Developmental Disabilities: An Overview
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My Background
Overview

Definitions of key terms

Language

Models of disability

Changing criteria
An individual with a disability is defined by the ADA as a person who has a physical or mental impairment that substantially limits one or more major life activities, a person who has a history or record of such an impairment, or a person who is perceived by others as having such an impairment.
Defining Developmental Disabilities

- A cognitive and/or physical disability that began before age 22, is expected to continue indefinitely, and substantially limits activities of daily life

Examples
- Autism spectrum disorders
- Cerebral palsy
- Down syndrome
- Fetal alcohol syndrome
- Intellectual disability
1 in 6 children in the U.S with a developmental disability
Increased prevalence from 1997 (13%) to 2008 (15%)
<table>
<thead>
<tr>
<th>Disability Type</th>
<th>Disability Type</th>
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<tbody>
<tr>
<td>autism</td>
<td>specific learning disability</td>
</tr>
<tr>
<td>deaf-blindness</td>
<td>speech or language impairment</td>
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<tr>
<td>deafness</td>
<td>traumatic brain injury</td>
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<tr>
<td>emotional disturbance</td>
<td>visual impairment (including blindness)</td>
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<tr>
<td>hearing impairment</td>
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<tr>
<td>intellectual disability</td>
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<tr>
<td>multiple disabilities</td>
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<td>orthopedic impairment</td>
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<td>other health impairment</td>
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Key Points

These are legal definitions, not medical/psychological diagnoses

Most legal definitions (ADA, DD Act) do not define specific diagnoses covered under the definition

People with the same diagnosis (e.g., autism spectrum disorder) may differ in their disability status

IDEA does specify categories of disability, but individuals must also show need for special education services
Defining Intellectual Disability

Intellectual disability is characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18.

American Association of Intellectual and Developmental Disabilities
“Significant limitations”

Two standard deviations below the mean
Assumptions of the AAIDDD Definition

1) Limitations in present functioning must be considered within the context of community environments typical of the individual’s age peers and culture.

2) Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor and behavioral factors.

3) Within an individual, limitations often coexist with strengths.

4) An important purpose of describing limitations is to develop a profile of needed supports.

5) With appropriate personalized supports over a sustained period, the life functioning of the person with ID generally with improve.
Key Points

Unlike “disability” and “developmental disability”, “intellectual disability” is a diagnosis

- The AAIDD definition is the most widely used
- ID is not a spectrum, there are no “levels”
- Intellectual disability is also defined in the DSM

Intellectual Disability is NOT:
- Intellectual disabilities (it’s not an umbrella category)
- Cognitive disability
- Learning disability (except in the British Commonwealth)
Defining Autism Spectrum Disorder

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
Defining Autism Spectrum Disorder

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history

2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
Defining Autism Spectrum Disorder

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history

3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.
Defining Autism Spectrum Disorder

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
Defining Autism Spectrum Disorder

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).
Defining Autism Spectrum Disorder

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).
Defining Autism Spectrum Disorder

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

4. Hyper- or hyporeactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).
Defining Autism Spectrum Disorder

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.
Severity of ASD

Level 3: Requiring very substantial support

Level 2: Requiring substantial support

Level 1: Requiring support
Key Points

This is a new definition of autism spectrum disorder
- The “spectrum” did not previously exist

Autism spectrum disorder is not an umbrella category

Autism spectrum disorder overlaps considerably with ID (roughly 50%), but is distinct from ID

There is no such thing as “high functioning autism”
Perspectives on “High Functioning”
What changed in the DSM-V?

Pervasive Developmental Disorder

- Pervasive Developmental Disorder-Not Otherwise Specified
- Asperger’s Disorder
- Autistic Disorder
- Rett Syndrome
- Childhood Disintegrative Disorder

Distinct Medical Condition
What changed in the DSM-V?

Why was this change needed?
What happened to the “Aspies”?  
Did this reduce the number of people with ASD?
Developmental Delay

What is meant by “developmental delay”?

How is “developmental delay” distinct from intellectual disability or developmental disability?

When should we stop using the term “developmental delay”? 
Terminology

IMPAIREDMENT
An impairment is any loss or abnormality of psychological, physiological, or anatomical structure or function

DISABLED
A disability is a restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being

HANDICAP
A handicap is a physical or attitudinal constraint imposed upon a person, regardless of whether or not they have a disability

*These terms should not be used interchangeably*
David
6 years old
Cerebral palsy
David
6 years old
Cerebral palsy

Impairment
Impairment

Disability

David
6 years old
Cerebral palsy
David
6 years old
Cerebral palsy

Impairment
Disability
Handicap
“The difference between the almost right word and the right word is really a large matter – ‘tis the difference between the lightning bug and the lightning”

- Mark Twain
Language about Disability

Language is fluid

Like any group of people, people with disabilities often do not agree on what terminology is “correct” for their “group”

Language plays an important role in shaping beliefs and behavior

Language used to describe people with disabilities, or the disabilities themselves, should be used with care

Not everyone with a disability will agree with the suggestions provided
Person-First Language

When speaking about people with disabilities, *put the person first*

Referencing the person before their disability conveys respect
- “Person with a disability” rather than “disabled person”

People are not medical conditions
- “People who have epilepsy” not “epileptics”

When interacting with a person with a disability, you should use their name

If relevant, you can ask a person how they would prefer to be called

Never assume someone is aware of or comfortable with the terms applied to them
Identity-First Language

Some people or groups of people will prefer Identity first language

Identity first language puts the identity first, as this cannot be disentangled from the person

“He’s an autistic person”
“She is Deaf”
Ongoing Controversy
Words to Avoid

- Special
- Burden
- Unfortunate
- Sick
- Fragile
- Deformed
- Retarded
- Cripple
- Deaf and dumb
- Dependent
- Abnormal
- Patient
- Dumb
Words to Avoid

- **Avoid** suggesting that people with disabilities are in any way menaces to society or somehow inferior
- **Avoid** suggesting that people with disabilities are in need of charity
- **Avoid** words like courageous, brave and inspirational

*I’m not your inspiration*

*Stella Young*
Shifting Paradigms

Medical Model of Disability  Social Model of Disability

Individuals with disabilities are defective and need to be fixed
Shifting Paradigms

Medical Model of Disability

Individuals with disabilities are defective and need to be fixed

Social Model of Disability

Disability is the result of a restricting context and the environment needs to be fixed
Views on Disability

What is the social model of disability? (Scope Video)