

Intellectual Disabilities

TIPS AND RESOURCES



What is an intellectual disability?

An intellectual disability is a condition that begins before age 18 and significantly limits intellectual functioning and adaptive behavior. Individuals with intellectual disabilities may have challenges with learning, reasoning, problem solving, and/or thinking abstractly and quickly, and may also have additional challenges with everyday social and practical skills. Those born with developmental disabilities may later be diagnosed with an intellectual disability, but an intellectual disability does not always indicate an underlying developmental disability.

In the U.S., 1 to 3 percent of the population has an intellectual disability. The condition is associated with a number of common syndromes including Down syndrome, autism spectrum disorder, and fragile X. Intellectual disability is the preferred and respectful term for what used to be known as *mental retardation*.

What causes an intellectual disability?

There are many causes of intellectual disability. Conditions may occur due to atypical genetic structure like Down syndrome, physical diseases such as whooping cough or measles, maternal malnutrition, or exposure to environmental toxins such as mercury, lead, illegal substances, or some medications before, during, or after pregnancy.

What are the effects of an intellectual disability?

In childhood, it may take an individual with an intellectual disability a little longer to learn to speak, walk, and take care of their personal needs. In school, delays and challenges in learning will probably require additional supports, but with those supports in place, students with intellectual disability can be educated in general education classrooms with their typically developing peers. For adults, employment and living in the community are possible with high expectations and quality supports and services.

While living with an intellectual disability presents many challenges, it is important to remember that individuals also will have many gifts, talents, and strengths to share. People with intellectual disabilities can have quality relationships, employment, and community participation.

An intellectual disability does not impede a person's ability to have a range of emotions and feelings or wants and needs. People with intellectual disabilities can have goals and dreams for their lives just like everyone else.

Can an intellectual disability be treated?

While there is no cure for intellectual disability, high-quality early intervention services in key areas such as speech therapy are effective in improving quality of life and in helping people reach their full potential. Holding high expectations for what individuals are capable of doing and promoting independence whenever possible can lead to satisfying and meaningful lives. It is important to understand that each individual is unique and will face different challenges and at different times.

Interacting with individuals with intellectual disabilities

Many (but not all) people with intellectual disabilities have communication challenges. It may be helpful to keep the following in mind:

- Allow additional time to exchange information. Speak slowly.
- Many people have stronger receptive (understanding) communication skills than expressive skills.

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- Conversely, a person's expressive speech may sometimes give an impression of better comprehension than is actually the case, so check to see if they understand.
- Some people may be delayed in responding to questions. Allow for pauses.
- Use plain language. Avoid jargon.
- Use short, simple sentences.
- Use concrete as opposed to abstract language, for example: "Show me"; "Tell me"; "Do this" with gesture; "Come with me"; "I'm going to..."
- Say "Put your coat on" instead of "get ready."
- Say "Are you upset? Are you sad? Are you happy?" instead of "What are you feeling?"
- Let the person know when you do and do not understand.
- Be sensitive to tone of voice and nonverbal cues.

Who We Are and Who We Serve

The **Vanderbilt Kennedy Center (VKC)** works with and for people with disabilities and their family members, service providers and advocates, researchers and policy makers. It is among only a few centers nationwide to be a University Center for Excellence in Developmental Disabilities, a *Eunice Kennedy Shriver* Intellectual and Developmental Disabilities Research Center, and a Leadership Education in Neurodevelopmental and Related Disabilities Training Program. Center programs and staff can assist families, educators, and other service providers. (615) 322-8240, toll-free (866) 936-8852, vkc.vumc.org

Tennessee Disability Pathfinder provides free information, referral sources, and help with navigating services via phone, email, and website. Assistance is available to individuals of all ages, all types of disabilities, and all languages spoken. Its website database has more than 3,000 agencies searchable by Tennessee county and service. Pathfinder is a project of the VKC and is partially funded by Tennessee Council on Developmental Disabilities and other state agencies. (615) 322-8529, toll-free (800) 640-4636, DisabilityPathfinder.org

Take Part in Research

StudyFinder is a searchable database that lists current VKC studies. Studies seek people of all ages with and without developmental disabilities. See vkc.vumc.org/studyfinder. Research Match is a secure place for volunteers and researchers to connect. See researchmatch.org.

Resources

The Arc Tennessee advocates for the rights and full participation of all people with intellectual and/or developmental disabilities. www.thearc.org, (800) 835-7077

The Arc U.S. promotes and protects the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes. www.thearc.org, (800) 433-5255

American Association on Intellectual and Developmental Disabilities (AAIDD) promotes progressive policies, sound research, effective practices, and universal human rights for people with intellectual and developmental disabilities. aaidd.org, (202) 387-1968

National Resource Center for Supported Decision-Making Seen as an alternative to conservatorship, Supported Decision-Making (SDM) is a series of relationships, practices, arrangements, and agreements designed to assist individuals with a disability in making and communicating to others their decisions about their own lives. supporteddecisionmaking.org, (202) 448-1448

Ten Commandments of Communicating About People with Intellectual Disabilities www.specialolympics.org/uploadedFiles/Regions/europe-eurasia/_Region_Front/TenCommandments_2012.pdf

Disability Etiquette: Engaging People With Disabilities www.tndisability.org/our-publications

National Institutes of Health IDD Tip Sheet report.nih.gov/nihfactsheets/ViewFactSheet.aspx?csid=100

