



REPRESENTING PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

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WHAT IS IDD?



DEFINITION OF IDD

- A student with an intellectual disability is one who has been determined to meet the criteria for an intellectual disability as stated in 34 CFR, §300.8(c)(6). In meeting the criteria stated in 34 CFR, §300.8(c)(6), a student with an intellectual disability is one who:
 - (A) has been determined to have significantly sub-average intellectual functioning as measured by a standardized, individually administered test of cognitive ability in which the overall test score is at least two standard deviations below the mean, when taking into consideration the standard error of measurement of the test; and
 - (B) concurrently exhibits deficits in at least two of the following areas of adaptive behavior: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health, and safety.

19 Tex. Admin. Code §89.1040(c)(5)
- Significantly sub-average general intellectual functioning that is concurrent with deficits in adaptive behavior and originates during the developmental period.

Tex. Health & Safety Code § 591.003(7)(West).
- DSM-V: A childhood-onset neurodevelopmental disorder characterized by deficits in intellectual (2 standard deviations below average IQ of 70) and adaptive functioning (limitations in communication, social skills, independence, and performance at work or school).

PLAIN ENGLISH

Full Scale IQ of 69 or below, or 75 or below with a related condition; and
Mild to Severe Deficits in adaptive behaviors

Related Conditions:

In accordance with the Code of Federal Regulations, Title 42, 435.1010, a related condition is a severe and chronic disability that:

- A. is attributed to:
 - i. cerebral palsy or epilepsy; or
 - any other condition, other than mental illness, found to be closely related to intellectual disability because the condition results in impairment of general intellectual functioning or adaptive behavior similar to that of individuals with intellectual disability, and requires treatment or services similar to those required for individuals with intellectual disability;
- B. is manifested before the individual reaches age 22;
- C. is likely to continue indefinitely; and
- D. results in substantial functional limitation in at least three of the following areas of major life activity: self care, understanding and use of language, learning, mobility, self-direction; and capacity for independent living



**Approved Diagnostic Codes for Persons with Related Conditions
Effective October 1, 2022 to September 30, 2023**

ICD-10 CM - Diagnosis Code	ICD-10 CM - Diagnosis Description
B91	Sequelae of poliomyelitis
C71.1	Malignant neoplasm of frontal lobe
C71.2	Malignant neoplasm of temporal lobe
C71.3	Malignant neoplasm of parietal lobe
C71.4	Malignant neoplasm of occipital lobe
C71.5	Malignant neoplasm of cerebral ventricle
C71.6	Malignant neoplasm of cerebellum
C71.7	Malignant neoplasm of brain stem
C71.8	Malignant neoplasm of overlapping sites of brain
C71.9	Malignant neoplasm of brain, unspecified
C79.31	Secondary malignant neoplasm of brain
C96.0	Multifocal and multisystemic (disseminated) Langerhans-cell histiocytosis
C96.5	Multifocal and unisystemic Langerhans-cell histiocytosis
C96.6	Unifocal Langerhans-cell histiocytosis
D42.0	Neoplasm of uncertain behavior of cerebral meninges
D42.1	Neoplasm of uncertain behavior of spinal meninges
D42.9	Neoplasm of uncertain behavior of meninges, unspecified
D43.0	Neoplasm of uncertain behavior of brain, supratentorial
D43.1	Neoplasm of uncertain behavior of brain, infratentorial
D43.2	Neoplasm of uncertain behavior of brain, unspecified
D43.4	Neoplasm of uncertain behavior of spinal cord
D44.0	Neoplasm of uncertain behavior of thyroid gland
D44.10	Neoplasm of uncertain behavior of unspecified adrenal gland

WHAT TO EXPECT FROM A PERSON WITH IDD?

- Children may be slower to meet developmental milestones such as sitting up, crawling, and walking. Children may be slower learners.
- Speech may be slower, a hybrid of communication models, or not utilized at all.
- May have deficits in memory and problem solving, and have difficulty in applying new information to current understanding.
- May struggle reading social cues and customs.
- May have trouble with activities of daily living, such as personal hygiene, maintaining their own routines, etc.



**LEGAL REPRESENTATION OF PEOPLE
WITH IDD** |

LEGAL DUTY TO CLIENTS WITH IDD:

Texas Disciplinary Rules of Professional Conduct 1.16. Clients with Diminished Capacity

(a) When a client's capacity to make adequately considered decisions in connection with a representation is diminished, whether because of minority, mental impairment, or for another reason, the lawyer shall, as far as reasonably possible, maintain a normal client-lawyer relationship with the client.

(b) When the lawyer reasonably believes that the client has diminished capacity, is at risk of substantial physical, financial, or other harm unless action is taken, and cannot adequately act in the client's own interest, the lawyer may take reasonably necessary protective action. Such action may include, but is not limited to, consulting with individuals or entities that have the ability to take action to protect the client and, in appropriate cases, seeking the appointment of a guardian ad litem, attorney ad litem, amicus attorney, or conservator, or submitting an information letter to a court with jurisdiction to initiate guardianship proceedings for the client.

(c) When taking protective action pursuant to (b), the lawyer may disclose the client's confidential information to the extent the lawyer reasonably believes is necessary to protect the client's interests.

TAKING PROTECTIVE ACTION COMMENTARY

- Such actions could include consulting with family members, using a reconsideration period to permit clarification or improvement of circumstances, using voluntary surrogate decision-making tools such as existing durable powers of attorney, or consulting with support groups, professional services, adult-protective agencies, or other individuals or entities that have the ability to protect the client.
- In taking any protective action, the lawyer should be guided by such factors as the client's wishes and values to the extent known, the client's best interests, and the goals of intruding into the client's decision-making autonomy to the least extent feasible, maximizing client capacities, and respecting the client's family and social connections.
- If it appears to be necessary to disclose confidential information to a third person to protect the client's best interests, a lawyer should consider whether it would be prudent to ask for the client's consent to the disclosure. Only in compelling cases should the lawyer disclose confidential client information if the client has expressly refused to consent. The authority of a lawyer to disclose confidential client information to protect the interests of the client is limited and extends no further than is reasonably necessary to facilitate protective action.

REPRESENTATION TIPS:

Do not make assumptions!!

Ask your client what, if any, accommodations they might need in your attorney-client relationship.

Engage with client on their level, in environment best suited to conversation. Build rapport and respect by taking your time and show you are really listening.

Be mindful of all forms of communication: words, tone, facial expressions, body language.

Be mindful of common communication deficits: acquiescence, masking, difficulty describing facts/details/sequencing, may not ask questions for clarification or admit they don't understand.

Provide an overview of what you need to discuss with them (first, next)

Check for understanding often by asking them to explain it back to you. Clarify your own understanding of what they said.

Ask simple, yes-no questions when possible.

Avoid asking if they understand, leading questions, open-ended ("do you have any questions for me?")



PREPARATION FOR ADULTHOOD FOR EMERGING ADULTS WITH IDD



SOCIAL SECURITY INSURANCE (SSI)

- SSI is a means-tested program for people with disabilities who meet income and resource limits.
 - Children: Disability is determined by "marked and severe functional limitations." Functional abilities are compared to those of children of the same age who do not have impairments.
 - Adults: The definition of disability is different for adults. Functional impairments are measured against the ability to work and perform substantial gainful activity (SGA), measured in part by an income level set annually by SSA.
- Confirm child is receiving SSI has been through redetermination through SSA to transition to adult SSI, and benefits are active.
- SSI is a very important resource for individuals with IDD, and is required for an individual to move into a HCS slot to cover costs of room and board.
- SSI can take approx. 1 year from application to benefits delivery, do not wait!!

HOME AND COMMUNITY SERVICE (HCS) AND OTHER MEDICAID WAIVERS

- Medicaid Waiver program administered through Local Intellectual Developmental Authority (LIDDA); MUST have a Determination of Disability (DID) to show onset of disability before 18
- DID is evaluation completed by LIDDA, but if well-developed recent outside evaluation meeting criteria exists, can be adopted by LIDDA as DID
- Eligible if IQ of 69 or below, or an IQ of 75 or below plus a related condition (not mental illness)
- Typically 10-15 year waiting list
- Imperative that children with IDD obtain a DID and be placed on interest list no matter what age.

MEDICAID WAIVERS

- HCS is not the ONLY Medicaid waiver to be aware of, but has highest dollar amount benefit per year for highest level of need
- HCS is a lifetime waiver, meaning the individual with IDD can live with their family, in their home, in a host home, or in a small group home with no more than 4 bed, for the rest of their life.
- Includes residential services, adaptive aids, day habilitation, minor home modifications (1 x), nursing care, respite, additional therapies (speech, OT, etc), supported employment, and other services.
- Other Medicaid waivers available include: Youth Empowerment Services (YES), Community Living Assistance and Support Services (CLASS), Deaf-Blind with Multiple Disabilities (DBMD), Tx Home Living (TxHML), Medically Dependent Children Program (MDCP)

Medicaid Waiver Comparisons

PROGRAM SERVICE ¹	Star+Plus	CLASS	HCS	DBMD	TxHML	MDCP
Residential services	Yes		Yes	Yes		
Adaptive aids	Yes	Yes	Yes	Yes	Yes	Yes
Behavior support		Yes	Yes	Yes	Yes	
Case management/service coordination	Yes	Yes	Yes	Yes	Yes	Yes
Day habilitation			Yes	Yes	Yes	
Dental treatment	Yes	Yes	Yes	Yes	Yes	
Emergency response services	Yes	Yes	Yes	Yes	Yes	
Employment assistance (finding a job)	Yes	Yes	Yes	Yes	Yes	Yes
Minor home modifications	Yes	Yes	Yes	Yes	Yes	Yes
Financial Management Services/Support Consultation ²					Yes	
Medical supplies	Yes	Yes	Yes	Yes	Yes	Yes
Nursing	Yes	Yes	Yes	Yes	Yes	
Professional Therapies ³	Yes	Yes	Yes	Yes	Yes	
Respite/MDCP Flexible Family Supports	Yes	Yes	Yes	Yes	Yes	Yes
Supported employment (keeping a job)	Yes	Yes	Yes	Yes	Yes	Yes
Transition assistance services	Yes	Yes	Yes	Yes		Yes
Transportation services		Yes	Yes	Yes	Yes	
Unlimited prescriptions ⁴	Yes	Yes	Yes	Yes	Yes	Yes
Personal attendant services w/ protective supervision	Yes					
Home-delivered meals	Yes					
Prevocational services		Yes				
Specialized Therapies ⁵		Yes				
Auditory integration/enhancement training		Yes				
Chore services				Yes		
Intervener				Yes		
Orientation and mobility				Yes		
Community First Choice personal attendant services and habilitation (CFC PAS/HAB) ⁶	Yes	Yes	Yes	Yes	Yes	Yes

¹ Programs provide services, such as nursing, adaptive aids, dental and therapies, once all non-waiver program requirements, including Medicaid, are met.



WHAT IS GUARDIANSHIP?



GUARDIANSHIP

- Requires a court order under Texas Estates Code § 1101.101 to establish and provide ongoing court oversight.
- Removes the person's freedom of choice, self-determination and independence by removing some or all of a person's decision-making rights.
- Assigns decision-making to a third party (the guardian) until death or otherwise modified.

Rights Removed in Guardianship

- Where to live
- If, when, or how to work
- Medical decisions
- Financial decisions
- Ability to drive a car
- Ability to vote
- Ability to get married

WHO IS AN INCAPACITATED PERSON?

“Incapacitated person” means:

(1) a minor;

(2) an adult who, because of a physical or mental condition, is substantially unable to:

- (A) provide food, clothing, or shelter for himself or herself;
- (B) care for the person's own physical health; or
- (C) manage the person's own financial affairs; or

(3) a person who must have a guardian appointed for the person to receive funds due the person from a governmental source.

Tex. Estates Code Ann. § 1002.017

GUARDIANSHIP FINDINGS

(1) find by **clear and convincing** evidence that:

(A) the proposed ward is an incapacitated person;

(B) it is in the proposed ward's best interest to have the court appoint a person as the proposed ward's guardian;

(C) the proposed ward's rights or property will be protected by the appointment of a guardian;

(D) alternatives to guardianship that would avoid the need for the appointment of a guardian have been considered and determined not to be feasible; and

(E) supports and services available to the proposed ward that would avoid the need for the appointment of a guardian have been considered and determined not to be feasible; and

WHAT CAN A GUARDIANSHIP NOT DO?

- Prevent the proposed ward from making bad decisions
- Prevent the proposed ward from physically leaving a home or placement
- Cannot physically force the proposed ward to take medication
- Cannot place the proposed ward in mental health hospital against their will
- Guardian is not responsible for personally funding the ward's living expenses or paying off the ward's past debts



ALTERNATIVES TO GUARDIANSHIP



OVERRELIANCE ON GUARDIANSHIP

- Belief that all persons with IDD require a legal guardian.
- Caregiver thinks it is necessary in order for caregiver to participate in school, health care or other decisions after age 18.
- Concern about young adult handling their own money.
- Belief legal guardianship required to access HCS or other Medicaid waiver programs
- May believe this is the only legal solution.

IMPORTANT THINGS TO REMEMBER

- The law presumes all adults have the capacity for decision-making – this applies to everyone, including people with disabilities.
- Decision-making is a learned skill – people with disabilities need opportunity, experience and support to learn to make well informed decisions.
- There are other legal ways to assist people with decision-making that do not restrict, limit or remove individual rights.
- Over-reliance in guardianship can hinder or prevent inclusion, self-determination and community integration in violation of the ADA.

ALTERNATIVES TO GUARDIANSHIP

- Supported Decision-making (SDMA)
- Power of Attorney
- Representative Payee

WHAT IS SUPPORTED DECISION-MAKING?

“A process of supporting and accommodating an adult with a disability to enable the adult to make life decisions, including decisions related to where the adult wants to live, the services, supports, and medical care the adult wants to receive, whom the adult wants to live with, and where the adult wants to work, without impeding the self-determination of the adult.”

Tex. Est. Code §§ 1357.002(3); 1357.003

- While there is no “one-size-fits-all” model for supported decision-making, it generally occurs when people receive assistance from one or more trusted friends, family members, professionals or advocates to help them understand the situations they face and choices and options they have so they can make their own decisions.
- Approved by Texas legislature as alternative to guardianship in 2015, courts **MUST** consider whether lesser restrictive alternatives are able to meet the proposed ward’s needs before entering guardianship order. *Tex. Est. Code § 1002.0015(10)*

SUPPORTED DECISION-MAKING AGREEMENT

Who can enter a SDMA?

- Any individual over 18 who has a physical or mental impairment that substantially limits one or more major life activity. *Tex. Est. Code § 1357.002(1) & (2)*
- The level of capacity a person must have in order to enter a supported decision-making agreement is not defined. However, the person must understand the nature and consequences of his or her entering a supported decision-making agreement when the supported decision-making agreement is signed. *In the Estate of Vackar, 345 S.W.3d 588, 597-598 (Tex. App.-San Antonio 2011, no pet.)*

Who can be the supporter?

- The law does not place any restrictions on who may become a supporter.
- The person who needs the support decides on someone they trust.
- Typically, the supporter may be a family member, relative or friend selected by the person with a disability.
 - *Tex. Est. Code § 1357.002(5)*

WHAT CAN A SUPPORTER DO?

A supporter may do any or all of the following:

- 1) Assist adult with a disability in understanding options, responsibilities and consequences of life decisions;
- 2) Assist adult with a disability in accessing, collecting and obtaining medical, psychological, financial, educational and treatment records;
- 3) Assist adult with a disability in understanding information in (2); and
- 4) Assist adult with a disability in communicating his or her decision to appropriate persons.

Tex. Est. Code § 1357.051

ACCESS TO CONFIDENTIAL INFORMATION

- A supporter is only authorized to assist adult with a disability to access, collect or obtain information.
- This includes protected health information under HIPAA and education records under FERPA.
- A supporter shall ensure that information is kept privileged and confidential and is not subject to unauthorized access, use or disclosure.
- A supported decision-making agreement does not prevent an adult with a disability from seeking personal information on his or her own without the assistance of the supporter.

Tex. Est. Code § 1357.054

FIDUCIARY DUTY

- **A supporter has a fiduciary duty to the adult with a disability.**
- A supported decision making-agreement creates a relationship of trust and confidence between the adult with a disability and the supporter and does not undermine the decision-making authority of the adult with a disability.

Tex. Est. Code § 1357.052(b) & (c)

WHEN DOES A SUPPORTED DECISION-MAKING AGREEMENT END?

A supported decision-making agreement ends:

- 1) When terminated by the adult with a disability or the supporter;
- 2) By the terms of the agreement;
- 3) If the Department of Family and Protective Services finds that adult with a disability has been abused, neglected or exploited by the supporter; or
- 4) The supporter is found criminally liable for the abuse, neglect or exploitation of the adult with a disability.

Tex. Est. Code § 1357.053

ASK FOR HELP

Disability Rights Texas

<http://www.disabilityrightstx.org/>

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