Developmental Disabilities: An Overview

ASHLEY WOODMAN, PH.D.

UMASS AMHERST

My Background





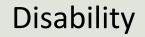
Overview

Definitions of key terms

Language

Models of disability

Changing criteria



Developmental Disability

Autism Intell Spectorah Disa Disalever

Defining Disability

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.

Americans with Disabilities Act

Defining Developmental Disabilities

Developmental Disabilities Act (2000)

 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



Trends in the Prevalence of Developmental Disabilities in US Children, 1997–2008



WHAT'S KNOWN ON THIS SUBJECT: US data on the changes in the prevalence of developmental disabilities are scarce. Although there are a few studies on individual disabilities, data examining the impact of the full range of developmental disabilities are unavailable.



WHAT THIS STUDY ADDS: Developmental disabilities make a significant contribution to overall childhood health. We show the health disparities that exist for specific populations and how selected conditions have increased over the past 10 years.

AUTHORS: Coleen A. Boyle, PhD,^a Sheree Boulet, PhD,^a Laura A. Schieve, PhD,^a Robin A. Cohen, PhD,^b Stephen J. Blumberg, PhD,^b Marshalyn Yeargin-Allsopp, MD,^a Susanna Visser, MS,^a and Michael D. Kogan, PhD^c

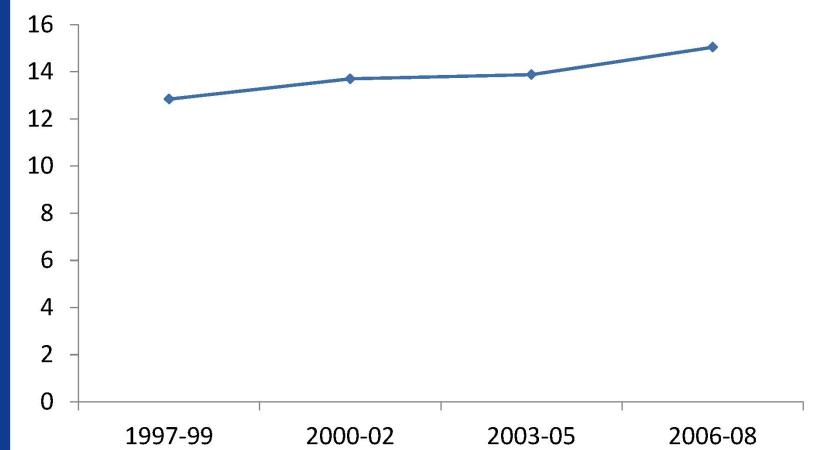
^aNational Center on Birth Defects and Developmental Disabilities and ^bNational Center for Health Statistics, Centers for Disease Control and Prevention, Atlanta, Georgia; and ^aMaternal and Child Health Bureau, Health Resources and Services Administration, Rockville, Maryland

KEY WORDS

developmental disabilities, prevalence, autism, attention deficit hyperactivity disorder

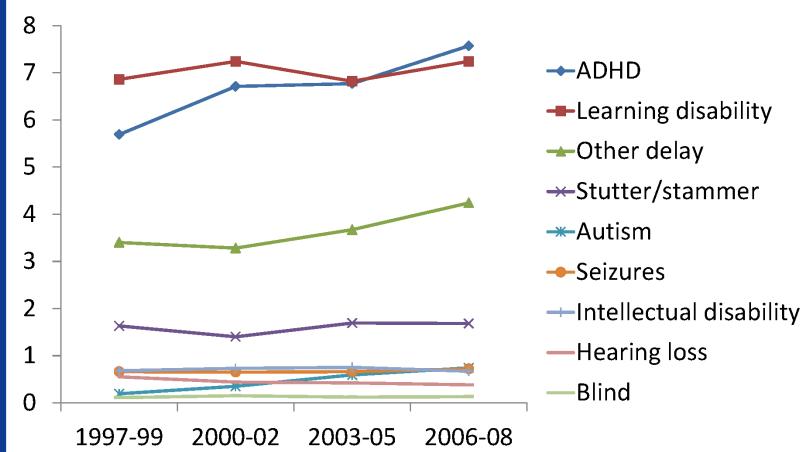
1 in 6 children in the U.S with a developmental disability Increased prevalence from 1997 (13%) to 2008 (15%)

Trends in Prevalence of Any Developmental Disability





Trends in Prevalence of Specific Developmental Disabilities





Individuals with Disabilities Education Act

autism

deaf-blindness

deafness

emotional disturbance

hearing impairment

intellectual disability

multiple disabilities

orthopedic impairment

other health impairment

specific learning disability

speech or language impairment

traumatic brain injury

visual impairment (including

blindness)

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

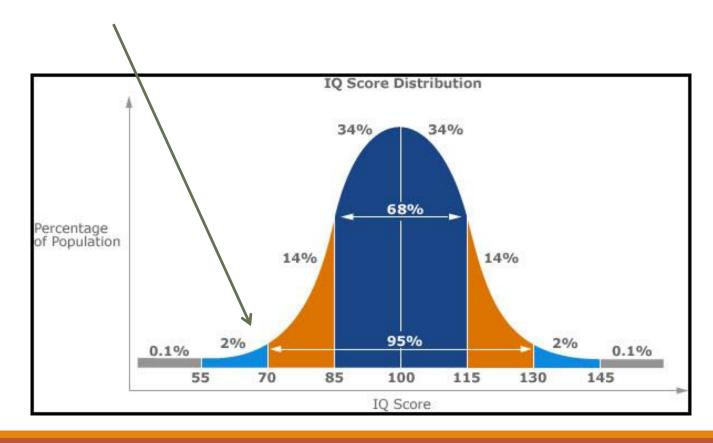
Defining Intellectual Disability

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 AAIDD 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, moto 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)

- 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.

- 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.

- 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.

- 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).

- 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).

- 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).

- 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).

- 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 cooccur; 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

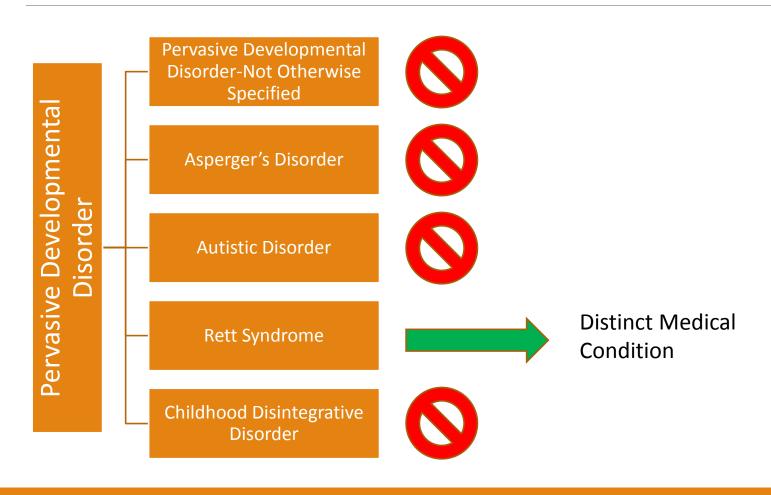
Autism spectrum disorder overlaps considerably with ID (roughly 50%), but is distinct from ID

There is no such thing as "high functioning autism"

Perspectives on "High Functioning"



What changed in the DSM-V?



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

IMPAIRMENT

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

DISABILITY

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



David 6 years old Cerebral palsy

Impairment

Disability



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 a 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

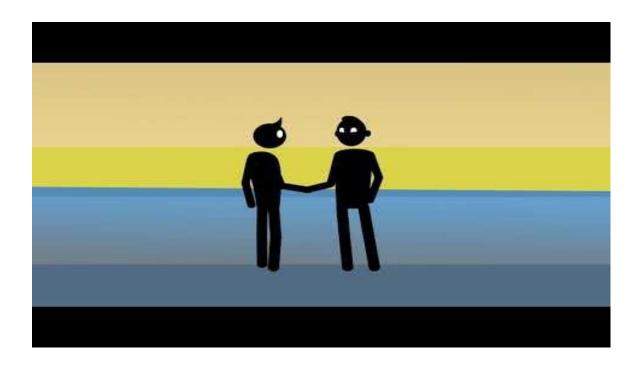
Some people or groups of people will prefer Identity first language

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



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

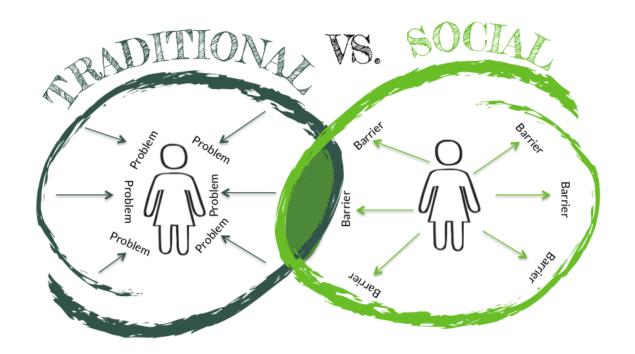
Medical Model of Disability

Social Model of Disability

Individuals with disabilities are defective and need to be fixed

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)