Diagnosing and Evaluating Children with Developmental Disabilities

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June 20, 2016

OUTLINE

• Introductions
• Background
• Definitions, terminology, and prevalence
• Determination of developmental disabilities
• Tools/process to assess children in the determination of developmental disabilities
• Q&A

Background

Intermediate Care Facilities for individuals with Intellectual Disability (ICD/IID or ICF/ID) program was established in 1971 as an optional service under states’ Medicaid programs.

This amendment to the Social Security Act permitted states to receive federal matching funds for institutional programs serving only individuals with ID for the first time.

The program authorizes the federal government to “waive” certain Medicaid statutory provisions and allow states to offer home and community-based services (HCBS) to individuals who would otherwise qualify for institutional services (Zaharia & Moseley, 2008).

Hence, eligibility for HCBS Medicaid waiver(s) is directly linked to a defined ICF/ID “level of care”.

Eligibility for DD services is defined at a state level. Eligibility can be defined either on the basis of a list of conditions/diagnoses (e.g., ID, ASD, cerebral palsy, etc.) or on a functional assessment basis.

Generally, states’ functional definition is inspired from the federal definition of developmental disabilities found in the Federal Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act).

Most states use a combination of both: functional + specific conditions.

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The Medicaid “waiver” programs were authorized in 1981 under Section 1915(c) of the Social Security Act to provide states with a means of providing home and community-based alternatives to institutionalization in an ICF/ID, nursing facilities and/or hospitals.

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**DD Act**

*Developmental Disabilities Assistance and Bill of Rights Act of 2000*

**Definition of Developmental Disability**

A. **IN GENERAL.** The term "developmental disability" means a severe, chronic disability of an individual that:

B. **INFANTS AND YOUNG CHILDREN.** An individual from birth to age 9, inclusive, who has a substantial developmental delay or specific congenital or acquired condition, may be considered to have a developmental disability without meeting 3 or more of the criteria described in (1) through (5) of subparagraph (A) if the individual, without services and supports, has a high probability of meeting those criteria later in life.


**MARYLAND Code, Health General Art. §7-101**

"Developmental disability" means a severe, chronic disability of an individual that:

1. Is attributable to a physical or mental impairment other than the sole diagnosis of mental illness, or to a combination of mental and physical impairments;
2. Is manifested before the individual becomes 22 years old;
3. Is likely to continue indefinitely;
4. Results in an inability to live independently without external support or continuing and regular assistance; and
5. Reflects the need for a combination of special, interdisciplinary, or generic care, treatment, or other services that are individually planned and coordinated for the individual.

**MARYLAND Code, Health General Art. §7-101 (CONTD)**

"External support" means:

1. Periodic monitoring of the circumstances of an individual with respect to:
   i. Personal management;
   ii. Household management; and
   iii. The use of community resources; and
2. Rendering appropriate advice or assistance that may be needed.
“Live Independently / Independent Living” means:

1. For adults:
   i. Managing personal care, such as clothing and medication;
   ii. Managing a household, such as menu planning, food preparation and shopping, essential care of the premises, and budgeting; and
   iii. Using community resources, such as commercial establishments, transportation, and services of public agencies; or

2. For minors, functioning in normal settings without the need for supervision or assistance other than supervision or assistance that is age appropriate.

Prevalence of DD

<table>
<thead>
<tr>
<th>Overall Prevalence for Noninstitutionalized US Children 3-17 Years Disability Prevalence</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Any developmental disability</td>
<td>13.9%</td>
</tr>
<tr>
<td>ADHD</td>
<td>6.7%</td>
</tr>
<tr>
<td>Autism</td>
<td>0.5%</td>
</tr>
<tr>
<td>Blind, unable to see</td>
<td>0.1%</td>
</tr>
<tr>
<td>Cerebral palsy</td>
<td>0.4%</td>
</tr>
<tr>
<td>Intellectual disability</td>
<td>0.7%</td>
</tr>
<tr>
<td>Learning disability</td>
<td>7.0%</td>
</tr>
<tr>
<td>Moderate to profound hearing loss</td>
<td>0.5%</td>
</tr>
<tr>
<td>Seizures</td>
<td>0.7%</td>
</tr>
<tr>
<td>Stammering/stuttering</td>
<td>1.6%</td>
</tr>
<tr>
<td>Other developmental delay</td>
<td>3.7%</td>
</tr>
</tbody>
</table>

Trends in Prevalence of Any Developmental Disability

Prevalence of ASD


Prevalence Rate of ASD


- 2007: 1 in 2,000
- 2009: 1 in 150
- 2012: 1 in 110
- 2014: 1 in 88
- 2016: 1 in 68

Prevalence of DD or ID

Prevalence study of individuals living in the community (non-institutionalized).

• 1.5% of US Population (Larson et al., 2001)

Prevalence of DD or ID
1.5% of US Population (Larson et al., 2001)

Percentages – Across Lifespan

- DD - no ID
- DD & ID
- ID - no DD

Prevalence of DD or ID
1.5% of US Population (Larson et al., 2001)

Diagnosis of Intellectual Disability

2 national diagnostic systems used to define/diagnose intellectual disability

• Diagnostic and Statistical Manual for Mental Disorders (5th Edition) (DSM-5; American Psychiatric Association, 2013)

Diagnosis of Intellectual Disability

Characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills.

These significant limitations originate during the developmental period. [AAIDD – specifies age 18.]

Intellectual Functioning

“Subaverage intellectual functioning” is typically measured with individually administered and psychometrically valid, comprehensive, culturally appropriate, psychometrically sound tests of intelligence. Clinical judgment is needed in interpreting the results of IQ tests (APA, 2013: p. 37).

- Wechsler Preschool & Primary Scale of Intelligence – 4th Edition
  - Ages: 2:6 – 7:7 years old
- Wechsler Intelligence Scale for Children – 5th Edition
  - Ages: 6:0 – 16:11 years old
- Wechsler Adult Intelligence Scale – 5th Edition
  - Ages: 16:0 – 90:11 years old
- Stanford-Binet Intelligence Scales – 5th Edition
  - Ages: 2:0 – 85:0 years old
  - Ages: 2:0 – 90:0 years old
- CAS, DAS, K-ABC, ...


Additional sources of information include educational, developmental, medical, and mental health evaluations. Scores from standardized measures and interview sources must be interpreted using clinical judgment (APA, 2013: p. 38).


Adaptive Behavior

Adaptive functioning is assessed using both clinical evaluation and individualized, culturally appropriate, psychometrically sound measures. Standardized measures are used with knowledgeable informants (e.g., parent or other family member, teacher, counselor, care provider) and the individual to the extent possible (APA, 2013: p. 37).

- Vineland Adaptive Behavior Scales – 2nd Edition
  - Ages: 0 – 90 years old
- Adaptive Behavior Assessment System – 3rd Edition
  - Ages: 0 – 89 years old
- Scales of Independent Behavior – Revised
  - Ages: 3 months – 80+ years old
- Adaptive Behavior Diagnostic Scale
  - Ages: 2 – 21 years old


Autism Spectrum Disorder

A. Persistent deficits in social communication across settings, including: social reciprocity, nonverbal communication, building and maintaining relationships.
Autism Spectrum Disorder

Restrictive Repetitive Behaviors

B. Restrictive, Repetitive patterns of Behavior (RRB), interests, or activities such as: stereotyped motor behaviors, use of objects or speech; insistence on sameness; highly fixed and restricted interests; hyper- or hypo-reactivity to sensory input or other sensory aspects.


Establishing a Diagnosis of ASD
(Huerta & Lord, 2012)

• Multi-faceted evaluation / interdisciplinary evaluation team.
• Inclusion of standardized tools:
  • Parent/Caregiver Interviews (ADI-R)
    • Ages: 2:0 years old - adulthood
  • Direct observation of child’s functioning and behavior (ADOS-2)
    • Ages: 18 months old - adulthood
  • Cognitive testing / intellectual functioning
  • Developmental / adaptive functioning
  • Language assessment => important to differentiate ASD from other developmental disabilities


Survey of States’ DD Determination

47 states responded to Zaharia & Moseley (2008) survey regarding DD determination for HCBS programs.

• All 47 states reported using some form of assessment of the individual’s functional ability.
• 8 of 47 states used a purely “functional definition” – with no specification regarding existing diagnostic conditions.
• 39 of 47 states used a combination of both impairments in functional skills (e.g., 3 of 6/7) + categorical criterion (person must have a diagnosis from a specified list – e.g., ID, ASD, cerebral palsy, etc.)

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DD Act

Definition of Developmental Disability

A. IN GENERAL. The term “developmental disability” means a severe, chronic disability of an individual that:

1. Is attributable to a mental or physical impairment or combination of mental and physical impairments;
2. Is manifested before the individual attains age 22;
3. Is likely to continue indefinitely;
4. Results in substantial functional limitations in 3 or more of the following areas of major life activity:
   i. Self-care.
   ii. Receptive and expressive language.
   iii. Learning.
   iv. Mobility.
   v. Self-direction.
   vi. Capacity for independent living.
5. Reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated.

Assessing Life Activity Areas or Adaptive Functioning

- AAIDD
- DSM-5

Adaptive Functioning/Behavior Domains:

- CONCEPTUAL
- SOCIAL
- PRACTICAL

Adaptive Behavior

Conceptual skills:
- language, functional academics, self-direction, money management, time concepts.

Social skills:
- interpersonal skills, responsibility, self-esteem, wariness/naïveté, follow rules, etiquette, social problem solving.

Practical skills:
- activities of daily living, occupational skills, safety, healthcare, travel.
Major Life Activity Areas ↔ Adaptive Behavior

<table>
<thead>
<tr>
<th>Life Activity Areas</th>
<th>Adaptive Skill Areas</th>
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<tbody>
<tr>
<td>Receptive and expressive language</td>
<td>Conceptual: communication, language</td>
</tr>
<tr>
<td>Learning</td>
<td>Conceptual: functional academics, time concepts.</td>
</tr>
<tr>
<td>Mobility</td>
<td>Practical: motor, travel.</td>
</tr>
<tr>
<td>Self-direction</td>
<td>Conceptual: self-direction</td>
</tr>
<tr>
<td></td>
<td>Social: responsibility, self-esteem.</td>
</tr>
<tr>
<td>Capacity for independent living</td>
<td>Practical: activities of daily living, health &amp; safety, follow rules.</td>
</tr>
<tr>
<td></td>
<td>Social: wariness/naïveté, social problem solving, interpersonal skills.</td>
</tr>
<tr>
<td>Economic self-sufficiency</td>
<td>Practical: occupational skills, money management.</td>
</tr>
</tbody>
</table>

Assessing Adaptive Functioning

Adaptive Behavior are skills that have been learned and are performed to meet expectations and demands of our environment and community – which are indexed on our chronological age.

When assessing “Adaptive Behavior” we always assess what the person TYPICALLY does. We are NOT assessing the skills that the person is “able” or “might be able” to do but does not perform.

AAIDD User’s Guide
(Schalock et al., 2012, p. 19)

- Use standardized assessment instruments;
- Select appropriate measures of adaptive behavior (normed on typical population – with appropriate same-age peers);
- Use multiple informants/sources/contexts;
- Assess in environments typical of individuals’ age and culture;
- Assess typical/actual functioning and NOT capacity or maximum ability;
- Many social adaptive skills not assessed on current measure of adaptive behavior (e.g., gullibility, naïveté);
- Adaptive behavior and problem behavior are separate constructs – and are not necessarily related.

Assessing Adaptive Functioning

Life Activity Areas:

Standardized Assessment Tools
- Vineland – II
- ABAS-3
- SIB-R

Records/Info You Want/Need

- Family history
- Medical records / pregnancy / birth information
- Good understanding of home environment
- School records (class placement, testing, school behavior & performance, repeated any grades, IEP)
- Previous psychological testing (reasons for referral, results)
- Previous diagnoses
- Social Security Administration (any records, assessment)
- Other state or government agency (e.g., state DD dept., child welfare, social services, etc.)
In Addition to Standardized Scales & Records Review

Meeting/Interviewing Significant Others

Informal Interview Questions

- Relationship to/History with __________?
- How long did you know ____________?
- Context?
- When was the last time you saw him or lived with him before he went to prison?
- How well do/did you know him?
- How well do you remember him today?

Conceptual Skills

“Compared to others of ________’s age … how are/were her/his adaptive behaviors?”

- Language – using and understanding
- Reading / writing (compared to same-age peers)
- Money concepts (budgeting, checking change, banking)
- Self-direction (making choices for self, independence, independent thought/action)

Social Skills

“Compared to others of ________’s age … how are/were her/his adaptive behaviors?”

- Interpersonal Skills
- Social Responsibility (knowing/doing right from wrong)
- Self-esteem
- Gullibility (likelihood of being tricked or manipulated?)

Social Skills

“Compared to others of ________’s age … how are/were her/his adaptive behaviors?”

- Naivete (simple/unsuspecting of others/lack of critical judgment: compared to others of his age)
- Follow rules/obey laws

Practical Skills

“Compared to others of ________’s age … how are/were her/his adaptive behaviors?”

- Personal care (Hygiene) – doing it her/himself versus parent?
- Domestic skills / Home-living skills
- Health & safety skills (personal safety – crossing street / illness / safe-sex – home safety)
- Work/vocational skills
Information Obtained is Only as Reliable/Good as the Source/Respondent

- Clinical judgment is critical here.
- Who can be a respondent? Anyone who had the opportunity to observe the individual function on a regular basis, over an extended period of time, in one or more natural contexts (e.g., school, home, community, etc.);
- Knowledgeable;
- Often requires more than one informant / measure → Check measure re: multiple respondents, reliability / convergence / contradictions;
- Respondent bias must be taken into account if ratings have consequences for rater; important to assess reliability.
- Make sure the respondent is reporting on observations of actual skill performance and not outcome (e.g., looked neatly dressed).

Assessing Developmental Disabilities in Children

- Clinical judgment plays a critical role throughout
- Use well normed and standardized assessment instruments
- Complement standardized assessment tools with a review of existing information from other sources + other conversations/interviews with others
- Include information from multiple sources and multiple respondents
- Early identification and provision of services and supports is critical to improving the long-term functioning and personal outcomes

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