communication changes may help clinicians understand potential traumatic stress experiences and the impact on the adult with ID.

Therapy can play an important role in addressing the trauma that adults with ID experience.	Focus group participants with ID emphasized:
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	<ul style="list-style-type: none"> <li>• The importance of having someone to talk to about trauma,</li> <li>• Engaging in trauma resolution,</li> <li>• Learning to understand what is safe and not safe,</li> <li>• Learning ways to reduce stress [64].</li> </ul>
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*“My therapist is trying to help me heal up those wounds that have been hurting.”  
-Focus group participant with ID*

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Addressing the Environment	<p>Providing some psychoeducation to support people can be beneficial to ensure they can adequately support the adult with ID.</p> <ul style="list-style-type: none"> <li>• The impact of trauma</li> <li>• How to set up an environment to be trauma informed.</li> </ul> <p>It will also be important to educate the client on how the environment and things in the environment may act as trauma triggers for the individual.</p>
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*“The client maybe hasn't done much changing, but perhaps the environment around them and the staff around them and the folks who are supporting them have become more trauma- informed and have responded to and are responding to them better...their environments change such that they're not under such intensive stress.” -Clinician*

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# MEDICAL CONSIDERATIONS

## Physical Health and Primary Care

Individuals with ID have higher rates of medical conditions than the general population. They experience more short-term and chronic illness, including neurological, cardiovascular, dermatological, and digestive issues [83]. These physical conditions can have a profound impact on the client's mental health. And certain behaviors, habits, and mental health symptoms can also adversely impact an individual's physical health.

<p>Consider Underlying health conditions and their impact</p>	<p>Some health conditions mimic the signs and symptoms of mental health conditions. Therefore, it is key to consider and thoroughly assess non-psychiatric explanations for behavior change or distress.</p> <p>Underlying health conditions can be significant contributory factors associated with the presenting concerns [85]. These can include:</p> <ul style="list-style-type: none"><li>• Infections,</li><li>• Dental concerns,</li><li>• Thyroid dysfunction,</li><li>• Gastrointestinal Issues</li><li>• Menstrual cramps, among others,</li></ul> <p>Epilepsy and dementia are especially common in adults with ID [84].</p>
<p>Assessment</p>	<ul style="list-style-type: none"><li>• As noted in the <a href="#">assessment</a> section above, the biopsychosocial model of care emphasizes conceptualization of the overlap of social, psychological, and physical health in assessment and treatment.</li></ul>

- It is important to cooperate with primary care providers who may be monitoring medications for psychiatric and other medical conditions.

## Cooperating with Psychopharmacology

Although nonpharmacological interventions are often effective for most mental health conditions in ID, some individuals will need additional support in the form of medication.

Principles of Medicating adults with ID	<p>Such cases can be referred to a physician who is versed in the following principles of medicating adults with ID and co-occurring mental health conditions, such as:</p> <ul style="list-style-type: none"> <li>• Start low and go slow.</li> <li>• Measure progress.</li> <li>• Remember that people with ID can vary widely in their optimal dose; some may be very sensitive and easily develop toxicity while others are very tolerant and require above-typical doses.</li> <li>• All the advice for clinicians about respect, advocating for the individual, enlisting the individual’s consent and motivation, etc. also apply to the psychopharmacologic relationship.</li> </ul>
Non-Prescribing Clinician role	<p>Clinicians can improve the efficiency and effectiveness of psychopharmacotherapy by the following:</p> <ul style="list-style-type: none"> <li>• Continue the psychotherapy; medication supports the patient in cooperating with psychotherapy and psychotherapy helps the patient capitalize on the gains from medication. The two treatments are complementary.</li> <li>• Communicate regularly with the prescriber.</li> <li>• With the client’s consent, share with the prescriber any psychological/behavioral data being collected</li> </ul>

Communication  
and  
Collaboration

during psychotherapy or behavioral support. This is as valuable for medication management as it is for monitoring psychotherapy progress, and it reduces client burden to have to supply it only once.

- Because of the clinician-client relationship, the client may share a delusion or other symptom that may be missed in the medication management visit; the clinician can help the client bring this up with the prescriber or report it to the prescriber with the client's consent.
- If feasible, attending the medication visits can show support for the client and ensure accurate communication. The clinician may catch and remedy any misunderstanding between patient and prescriber.

# FUTURE CONSIDERATIONS AND RESOURCES

## Considerations for Future Research

Over the last two decades, research on the treatment of mental health conditions in adults with ID has advanced. The body of research has improved regarding design, rigor, treatment and outcome measures. However, most of the existing research does not have sufficient design rigor and replication necessary to determine the effectiveness of specific psychotherapy modalities for specific disorders.

It is only with scientific rigor that we can feel confident in the results of treatment outcome research and subsequently generate sound treatment guidelines in ID populations for diagnoses such as Generalized Anxiety Disorder, Major and Persistent Depressive Disorder, etc. Future researchers should consider well-powered studies using a randomized-control design with stringent eligibility criteria is needed to establish a strong empirical basis for mental health treatments in adults with ID. It is our recommendation that future research protocols should address the following [6]:

1. *Adequate Participant Characterization:* Study inclusion criteria should be explicitly stated with replicable precision. Diagnoses of study participants must be assessed using standardized measures appropriate for the population and should be explicitly described. This applies to both ID diagnosis as well as psychiatric diagnosis. Individual identity such as age, sex, race, etc. must be collected and reported.
2. *Appropriate and Rigorous Outcome Measures:* Outcome variables should be defined with operational precision, replicable, and linked to the dependent variable. Priority should be given to measures with existing reliability and validity data in ID populations. When available, reliability and validity data on instruments used should be reported as a part of study results.
3. *Clinical Rigor:* Treatment fidelity should be assessed as a part of the data collection and included in the analysis plan. Treatment protocols, including accommodations, should be described with replicable precision. Consider

the use of treatment manuals to assist with fidelity as well as dissemination.

4. *Robust Statistical Analyses*: Power analyses should be conducted prior to initiating a study and should be reported in the methods. Effect size, in addition to the statistical significance of results, should also be reported.

Other steps can be taken to improve the clinical research and the clinical care of patients with ID and co-occurring mental health conditions. Within the field of intellectual disability, there is often a divide between researchers and clinicians, especially as it relates to mental health. Additionally, individuals with ID have been largely excluded from participation in mental health treatment research. Yet individuals with ID present with high rates of psychopathology and often require psychotherapy. In the absence of available research, many community clinicians have drawn on best practices in non-ID samples to meet the immediate needs of their clients. As research in this area evolves, these clinicians can be a source of valuable information in the development of treatment protocols for research.

Finally, all research should be guided by implementation science principles, one of which is stakeholder engagement. Given the exclusion of people with ID in mental health treatment studies, **now is the time to include individuals with ID as key stakeholders in the development of well-designed studies through participatory action research**. It is through stakeholder engagement, rigorous clinical trials, and other considerations related to implementation science that the field can truly advance.

## Additional Resources

Below are some additional resources and guidelines presented in alphabetical order which may be of use. We are providing them to you as a resource, please note that our inclusion does not imply our endorsement as we have not systematically evaluated these.

1. [APA Guidelines for Assessment and Intervention with Persons with Disabilities](#)
2. [IDD Toolkit](#)
3. [NICE Guidelines On Helping People With Learning Disabilities Who Have a Mental Health Problem](#)

4. [START Integrated Mental Health Treatment Guidelines for Prescribers in Intellectual and Developmental Disabilities](#)

## URLs which are cited within the guidelines

Below are the URLs which were included in the above text as hyperlinks. They are listed in the order in which they were presented in the text.

### Cultural Considerations/Intersectionality

1. Association of University Centers on Disability (AUCD):  
<https://www.aucd.org/urc/Resources/Diversity-and-Inclusion>
2. Mental Health and Developmental Disability Training Center:  
<https://www.mhddcenter.org/accessing-services-for-individuals-with-developmental-disabilities-cultural-and-linguistic-diversity/>
3. National Center for Cultural Competency: <https://nccc.georgetown.edu/>
4. AAIDD ID and Intersectionality: <https://www.aaid.org/intellectual-disability/intersectionality>
5. What is Intersectionality: <https://www.intersectionaljustice.org/what-is-intersectionality>

### Follow Ethical Principles

1. AAIDD Guardianship standards and position statement:  
<https://www.aaid.org/news-policy/policy/position-statements/guardianship>
2. Guardianship levels/types:  
<https://www.justice.gov/elderjustice/guardianship>
3. Administration for Community Living state protection and advocacy systems: <https://acl.gov/programs/aging-and-disability-networks/state-protection-advocacy-systems>
4. Characteristics of ableism: <https://www.healthline.com/health/what-is-ableism>
5. Implicit Bias Toolkit: [https://qi.ipro.org/wp-content/uploads/Stigma-Implicit-Bias-Toolkit\\_v1e-508c.pdf](https://qi.ipro.org/wp-content/uploads/Stigma-Implicit-Bias-Toolkit_v1e-508c.pdf)
6. Examples of microaggressions: <https://www.vancouver.wsu.edu/equity-diversity/examples-disability-microaggressions-everyday-life>



## Empower Clients to Self-Advocate and Promote their Capacity for Self-Determination

1. Supported decision making: <http://www.supporteddecisionmaking.org/>
2. Multicultural components of self-determination: <https://selfdeterminationtheory.org/topics/application-cultural/>
3. The University of Kansas self-determination resources: <https://selfdetermination.ku.edu/>

## Communication

- APA Inclusive Language Guidelines: <https://www.apa.org/about/apa/equity-diversity-inclusion/language-guidelines.pdf>
2. Test for Reception of Grammar: <https://www.pearsonclinical.co.uk/store/ukassessments/en/Store/Professional-Assessments/Speech-%26-Language/Vocabulary/Test-for-Reception-of-Grammar/p/P100009232.html>
  3. AAC Institute: <https://aacinstitute.org/what-is-aac/>
  4. Customized Universal Design: <https://udlguidelines.cast.org/>

## Accommodations and Support within Therapy

1. CBT for ID: <https://link.springer.com/content/pdf/10.1057/978-1-137-47854-2.pdf>
2. Beat-it behavioral activation intervention: <https://www.nes.scot.nhs.uk/our-work/learning-disability/>
3. StepUp: <https://www.nes.scot.nhs.uk/our-work/learning-disability/>
4. Biza Stenfert Kroese email: [b.stenfert-kroese@bham.ac.uk](mailto:b.stenfert-kroese@bham.ac.uk)
5. Guidelines for adapting specific therapies including Dialectical Behavior Therapy: <https://www.nasdds.org/i-dd-and-mental-health-support-resources/>
6. Pesky gNATs software: <http://peskygnats.com/>
7. ABCs of Plain Language: [https://www.aucd.org/docs/ABCs%20of%20Plain%20Language\\_final.pdf](https://www.aucd.org/docs/ABCs%20of%20Plain%20Language_final.pdf)
8. NIH Plain Language: <https://www.nih.gov/institutes-nih/nih-office-director/office-communications-public-liaison/clear-communication/plain-language>
9. Center for Plain Language: <http://centerforplainlanguage.org/>

10. Plain Language Checklists:  
<https://www.nih.gov/sites/default/files/institutes/plain-language/nih-plain-language-checklist.pdf>
11. Easy Health: <https://www.easyhealth.org.uk/>
12. Easy read documents: <https://www.easyhealth.org.uk/pages/easy-read-health-leaflets-and-films>
13. Flesch-Kincaid calculator: <https://charactercalculator.com/flesch-reading-ease/>
14. American Psychological Association Guidelines for Assessment and Interventions for Persons with Disabilities:  
<https://www.apa.org/about/policy/guidelines-assessment-intervention-disabilities.pdf>

#### Assessment

1. Clinical Outcome Routine Evaluation-Learning Disabilities 30-Item:  
<https://www.coresystemtrust.org.uk/home/instruments/ld-core-information/>
2. Assessments of psychiatric symptoms in ID:  
[https://www.3dn.unsw.edu.au/sites/default/files/Assessment%20Table\\_Psychopathology\\_V2.pdf](https://www.3dn.unsw.edu.au/sites/default/files/Assessment%20Table_Psychopathology_V2.pdf)
3. Psychiatric Assessment Schedule for Adults with Developmental Disabilities:  
<https://www.pavpub.com/mental-health/assessment/the-mini-pas-add-interview-handbook-3rd-edition>
4. Brief Symptom Inventory:  
<https://www.pearsonassessments.com/store/usassessments/en/Store/Professional-Assessments/Personality-%26-Biopsychosocial/Brief-Symptom-Inventory/p/100000450.html>
5. Novaco Anger Scale and Provocation Inventory:  
<https://www.wpspublish.com/nas-pi-novaco-anger-scale-and-provocation-inventory>
6. WHOQOL-BREF and WHO Quality of Life – for persons with disability:  
<https://www.infond.org/toolkits/nmd-toolkit/whoqol-bref>
7. Personal wellbeing index-intellectual disability:  
<https://www.acqol.com.au/uploads/pwi-id/pwi-id-english.pdf>
8. RRTC Nisonger adaptations for adults with dual diagnosis:  
[https://www.rrtcnisonger.org/wp-content/uploads/2022/12/Paper-19-and-20-Clear-Language-Product\\_FINAL.pdf](https://www.rrtcnisonger.org/wp-content/uploads/2022/12/Paper-19-and-20-Clear-Language-Product_FINAL.pdf)

## Trauma

1. Sexual assault webinar:  
<https://www.youtube.com/watch?v=8kDn6RWM5t0>
2. Assessment of abuse webinar: <https://www.youtube.com/watch?v=1QdnZ-i6Fas>
3. Assessment of trauma webinar:  
<https://www.youtube.com/watch?v=tAPQHZZoqXY>
4. Dr. Langdon's email: [peter.langdon@warwick.ac.uk](mailto:peter.langdon@warwick.ac.uk)
5. Trauma-informed approach webinar :  
<https://www.youtube.com/watch?v=EGw3npymTYg>

## Additional Resources

1. APA Guidelines for Assessment and Intervention with Persons with Disabilities: <https://www.apa.org/pi/disability/resources/assessment-disabilities>
2. NICE Guidelines on helping people with learning disabilities who have a mental health problem: <https://www.nice.org.uk/guidance/ng54>
3. START Integrated Mental Health Treatment Guidelines for Prescribers in Intellectual and Developmental Disabilities:  
<https://centerforstartservices.org/IDD-MH-Prescribing-Guidelines>
4. IDD Toolkit <https://iddtoolkit.vkcsites.org/>

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