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Intellectual Disability: Diagnosis, Support, Waivers, and Transitioning to Adult Care

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Intellectual Disability (also known as Intellectual Developmental Disorder) is characterized by difficulties with cognitive abilities, such as learning from experience, reasoning, planning, academic skills, and abstract thinking, as well as daily living skills. Additionally, these cognitive and adaptive deficits must be evident in the developmental period, generally under age 18. Psychologists diagnose Intellectual Disability (ID) by administering standardized IQ tests and gathering ratings of a child's adaptive functioning from primary caregivers and/or

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other important adults in the child's life (e.g., teachers). To meet criteria for ID, scores for both cognitive abilities and adaptive skills need to be at or below the second percentile compared to same-aged peers. Psychologists then determine the level of ID (i.e., mild, moderate, severe, and profound) by looking at how the child's skills are affected across conceptual, social, and practical domains. Approximately 1% of people in the U.S. meet criteria for ID, and most (approximately 80%) are in the mild category.

Preschool-aged children with mild ID might not clearly stand out from their peers. They might learn letters, shapes, numbers, and colors similarly to other children their age, though they might be socially immature. As these children progress through school and transition into adulthood, they tend to need more support with academic skills and might struggle with abstract thinking. Older children and adults with mild ID are likely to have difficulty judging nuanced social situations and risk being taken advantage of. They also are likely to need some support with complex daily living skills: money management, grocery shopping, and meal planning.

For those with moderate ID, difficulties are noticeable early in life. They are likely to talk later and take longer to learn pre-academic skills. Most people with moderate ID demonstrate elementary-level academics by adulthood. They are more likely to use less complex language, but build meaningful relationships with important people in their lives. People with moderate ID can care for personal hygiene needs, though they often need more support with household care tasks.

Severe ID is characterized by limited conceptual skills: reading, math, and problem-solving. People with severe ID often have limited vocal communication, which they use to develop relationships with family and friends. Language is more focused on social communication than on describing what is happening around them. Practically, people with severe ID require support in all daily activities.

People with profound ID do best with conceptual skills tied to physical objects (e.g., matching or sorting), though co-occurring physical impairments sometimes prevent them from learning these skills. They generally have limited language comprehension (i.e., understand some gestures and simple phrases) and often use nonverbal means to communicate their wants, needs, and feelings. Like people with severe ID, people with profound ID enjoy relationships with family members and caregivers and need support with all daily activities.

Several disorders frequently co-occur with ID, including cerebral palsy, epilepsy, attention deficit hyperactivity disorder, depressive disorder, anxiety disorder, and autism spectrum disorder. If co-occurring sensory impairments, such as blindness, motor impairments, mental health conditions, or severe challenging behavior prevent someone from fully participating in a standardized assessment, psychologists can diagnose Unspecified

Intellectual Disability. This requires the person be re-evaluated in the future when better able to participate in testing, or when better testing methods are locally available.

Interventions and level of support

Although an ID diagnosis gives some idea of the support a person needs, it is not a measure of their potential. No one living or working with a person with an ID should assume that person cannot do or learn something. Instead, the focus should be on the amount and type of supports needed to help the person thrive. Children with ID often benefit from therapies — such as speech, occupational, or physical therapy — depending on the skills they lack most. They are also likely to benefit from Individualized Education Plans (IEPs) at school to support their academic development. The level and type of supports needed at school vary from child to child. A preschooler with mild ID might need some extra help with toilet training, but otherwise participate in the general education classroom with the rest of their classmates. A middle school-aged child with moderate ID might benefit from more time with a special education teacher and/or a smaller class.

If children with ID demonstrate challenging behaviors, they are likely to benefit from similar strategies as those used for children without ID (e.g., clear rules and consequences). However, parents and caregivers should consider the child's developmental level as well as their age when giving consequences. For example, a child with minimal verbal skills is less likely to learn from talking about what they did wrong but might be motivated to follow rules to earn favorite items or activities.

Transition to adulthood

The transition to adulthood can be overwhelming for people with ID and their families. Planning should begin very early, even before the child enters school. Parents and caregivers can teach the skills necessary to cope with transition and change, as well as give the child — no matter the level of support they need — access to various experiences at home, at school, and in the community

Judy Warth, BBS, a certified employment support professional from the Center for Disabilities and Development, breaks down future planning into the following areas.

Daily living and housing

Here is where all the waivers come into place for assistance and support. There are many ways families, support systems, and educators can guide in these areas, including:

- Doing chores at home — cooking, cleaning, laundry, etc.
- Begin money management — spending money or having a preloaded debit card.
- Dream about the options and look at what is available by doing tours, looking at apartments, and basic planning.

Daytime activities

This is much more than simply filling the time otherwise spent in school. This includes dreaming about the future, what do you want to be when you grow up? etc., and aligning activities in those directions, combined with:

- Doing chores at home, which begins to introduce basic work concepts and work ethic.
- Volunteering and part-time or summer jobs are invaluable, as they are for most neurotypical youth. Not only do youth get a chance to connect with others, develop work skills, and earn spending money, they begin to figure out what they like and don't like about work. This can also be enhanced by school-work experience programs.

- Engaging in integrated school activities of interest such as drama, sports, gaming clubs, and cheerleading, which offer opportunities to connect and learn and build important social and decision-making skills.
- Connecting with vocational rehabilitation services. The process should begin at 14 through what vocational rehabilitation services calls "pre-employment transition services." Several good experiences can happen there, including tours, job shadows, and internships, as well as help planning, mock interviews, applications, etc. Vocational rehabilitation services can help youth after graduation. Vocational providers should place emphasis on creating natural supports in the workplace. Visit: **https://worksupport.com/documents/article15.pdf**.
- Helping people dream even if the dreams seem unattainable. Providing hope and guidance to someone can produce positive and sometimes surprising results.
- Additional education. Some people with ID/developmental disabilities will go to college or trade schools. Encourage exploration and connect with disability services to begin receiving the needed accommodations. Many colleges have specialized programs designed to support students with disabilities.

Social life and relationships

Everyone needs friends and a social network. Looking for a significant other is also something many young adults engage in. Encourage and support engagement in church, community groups, school activities, etc., so friendships can be established and maintained.

Provide information on sexual self-advocacy so people can make heathy and informed choices. Visit: **https://www.elevatustraining.com/**.

Healthcare and advocacy

Facilitate connecting individuals with adult healthcare providers, including family physicians, gynecologists, etc. It is important to build healthcare self-advocacy skills through systematic instruction. Below are some resources that can assist with the transition to healthcare independence:

- **https://www.gottransition.org/youth-and-young-adults/**
- **https://chsciowa.org/programs/health-care-transition-adulthood**
- **https://www.ohsu.edu/oregon-office-on-disability-and-health/taking-charge-my-health-care-toolkit**

Build and engage a network that can help. Identify people who want to help in the future. They may include family members, a boyfriend or girlfriend, friends, teachers, staff, a case manager, co-workers, church friends — anyone known and trusted who is interested in helping the person live the life they want. Help to develop decision-making skills through supported decision-making and person-centered planning with the following resources:

- **https://supporteddecisions.org/about-supported-decision-making/**
- **https://www.maineddc.org/**
- **https://acl.gov/programs/consumer-control/person-centered-planning**

Get connected with helpful resources

Finding resources and services can be stressful and confusing. Sally Rieck, MSW, a licensed independent social worker at the Center for Disabilities and Development, provides the following information for families.

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IOWA HEALTH CARE

Iowa's Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program presents:

PROVIDING QUALITY CARE FOR PEOPLE WITH DISABILITIES

A **self-paced course** created to help pre-service and practicing healthcare providers improve the health of people with disabilities across the lifespan.

This course is for you if:

- You want to increase confidence in providing care to people with disabilities.
- You want to learn best practices to provide person- and family-centered care, including shared decision making and culturally responsive care.
- You want to learn how to incorporate effective communication techniques, including plain language and delivering difficult news, into practice.
- You want to understand your role in how to support people with disabilities to live and work in the community they choose.

The course takes approximately 4.5 hours and includes seven modules covering:

- Disability Basics
- Family- and Person-Centered Care
- Shared Decision Making
- Patient-Provider Communication
- Culturally Responsive Care
- Clinical Care for Persons with Disabilities
- Living, Learning, and Working in the Community

SIGN UP

"I would recommend this course to others! It provides such great information and a variety of sources from life experiences, experts, to individuals with disabilities and how to work through biases, concepts, and put them into action and practice with patients."
– Doctoral Candidate, Occupational Therapy

Contact Julie Temple (**julie-temple@uiowa.edu**) with any questions about the course.

T2A
Transition to Adulthood

TRANSITION TO ADULTHOOD CLINIC

FOR TEENS AND YOUNG ADULTS AGES 16 - 30

Studies show that dreaming, planning and taking positive steps increases the likelihood of success as a person enters adult life. The Transition to Adulthood Clinic at the Center for Disabilities and Development (CDD) helps people who face barriers to independent living navigate this transition. It helps them, and their families and support systems, develop a plan for the future.

A visit to our clinic will include meeting with an occupational therapist, an employment specialist, a clinical social worker, a self-advocate, and a nurse. A psychologist is available for people who need evaluations for the Intellectual Disability Waiver.

Program Outline

- Discuss the individual's and family's goals to promote self-advocacy and functional independence, make recommendations, and develop an action plan
- Provide support for living, education, and work
- Assist in communicating with adult care providers to help make a smooth transition of care
- Offer ideas and a plan to help meet targeted goals

Discussion Topics

- Activities of Daily Living necessary for successful independent living and self-care, both at home and in the community
- Developing skills to speak and advocate for oneself
- Living arrangements
- Health insurance coverage
- Life in the community after high school
- Healthy lifestyle choices
- Relationships and sexuality
- Community employment and access
- Guardianship waivers, SSI, and health insurance coverage

To find out more or make an appointment, contact:

University of Iowa Stead Family Children's Hospital
Center for Disabilities and Development
877-686-0031 (toll-free); 319-353-6900 (local)
uichildrens.org/cdd

Iowa's University Center for Excellence on Developmental Disabilities

IOWA
HEALTH CARE
Stead Family
Children's Hospital

Waivers

There are currently seven waivers that Iowa offers for which a person may qualify based on diagnoses, needs, and/or age. There are up to three waivers that apply to someone with an intellectual disability: the Intellectual Disability (ID) waiver, the Health and Disability (HD) waiver, and if they have a brain injury as defined by Iowa law, they will qualify for the Brain Injury (BI) waiver. A person can be on multiple waiver wait lists, but can receive services only through one at a time.

A person with ID is most likely to benefit from the Intellectual Disability waiver. In addition to offering respite and adult daycare, the ID waiver offers day habilitation, very beneficial after young people finish high school. It also offers supported community living, essential in helping people with disabilities live independently.

This could be different if the person with ID has many physical limitations and/or complex medical needs requiring assistance such as home health aides and extensive home/vehicle modifications.

This Waiver Comparison Chart gives a good breakdown of services the different waivers offer: **https://hhs.iowa.gov/media/10676/download?inline.** The waivers are likely going to be changing at the end of this year.

The state of Iowa plans to go from seven waivers to two waivers: Children and Youth and Adults and Aging. See link for more information, visit: **https://hhs.iowa.gov/programs/welcome-iowa-medicaid/current-projects/home/faq-waiver-redesign**.

Information is scarce about the waiver redesign in terms of what the wait list will look like, disability determination requirements to get on wait lists, IQ testing requirements, etc. The new waiver system is currently slated to start in December 2025.

Guardianship/guardianship alternatives

First and foremost, an adult with a disability does NOT automatically need a legal guardian. There are several less-restrictive alternatives to guardianship, including shared decision-making, in which an adult with a disability works with their parent/caregiver/support person to make decisions they may need assistance with understanding, e.g., different types of medical treatments a disabled person can ultimately consent to or not after discussing with someone they trust.

Medical power of attorney, shared decision-making, and signing releases for parents/caregivers/support people to access medical information are a few examples of less-restrictive alternatives to guardianship. Guardianship may be the most beneficial for someone who has more significant cognitive impairments and/or is nonverbal and can't advocate for themselves. Guardianship also may be beneficial for someone with significant behavioral and/or mental health challenges whose inability to make safe, reasonable decisions puts their well-being in jeopardy.

Applying for guardianship is typically done with an attorney. The process can start when a person is 17 1/2 years old. A judge might require recent cognitive testing. Guardianship must be affirmed by a court order signed by a judge to be considered valid in the state of Iowa. For those who cannot afford an attorney, there is the option of drawing up your own petition using criteria from the Iowa Administrative Code.

Some attorneys offer what's called unbundled services, which can be significantly less expensive. There is a form, "filing for guardianship without an attorney," that includes all the necessary information about the above for consideration.

Supplemental Security Income

SSI benefits depend on a person's income and resources. Many children with disabilities don't qualify for SSI before they turn 18 because their parents have too much income/resources. Once a person turns 18, they will qualify for SSI regardless of their parents' income, even if they're still living at home. Applying requires filling out a disability report and completing a phone interview. A parent cannot apply for SSI for their disabled adult child unless they have guardianship. The Adult Disability Starter Kit has a lot of good information, visit: **https://www.ssa.gov/pubs/EN-64-110.pdf.**

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What's in this issue

INSERTS

If you have questions about **billing** related to EPSDT Care for Kids services, please call Provider Services: **1-800-338-7909**. If you have questions about **clinical issues** and EPSDT Care for Kids services, please call **1- 800-383-3826.** Please note: Due to budget restraints, the *EPSDT Care for Kids Newsletter* is sent to offices and organizations, rather than to individuals. **The newsletter is also available online at www.iowaepsdt.org**. Readers are welcome to photocopy or download material from the newsletter to share with others. If you wish to reproduce material from the newsletter in another publication, whether print or electronic, please obtain permission prior to publication by contacting Michelle Johnston at **michelle-johnston@uiowa.edu**. Please include the following acknowledgment with reprinted material: Reprinted by permission of the Iowa *EPSDT Care for Kids Newsletter.*

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