

# ID/DD

## Intellectual Disability / Developmental Disability

IDDs are disorders that are typically present at birth and affect an individual's physical, intellectual and emotional development.

### IMPORTANT FACTS

Individuals with IDD are more likely to experience mental health problems than the general population. This is due to several factors:

- Communication deficits can lead to difficulties with social connections, potentially resulting in feelings of loneliness, anxiety and emotional dysregulation.
- Difficulties with independent task completion and learning can contribute to low self-esteem, low self-efficacy and increased frustration.
- Individuals with IDD are more likely to have increased vulnerability and be the victims of abuse, which can lead to trauma and stress related disorders.
- They may also experience more family stress and have an increased risk for adverse childhood experiences.

### IMPORTANCE OF ASSESSMENT

A key purpose of describing limitations is to develop a profile of needed supports. Valid assessment considers cultural and linguistic diversity, as well as differences in communication, sensory, motor and behavioral factors.

Types of assessments:

- Cognitive: WISC-V, Stanford-Binet-5 or DAS-II.
- Adaptive: Vineland-3 or ABAS-3.
- Standard: language, hearing and vision screenings.
- Culturally and linguistically responsive assessment and use of interpreters when needed.

### CHALLENGES IN DIAGNOSIS

- Individuals may have difficulty self-reporting symptoms.
- Many diagnostic tools lack norms for the IDD population.
- It can be difficult to differentiate behaviors due to IDD versus a secondary mental health concern.
- Diagnostic overshadowing can occur, where psychiatric concerns are wrongly attributed solely to the IDD.

### CHROMOSOMAL, GENETIC OR METABOLIC IDDS

- Down Syndrome.
- Fragile X.
- Rett.
- Prader-Willi
- PKU (untreated).

### IDD CAUSES

- **Prenatal exposures:** Fetal alcohol spectrum disorders, infections like cytomegalovirus or toxins like lead.
- **Perinatal:** hypoxic-ischemic injury, prematurity complications.
- **Postnatal/early childhood:** severe traumatic brain injury, meningitis, severe malnutrition and neglect.
- **Environmental deprivation and toxicity:** lead, mercury and severe neglect.

**While there's no cure for IDDs, an individual's potential is not limited. With the appropriate support, children with IDDs can learn, grow and thrive.**

## COMMONLY DIAGNOSED CO-OCCURRING DISORDERS

- Attention deficit hyperactivity disorder (ADHD) — higher prevalence than the general population.
- Autism.
- Cerebral palsy.
- Anxiety disorders — specific phobia, agoraphobia, generalized anxiety disorder.
- Conduct and externalizing disorders.
- Depressive disorders like major depressive disorder and persistent depressive disorder.
- Other disorders sometimes diagnosed include bipolar disorder and PTSD.

When symptoms of another disorder are present, they should be taken seriously, evaluated and treated as indicated. When unsure, addressing the behavior of concern directly can prevent treatment delays.

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## PSYCHOLOGICAL INTERVENTIONS

- Behavioral therapies, such as applied behavioral analysis (ABA) and positive behavioral support (PBS), have demonstrated effectiveness for mental health treatment and increasing adaptive behaviors like conceptual, social and practical skills.
  - Adapted cognitive behavioral therapy (CBT) including visuals, concrete language, in-session practice and caregiver involvement has supportive evidence for mild-moderate IDD; outcomes improve with modifications.
  - Contextual therapies (e.g., mindfulness-based therapy, dialectical behavior therapy, acceptance and commitment therapy) may also be effective due to their integration of environmental and contextual factors.
  - Interventions should be tailored to the individual's preferences, understanding, communication style, strengths and needs.
  - Additional supports between sessions are beneficial.
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## MEDICATION (PSYCHOPHARMACOLOGY)

- Diagnosis should not be based on a single symptom.
- Evidence-based treatments for neurotypical patients may not have included individuals with IDD; therefore, the recommendation is to start low and go slow with medication doses.
- Monitor treatment response using behavioral data, rating scales and measures of side effects.
- More is not always better; a rush to polypharmacy can complicate treatment.
- If you or your health care provider feel unsure or that things are not making sense, consult with a specialist.
- In summary, while IDD is a lifelong neurodevelopmental disorder indicating significantly below-average adaptive and intellectual skills, it is not a hopeless condition. Individuals with IDDs can learn and grow with appropriate supports. Co-occurring mental health challenges should be seriously addressed with tailored and effective interventions.

## CHARACTERISTICS

Significant limitations in intellectual functioning like:

- Reasoning.
- Problem-solving.
- Abstract thinking.
- Learning.

Significant limitations in adaptive behavior like:

- Skills needed for daily living such as communication.
- Social skills.
- Personal independence.

Onset occurs during the developmental period commonly defined as before age 18 per DSM; American Association on Intellectual and Developmental Disabilities (AAIDD) uses before 22. This age is based on recent scientific research showing that important brain development continues into early adulthood. If these problems began after this developmental period, the correct diagnosis would be a neurocognitive disorder.

For children under age 5, global developmental delay may be used. For older children when assessment is precluded, unspecified intellectual disability may be considered.

**With appropriate personalized supports over a sustained period, the life functioning of the person with ID generally will improve. Some individuals, especially those with more severe deficits, may need life-long support.**

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## SYSTEMS OF SUPPORT

These are resources and strategies that promote development and well-being. They are designed to be:

- Person-centered, comprehensive, coordinated and outcome-oriented.
  - Built on values, facilitating conditions and support relationships.
  - Incorporate choice and personal autonomy, inclusive environments, generic supports and specialized supports.
  - Integrate and align personal goals, support needs and valued outcomes.
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## RESOURCES TO HELP

- [childmind.org/guide/quick-guide-to-intellectual-developmentdisorder1](http://childmind.org/guide/quick-guide-to-intellectual-developmentdisorder1).
  - [cdc.gov/child-development/about/developmental-disabilitybasics.html](http://cdc.gov/child-development/about/developmental-disabilitybasics.html)
  - [parentcenterhub.org/intellectual/](http://parentcenterhub.org/intellectual/)
  - [aaid.org/home](http://aaid.org/home)
  - [ssa.gov/disability](http://ssa.gov/disability)
  - [oklahoma.gov/okdhs/services/dds](http://oklahoma.gov/okdhs/services/dds)
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## REFERENCE

1. Rich, Sara. Dual Diagnosis: Intellectual Developmental Disabilities and Mental Health Problems. Presentation for OSU-CME session, 2024
2. Eunice Kennedy Shriver National Institute of Child Health and Human Development. (n.d.). Intellectual and developmental disabilities (IDDs). U.S. Department of Health and Human Services, National Institutes of Health. Retrieved June 26, 2025, from [nichd.nih.gov/health/topics/factsheets/idds](http://nichd.nih.gov/health/topics/factsheets/idds)
3. Schalock, R. L., Luckasson, R., & Tassé, M. J. (2021). An overview of intellectual disability: Definition, diagnosis, classification, and systems of supports (12th ed.). American Association on Intellectual and Developmental Disabilities. Retrieved from [researchgate.net/publication/355661119](http://researchgate.net/publication/355661119)

## NATURE OF SUPPORTS

- Include more opportunities for practice.
  - Provide more structured setting.
  - Offer increased opportunities for reinforcement.
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## BEHAVIOR, SAFETY AND CRISIS

- Behavior support plans.
  - Functional behavior assessment (FBA).
  - Crisis and suicide screening adapted for communication level (simple language, caregiver collateral). There is increased suicide risk in autistic youth and the need for adapted screening.
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## HELP FOR FAMILIES

- Early Intervention (Part C).
- IEP/504 (IDEA/Section 504) — transition planning (IEP) beginning by age 16 or earlier in practice.
- Care coordination.
- Medicaid waivers.
- Social Security Income (SSI)/SSA.
- State Developmental Disabilities Services (DDS).