

Global Developmental Delay and Intellectual Developmental Disorder

History, work up and more

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Objectives:

1. Review diagnostic criteria of GDD and IDD
2. Understand work up and interventions/ support for GDD and IDD
3. Place both of these diagnosis within historical context
4. Discuss prognosis of GDD and IDD

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Definitions and Diagnostic Criteria

Why do we diagnosis?

Outcomes/ prognosis

3

I have nothing to disclose.

4

Definitions and Diagnostic Criteria

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Developmental Milestones

Gesell Developmental Schedules, first published in **1925** by Dr. Arnold Gesell. First set of “standardized stages”

Denver Developmental Screening Test (DDST) was published in **1967** to identify young children, up to age six, with developmental problems

Bayley Scales of Infant Development, first published by psychologist Nancy Bayley in **1969**.


Centers for Disease Control and Prevention (CDC) first released their **developmental milestones** in **2004** as part of the “Learn the Signs. Act Early.”

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CDC Milestones

SPECIAL ARTICLES | FEBRUARY 08 2022

Evidence-Informed Milestones for Developmental Surveillance Tools **FREE**

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Global Developmental Delay DSM-5

Significant delays in 2 or more developmental domains:

- Motor (gross and/or fine)
- Speech/language (expressive and/or receptive)
- Cognition
- Social/personal
- Adaptive/ activities of daily living

Children less than 5

Not meeting typical milestones

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Developmental Delay- Part B and Part C IDEA

Part C added in 1986

Federal Grants to cover services for 0-3

Developmental delay- 0-3 (Part C) 3-9 (Part B)

- Delays in 1 or more of the following areas:
 - Physical development
 - Cognitive development
 - Communication development
 - Social or emotional development
 - Adaptive development

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Developmental Delay

Definition under part C is left up to the states.

Massachusetts definition:

The infant or toddler's development is at least 1.5 standard deviations below the mean, as measured by the *Battelle Developmental Inventory* – 2nd Ed. (BDI-2), in one or more areas of development, including: physical development (includes gross and fine motor),

- cognitive development,
- communication development (includes expressive and receptive),
- social or emotional development, or
- adaptive development.

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History of IDD terms:

1552 B.C. first recorded reference to "mental retardation": Therapeutic Papyrus of Thebes.

Howe's *On the Causes of Idiocy* (1845): 1st classification based on severity

Idiots: had some muscular control and some cognitive functioning.

Fools: have almost no reasoning skills and major delays in speech.

Simpletons: This group possessed motor skills and adequate reasoning skills.

Cretin: come from the French word meaning Christian. Originally reflected the notion that people with IDs were still Christians and should be treated with kindness..

Amentia It is mostly associated with dementia. The difference between amentia and dementia was age. Amentia was used when someone developed deficits in mental functioning early in life.

Idiot is derived from the Greek language. It was used to classify people with severe intellectual disabilities. It referred to people who could not take care of themselves and required 24-hour care. The term gradually became mainstreamed. By the mid-1890s, its derogatory usage caused the medical community to discontinue its use.

Imbecile is a French term. It is derived from a Latin word meaning "without support." The term originally referred to someone who was physically weak. This term was used from the mid-16th century, to the early 19th century. Imbecile was a medical term to classify people with moderate ID. Like the term idiot, it gradually entered the vernacular and became a term of abuse.

Moron was an invented word. A psychologist named Henry Goddard developed the term. It was used to classify people with mild intellectual disabilities.

Feebly Minded comes from the Latin word *febilis*. It means, "to be lamented." It referred to people who were not profoundly disabled, but still required intervention and care.

Mental Retardation: Term 1st included in DSM II → replaced by ID in DSM 5 and IDD in DSM 5TR

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DO
IQ
TESTS
WORK?



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DSM-IV definition

According to DSM-IV criteria, an individual is diagnosed with mental retardation if they have significantly below average intellectual functioning, as defined by an intelligence quotient (IQ) at or below 70.

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Intellectual Disability (ID) → Intellectual Developmental Disorder (IDD)

- IDD- updated in the DSM 5 TR
- Includes:
 - [(F70) mild
 - (F71) moderate
 - (F72) severe
 - (F73) profound

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Intellectual Developmental Disorder

DSM 5 Criteria from DSM5 TR manual, 2013

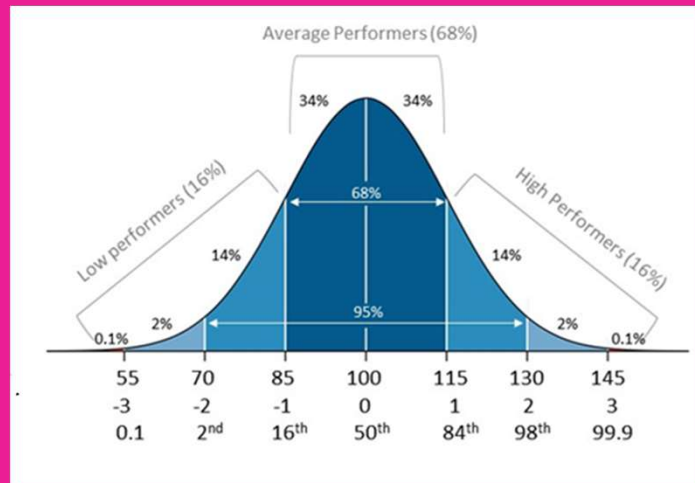
Disorder with the onset during the developmental period that includes both intellectual AND adaptive functioning deficits in conceptual, social & practical domains. The following 3 criteria must be met:

- **Deficits in intellectual functions**, such as reasoning, problem solving, planning, abstract thinking, judgement, academic learning, and learning from experience, confirmed by both clinical assessment and individualized, standardized intelligence testing
- **Deficits in adaptive functioning** that results in failure to meet developmental and sociocultural responsibility. Without ongoing support, the adaptive deficits limit functioning in 1 or more activities of daily life, such as *communication, social participation, & independent living*, across multiple environments, such as home, school, work & community.
- **Onset** of intellectual & adaptive deficits **during the developmental period**

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IQ Testing

Descriptive Range	Standard Scores
IDD	<70
Borderline	70-85
Average	85-115
Above Average	115-130
Very Superior	>130



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What is Adaptive Behavior?

- Collection of learned **conceptual**, **social**, and **practical skills** needed to effectively and independently care for oneself, respond to others, and meet environmental demands of daily living at home, school, work and within the community.



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What is Adaptive Behavior?

- As environments change, people must learn new skills in order continue to meet the environmental demands.
- Typical Skills (not peak ability)
- What an individual ***does do*** (not what *can* they do) without prompts, supports or reminders
- Age related



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"Developmental delays are **commas,
not **periods**. your child can still get there"**



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Qualifying for services

GDD

- Access to EI
- Access to IEP
- Speech, PT and OT through insurance

IDD

- SSI
- DDS
- IEP supports
- IEP until 22
- Vocational support through DDS

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FROM THE AMERICAN ACADEMY OF PEDIATRICS | CLINICAL REPORT | SEPTEMBER 01 2014

Comprehensive Evaluation of the Child With Intellectual Disability or Global Developmental Delays **FREE**

John B. Moeschler, MD; Michael Shevell, MDCM; COMMITTEE ON GENETICS; John B. Moeschler, MD; Michael Shevell, MD; Robert A. Saul, MD; Emily Chen, MD; Debra L. Freedenberg, MD; Rizwan Hamid, MD; Marilyn C. Jones, MD; Joan M. Stoler, MD; Beth Anne Tarini, MD

Pediatrics (2014) 134 (3): e903–e918.

<https://doi.org/10.1542/peds.2014-1839>

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TABLE 1

The Purposes of the Comprehensive Medical Genetics Evaluation of the Young Child With GDD or ID

1. Clarification of etiology
2. Provision of prognosis or expected clinical course
3. Discussion of genetic mechanism(s) and recurrence risks
4. Refined treatment options
5. Avoidance of unnecessary or redundant diagnostic tests
6. Information regarding treatment, symptom management, or surveillance for known complications
7. Provision of condition-specific family support
8. Access to research treatment protocols
9. Opportunity for comanagement of appropriate patients in the context of a medical home to ensure the best health, social, and health care services satisfaction outcomes for the child and family

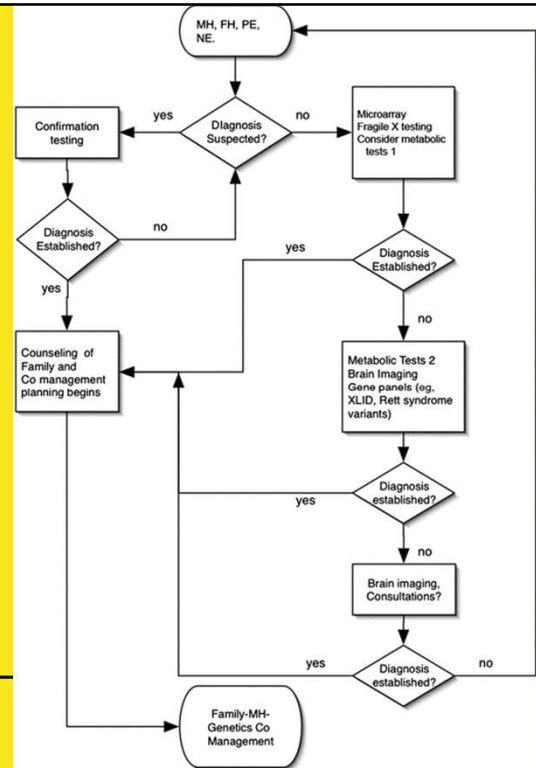
Pediatrics. 2014;134(3):e903–e918. doi:10.1542/peds.2014-1839

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CMA and Fragile X

Consider metabolic, gene panels and imaging/ consults pending NE and initial work up

Pediatrics. 2014;134(3):e903-e918. doi:10.1542/peds.2014-1839



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Outcomes...

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Outcomes

Outcomes for GDD vary based on services, interventions and socioeconomic factors

Vary based on cause/ underlying diagnosis

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Typical adaptive needs and supports according to severity of intellectual disability

Severity level		Adaptive skill domains		
DSM-5 categories	AAIDD categories	Conceptual	Social	Practical
Mild	Intermittent	Children require academic supports to learn skills expected for age. Adults may have difficulties with functional academic skills such as planning, reading, and money management.	Social skills and personal judgement are immature for age. The individual is at risk of being manipulated by others (gullibility).	Most individuals achieve independence in daily living and personal care activities; most are employable in jobs requiring simple skills and are often able to live independently. They typically need support for making decisions in health care, nutrition, shopping, finances, and raising a family.
Moderate	Limited	For children, conceptual and academic skills lag well behind those of peers. For adults, academic skills are typically attainable at an elementary level. Complex tasks such as money management need substantial support.	Successful friendships with family/friends are possible using simple spoken language, but the individual is limited by deficits in social and communicative skills. Social cues, social judgment, and social and life decisions regularly need support.	Most individuals are capable of personal care activities with sufficient teaching and support, and achieve independent self-care with moderate supports, such as is available in a group home. Adults may be employable in a supported environment.
Severe	Extensive	Individuals have little understanding of written language, or number, time, and money concepts. Caretakers provide extensive supports for problem-solving.	Individuals benefit from healthy supportive interactions with family/familiar people and may use very basic single words, phrases, or gestures pertinent to their direct experience.	Individuals are trainable in some basic activities of daily living with significant ongoing support and supervision.
Profound	Pervasive	Individuals may use objects in a goal-directed fashion for self-care and recreation.	Although understanding of symbolic communication is very limited, individuals may understand some gestures and emotional cues, and can express themselves nonverbally.	Individuals are typically dependent upon support for all activities of everyday living. Co-occurring sensory or physical limitations are common.

Uptodate article ID

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Mild Intellectual Disability

- **Skill Development:** Attain skills at 50% to 66% the rate of typically developing peers.
- **Academic Achievement:** Achieve reading levels between 3rd and 6th grade by late adolescence; some adults may remain functionally illiterate.
- **Social and Communication Skills:** Generally possess better social skills and communication; capable of forming friendships and engaging in social activities.
- **Daily Living and Independence:** Most can perform independent daily activities; many live independently with support in areas like health, finances, and parenting.
- **Vocational and Long-Term Outcomes:** Potential for employment in roles requiring basic skills, especially with individualized support; success linked to cognitive and adaptive abilities, behavior, educational attainment, and vocational training

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Moderate Intellectual Disability:

- **Skill Development:** Develop skills at approximately 33% to 50% the rate of typically developing children.
- **Academic Achievement:** Typically achieve academic skills up to 1st to 3rd grade level; can learn to read essential words and signs.
- **Social and Communication Skills:** Capable of simple spoken language and forming basic social connections; significant limitations in social judgment and decision-making.
- **Daily Living and Independence:** Most learn basic self-care and daily living skills with appropriate support; complex tasks like money management require assistance.
- **Vocational and Long-Term Outcomes:** Often engage in supported, noncompetitive employment; few are able to marry or raise children.

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Severe Intellectual Disability:

- **Skill Development:** Gain skills at approximately 25% to 33% of the rate of typically developing children.
- **Academic Achievement:** Limited understanding of written language or numerical concepts; caretakers provide extensive help in problem-solving.
- **Social and Communication Skills:** May develop basic communication skills, often using single words or gestures; benefit from interactions with familiar individuals.
- **Daily Living and Independence:** Require training in social and self-help skills; significant ongoing support and supervision needed.
- **Vocational and Long-Term Outcomes:** May participate in sheltered vocational settings; generally do not marry or raise children; associated with reduced lifespan.

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Profound Intellectual Disability:

- **Skill Development:** May express themselves nonverbally; outcomes highly variable.
- **Academic Achievement:** Do not learn to read; may understand simple instructions or gestures.
- **Social and Communication Skills:** Usually dependent in all aspects of daily living; benefit from training in self-help skills, though progress is very slow.
- **Daily Living and Independence:** Require comprehensive assistance; often have concurrent sensory and physical limitations.
- **Vocational and Long-Term Outcomes:** Do not engage in employment; profound ID is associated with reduced life expectancy.

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key takeaways

Definition:

- GDD- delay in 2 domains
- IDD- delay in cognitive and adaptive skills

WHY?

- services, supports and medical work up

Outcomes

- Vary based on severity
 - Not all GDD»IDD
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Questions?

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