UNDERSTANDING YOUR DIAGNOSIS

Intellectual Disability

Also called Intellectual Developmental Disorder

Intellectual disability means your child learns more slowly and needs extra help with everyday skills.

HOW COMMON	OFTEN NOTICED	MOST COMMON LEVEL	YOU ARE NOT ALONE
About 1 to 2 in 100 people	In the childhood years	Mild - about 85%	Millions of US families

What this is

- Intellectual disability means learning, reasoning, and everyday skills develop more slowly than usual. It is not a mental illness.
- The level is set by how much help your child needs each day, not by an IQ number alone. Most children are in the mild range.
- Your child can and will learn. Progress is slower and needs more repeating, but skills keep building well into adulthood.
- This is a lifelong difference, not an illness that gets worse. Losing skills your child already had means something else is going on.

What it can look and feel like

- Milestones come later: sitting, walking, first words, using the toilet, dressing, and tying shoes all take longer than expected.
- Reading, writing, and math are hard from the start, and your child leans on memorizing rather than working things out.
- Everyday skills lag behind: handling money, telling time, cooking, catching the bus, or remembering to take medicine.
- Ideas that cannot be seen or touched are hard. Your child does much better with concrete, step-by-step directions and examples.
- Your child may be very trusting and easy to talk into things, and unsure who is being kind and who is taking advantage.
- New behavior problems usually mean something hurts, something is confusing, or a task is too hard, not that your child is misbehaving.
- Mild forms may not be noticed until school demands rise. Greater needs are usually clear in the first year or two of life.

What is happening in your brain and body

- The brain develops along a different path, so learning happens more slowly and fewer steps can be held in mind at one time.
- Thinking speed and short-term memory are limited, so a long string of instructions gets lost partway through.
- Skills do not spread on their own from place to place. What is learned in the clinic usually has to be taught again at home.
- About **1 in 3** children have a cause found on genetic testing, such as Down syndrome or fragile X syndrome.
- Seizures, vision or hearing loss, and movement problems happen more often here, so regular medical checkups really matter.

What can make it more likely

- Genetic conditions are the most common known cause. A blood test called a chromosomal microarray often finds one.
- Things during pregnancy can play a part, including alcohol, certain infections, and untreated thyroid problems in the parent.
- Trouble around birth, like low oxygen or being born very early, and later events like meningitis or a head injury can cause it.
- In many families no cause is ever found. That is common, and it does not mean that anyone did anything wrong.

What to expect

- Skills grow throughout childhood and keep growing in adulthood. The pace is slower, but the direction is forward.
- Most adults with mild intellectual disability live, work, and manage daily life with some support from family or services.
- Support is lifelong for some. Planning for adulthood should start by about **age 16**, well before school services end.
- Mental health conditions are more common here and they are treatable. Never assume a change is just part of the disability.

What helps

Treatment works. Most people get better.

Talking therapies

- No therapy removes intellectual disability. The real work is teaching skills and building supports that fit your child's needs.
- **Applied behavior analysis** breaks a skill into small steps and teaches it with practice and reward, especially for hard behavior.
- **Positive behavior support** changes what happens before a behavior, setting your child up to succeed instead of correcting after.
- **Speech, occupational, and physical therapy** target talking, self-care, and movement. These can continue across the whole lifespan.
- Adapted **talk therapy** using simple words, pictures, and role-play treats anxiety and low mood at mild and moderate levels.

Medicines

- No medicine treats intellectual disability itself. Medicines are for a separate condition, such as anxiety, low mood, or **ADHD**.
- Start low and go slow. Your child may be more sensitive to sleepiness and other side effects than other children are.
- **Antipsychotics** can reduce severe aggression or self-injury, but they need regular weight, blood, and movement checks.
- Any behavior medicine should have a clear target, be reviewed often, and be lowered or stopped once it is no longer needed.
- Check for pain first. An ear infection, toothache, constipation, or reflux drives a lot of new behavior. Doses come from your prescriber.

Everyday things that help

- Teach the skill where it will actually be used. Practice buying milk at the store, not just naming coins at the kitchen table.
- Use pictures, checklists, and the same steps in the same order every time. Repetition is how the learning sticks.
- Sign up for early intervention before age 3 and school services after, and keep an **IEP** with real-life daily living goals.
- Protect your child from being taken advantage of, online and in person, and teach safety in plain, practical words.
- Take the respite care and family support you are offered. No one can do this alone, and accepting help is not failing.

Get help right away if

- Your child talks about dying or hurting themselves. Call or text **988**, or go to the nearest emergency room.
- A sudden change in behavior, alertness, or skills. Get a medical check the same day to look for pain or illness.
- A first seizure, a serious injury, or any sign of abuse or neglect. Get help right away.

Questions to ask your care team

- *How much support does my child need, and what will that look like at home and at school?*
- *Should we do genetic testing, and what would we do differently if it finds a cause?*
- *What services can we apply for now, and is there a waiting list I should join today?*
- *How do we plan for adulthood, including work, housing, and help with decisions?*

Where this information comes from

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NOTE

Sources are listed in APA 7th edition style. This handout is general health information, not medical advice, and it does not replace talking with your own doctor, therapist, or prescriber. Medicine choices and doses are decided with your prescriber. If you are in danger or thinking about hurting yourself, call or text 988 in the United States, or go to your nearest emergency room.