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BUILDING Mental Wellness LEARNING COLLABORATIVE

Mental Health and Children With Developmental Disabilities

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Best Evidence for Advancing Childhealth in Ohio NOW BEACON

Objectives

- Review definitions of intellectual disability and dual diagnosis
- Describe various mental health conditions that are more likely to be associated with developmental disabilities, including specific genetic syndromes
- Explain a few of the ways the primary care provider can deliver mental health care within the medical home model

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Developmental Disorders Defined

- Dual Diagnosis
  - Term used for over 20 years
  - Presence of both a developmental/intellectual disability and a mental health problem
    - Also used as a term to describe the presence of a mental health problem and substance abuse
  - Although sources vary, current estimates are that 30-35% of all persons with an intellectual/developmental disability have a mental health disorder
    - 3-4 times higher than the general population
  - Often times under-recognized and undertreated.

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Pediatr Clin North Am. 1993
American Assoc on Mental Retardation, 2002

Intellectual Disability

- Developmental/intellectual disability DSM-5 updates
  - Name change: Intellectual Disability vs Mental Retardation
    - Brings DSM into alignment with WHO ICD-11 terminology
    - Also follows the 2010 US Public Law 111-256 directives for change within IDEA wording
  - No longer on separate Axis
    - Previously placed on “Axis II” to differentiate ID from other mental disorders.
    - Now on single axis with equal weight

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DSM Updates

DSM-IV TR (2000)

- Intellectual and adaptive functioning that is significantly below average with onset prior to age 18 years.
- Significantly subaverage functioning was defined as an IQ score of 70 or below
- Adaptive functioning refers to the effectiveness of the individual meeting standards for daily living within a given age and cultural group
- Four degrees of severity: Mild, Moderate, Severe, and Profound based on IQ scores

DSM-5 (2013)

- Deficits in intellectual and adaptive functioning with onset during the developmental period occurring in 3 domains:
  - Conceptual (language, reading, math, etc)
  - Social (empathy, social judgment, interpersonal communication, etc)
  - Practical (personal care, job, money management, recreation, etc)
- Four degrees of severity based on adaptive functioning, not IQ scores. Changes focus to level of support
- IQ scores still used in assessment

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DSM-5 ID Levels of Severity

- **Mild:**
  - Conceptual- may have difficulties in preschool. Older children have problems with academics (reading, math, etc).
  - Social- immature in social interactions, more concrete, difficulties regulating emotions.
  - Practical- may be age appropriate in childhood
- **Moderate:**
  - Conceptual- slow language and pre-academic development in preschoolers. Markedly behind peers in school
  - Social- Social language is much less complex than peers. Able to develop relationships, but may miss social cues
  - Practical- Requires extended time to learn basic self-care. Independent as adults.

DSM-5 ID Levels of Severity cont'd

- **Severe:**
  - Conceptual- Little understanding of written language. Extensive support needed throughout life
  - Social- Spoken language is limited, interactions focused on the "here and now". Primarily relationships limited to family
  - Practical- Require supervision at all times and support for all ADLs. Maladaptive/self-injurious behavior maybe present
- **Profound:**
  - Conceptual- Skills are practical rather than symbolic. May attain matching/sorting skills if not physically limited
  - Social- Limited symbolic communication. Expresses through nonverbal/nonsymbolic communication
  - Practical- Dependent on others for all aspects of daily care. May assist with daily work tasks with supervision

Global Developmental Delay

- Diagnosis for individuals under the age of 5 years.
- Child fails to meet developmental milestones
- Unable to undergo systematic assessments or standardized testing
- For purposes of dual diagnosis, can be used interchangeably with ID

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Prevalence

- Persons with ID may experience any mental health problem
- More common types:
  - Mood disorders
    - Depression, bipolar, dysthymia
  - Anxiety disorders
    - Panic attack, agoraphobia, OCD, PTSD, generalized anxiety
  - Psychotic disorders
    - Schizophrenia
  - Personality disorders
    - Paranoid, anti-social, borderline, or avoidant
  - Adjustment disorders
    - Mood change or conduct disturbance
- Under recognized

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Pitfalls

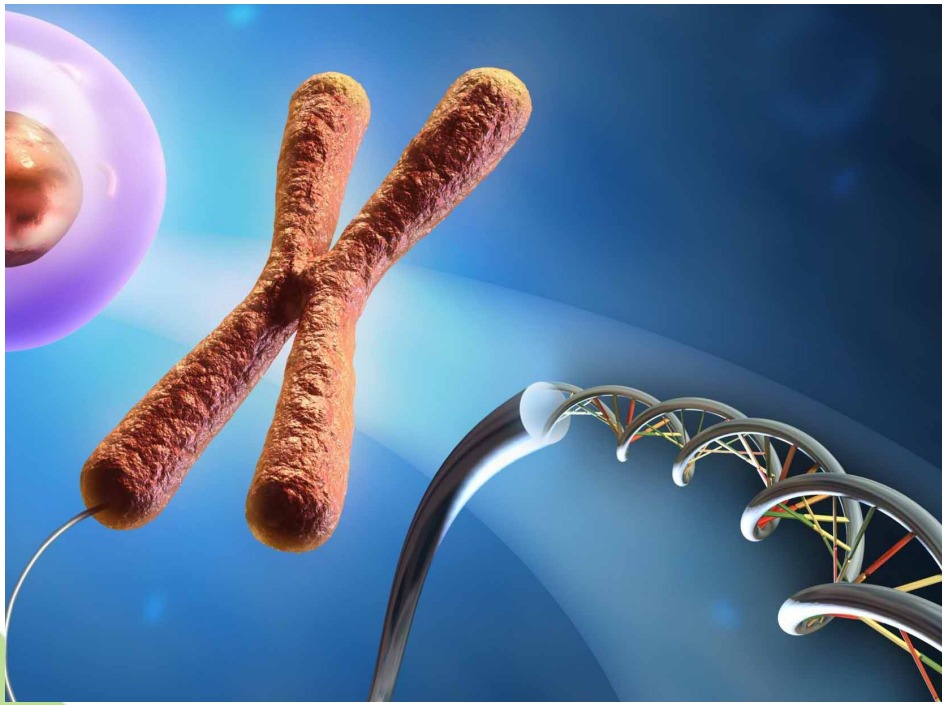
- Mental Health issues are difficult with any child
- With additional factors from an associated intellectual disability, common mental health conditions may present differently
  - Behavior changes, socialization, personality
- These same behaviors may be the result of an underlying medical condition or pain
- Concerns must be placed within appropriate developmental context
- Children with disabilities are at higher risk for other issues
  - Bullying, psychological/physical/sexual maltreatment, neglect/ostracism

Pitfalls

- Diagnostic Overshadowing
  - Attribute new problems/behaviors to underlying condition
  - Effectively “rules out” presence of another condition
- Baseline Exaggeration
  - Symptoms of a new mental health condition simply reflect increase of longstanding behavioral problems
- Applicability of DSM criteria
  - Written to describe typically developing individuals
  - Many contain subjective components that can never be met in a non-communicative individual

Genetic Syndromes

- Many specific syndromes have association with specific mental health issues



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Trisomy 21 – Down Syndrome

- Leading cause of intellectual disability – mild/moderate (1.2 in 1000)
- Impulse control problems, ODD
- ADHD
- Autism Spectrum Disorder
- Repetitive Movement Disorder
- Generalized Anxiety, Obsessive-Compulsive Disorder
- Depression

Image: www.ndss.org

CDC, 2003

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Fragile X Syndrome

- Second leading cause of intellectual disability – (0.2 in 1000)
- Often hypersensitive to stimuli or easily over aroused
- Impulse control disorders, ODD
- ADHD
- Aggression to self and/or others
- Autism or autism-like behaviors
- Social anxiety

Am J Hum Genetics, 2009

Image: www.fragilex.org

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Klinefelter (XXY) and XYY syndromes

- XXY
  - Learning disabilities, delayed language
  - Anxiety and ADHD
  - During adolescence: ADHD, depression, substance abuse
  - Not at higher risk for psychiatric disorders or legal problems
- XYY
  - Learning disabilities, delayed language, motor delay. Wide variability
  - Distinct subset with impulsivity and difficulty adapting to social settings
    - ADHD, Autism Spectrum Disorder
  - Past research falsely linked XYY to criminality

Turner (XO) Syndrome

- Short stature, ovarian hypofunction, heart defect (coarctation)
- **Normal** intelligence
- Adolescence
  - Depression/dysthymia, anxiety, eating disorders, body image problems, ADHD

Image courtesy of yingyo at FreeDigitalPhotos.net

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Cri-du-Chat (5p-) Syndrome

- Intellectual disability, microcephaly, hypotonia, growth delay
- Hypertelorism, low-set ears, small jaw, rounded face
- High-pitched cry
- Severe intellectual disability
- Hyperactivity, ADHD

Image: childrenshospitalblog.org

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Velo-Cardio-Facial (22q11-) Syndrome

- DiGeorge syndrome, Shprintzen syndrome, CATCH22
- Highly variable presentation
- Immune deficiency/autoimmune disorders, hypocalcemia, renal anomalies, short stature
- Developmental delays, language delays, learning delays
- Childhood – ADHD (M>F), anxiety
- Autism Spectrum Disorder
- Psychotic disorder/Schizophrenia in 41% of adults*

*Am J Psychiatry. 2014

Autism

- Wide variety of phenotypes
- With/without intellectual disability
- Mental health issues often dismissed as being result of autism alone
- ADHD (30-50%)
- Anxiety – phobias, GAD, panic disorder, OCD (8-33%)
- Depression – 10% children, 30% adolescents

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Encourage Mental Wellness in Primary Care

- Consider individual risk factors
- Address specific concerns within the appropriate developmental context
- When addressing behavioral problems, start with a functional behavioral analysis approach
- Provide opportunities for optimal outcomes
  - Developmental Disabilities Literacy Promotion Guide (Reach Out and Read)
  - Executive Function Activities (age specific) – developingchild.harvard.edu
  - Engage with local Early Intervention/Help-Me-Grow
- Provide a Medical Home for the chronic developmental needs

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Function of Behavior

- The function of a behavior refers to the source of environmental reinforcement for it
  - In other words: the why behind the tantrum
- Most behaviors in childhood can be tied to a few key causes:
  - Social attention
  - Tangibles/Activities
  - Escape/Avoidance
  - Automatic Reinforcement

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Functions of Behavior

- Social Attention
  - To gain notice or reaction from another person
  - Can be positive or negative attention
  - Examples – to get others to laugh or to get an adult to scold them

- Tangibles/Activities
  - Get access to preferred toys, people, activities
  - Examples – scream/tantrum until gets a candy from the check-out lane

Functions of Behavior

- Escape/Avoidance
  - Get away from a person, place, demand, activity; or avoid it in the first place
  - Examples – self-injury to avoid playing with others; frequent bathroom breaks during class

- Automatic Reinforcement
  - Self stimulating in nature. It is reinforcing independent of the external/social environment
  - Examples – stereotypic rocking/spinning as seen in Autism. Rubbing a banged knee after a fall

Functions of Behavior

- By understanding these functions, families can begin to unravel some of the troubling behaviors.
  - A tantrum is a way to manipulate a social interaction to get a specific need (one of the 4 functions) met.
  - By identifying the function, parents can teach their child how to get their needs met differently
- This won't treat a mental health disorder, but it can aid in pre-clinical behavioral issues and behavior management is often a foundation for most mental health treatment plans
- Therapy can start in the primary care office

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Mental Health – Medical Home

- Medical Home is vital for individuals with chronic health care needs
- The addition of developmental and/or mental health issues expands the importance of a medical home
  - Not a building, an approach to providing comprehensive primary care
  - Partnership with medical care team, family, and the school and/or mental health care team
- Provides family with resources and care throughout continuum

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Mental Health – Medical Home

- Core team
  - Parent/guardian
    - Knows the child best, provides valuable information
  - Health care professional
    - Creates the care plan with input from others
  - Child care providers/teachers
    - Typically implement the care plan

- Other team members
  - Therapists (occupational/physical/speech-language)
  - Pediatric subspecialists
  - Psychologists/Counselors
  - Social workers

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Managing Chronic Health Needs in Child Care and Schools, AAP 2010

Summary

- Children with developmental disabilities are at higher risk for co-existing mental health conditions
- Mental health disorders in children can present very differently and are both under-recognized and underdiagnosed in this subset of children
- Some specific syndromes are at higher risk for being associated with mental health disorders
- Primary care providers can assist by monitoring for mental health needs, aiding families with general assistance in behavior modification and providing a medical home for children with chronic developmental healthcare needs

Additional information

- National Association for the Dually Diagnosed
  - www.thenadd.org
- Managing Chronic Health Care Needs in Child Care and Schools
  - American Academy of Pediatrics
- Building Mental Wellness
  - ohioaap.org/projects/building-mental-wellness
- Executive Function Activities
  - developingchild.harvard.edu

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