Communicating the Diagnosis of IDD and Autism to Culturally Diverse Families

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Disclosures

Dr. Stobbe has no financial relationships with an ineligible company relevant to this presentation to disclose.

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Objectives

- Establishing your own understanding of “what is a neurodevelopmental disorder”
- Recognize the wide variety of perspectives towards neurodevelopmental disorders
- Develop a sensitivity and preparedness to the influences of cultural perspectives towards the diagnosis of a neurodevelopmental disorder

What is a neurodevelopmental disorder?

- DSM-5 definition
  - Disorders emerging during childhood or adolescence
  - Affect behaviors important for “normal” interactions
  - Some effect multiple functional domains, others are more circumscribed
- Common examples
  - Intellectual Disability
    - Deficits in intellectual and adaptive functioning
  - ADHD
    - Estimates of 6-7% of children (5% of adults)
  - Autism Spectrum Disorder
    - Prevalence now identified as 1 in 44
  - Communication disorders
    - Including Social Pragmatic Communication Disorder
  - Learning disorders
  - Others (Tic Disorder, Stereotypic Movement Disorder)

Important Points

- Diagnoses are not “mutually exclusive” – you can have more than one
- A child may be appropriately labeled “developmentally delayed” before coming to a more definitive label
- The diagnosis is not based on the underlying biology

A parent’s journey

- Receiving the diagnosis - the “shock and awe” phase
  - Risk of ignoring recommendations as defense mechanism
- Implementing the plan – “Shoveling the coal” phase
  - Risk of sub-optimal resource allocation
- Discovering the path forward – “Acceptance/celebration” phase
  - Can take years before getting to this place
  - Focus becomes optimizing quality of life

What phase are your parents/caregivers?

Explaining the definition of the diagnosis – what does it mean?

- Need to explain these diagnoses are *based on a pattern of development and observable behaviors* – it is NOT based on an understanding of the biology or the cause
- “know your audience”
  - Family “readiness” for the diagnosis
  - Lived experience (prior knowledge)
    - Educational level, prior interactions/experiences, trust level of the medical system
  - **Cultural factors**
  - Age of patient/client (include in the discussion if able)

Medical model vs social justice model

- Does the client/family see the diagnosis as a disorder or identity or both?
- Will influence use of person first language (a person *with autism*) or identity first (an *autistic* person)

Cultural influences

- Children from BIPOC groups less likely to receive an autism dx than white counterparts even if meeting ASD criteria (Jarguin, 2011)
- Children from BIPOC groups receive a diagnosis later in life and present with more severe symptoms (Mandell, 2009)
- E.g. - Lower prevalence of neurodevelopmental disorders in Hispanic/Latino children
  - Not explained by healthcare access/utilization or language differences (Garcia, 2019)
    - Maybe influenced by knowledge and understanding caregiver? Bias in provider approach? Other?

Cultural influences (Stahmer, 2019)

- Attitudes toward parenting
- Attitudes/perceptions toward typical development
- Stigma of diagnoses
- Ease of communication with healthcare provider
- Level of acculturation

- ***Bias and delivery of care by healthcare provider***

Avoiding the diagnosis becoming a barrier

- “shopping” for a label
- Getting the focus off the diagnosis –
  - Shift focus to identifying strengths/weaknesses
  - discover best ways to learn
  - identifying and providing appropriate and necessary supports
  - focus on optimizing quality of life
- Remember - co-occurring medical and/or psychiatric diagnoses/conditions can confuse discussion of underlying neurodevelopmental diagnoses (and subsequent impact on decision-making)

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Questions

THANK YOU!

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