ADDRESSING THE NEEDS OF YOUTH WITH INTELLECTUAL DISABILITIES AND DEVELOPMENTAL DISABILITIES IN THE JUVENILE JUSTICE SYSTEM

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Learning Objectives

Participants will be able to:

1. Describe the terms Intellectual Disability and Developmental Disability
2. Recognize the different categories of Developmental Disabilities
3. Identify the process of assessing a youth for an Intellectual and/or Developmental Disabilities through psychological testing and/or Multidisciplinary Team assessment
4. Define the difference between rehabilitation services versus habilitation services
5. Understand the important role Special Education plays in the life of a person with an Intellectual and or Developmental Disability
6. Recognize the critical role of family engagement in the success of persons with Intellectual and/or Developmental Disabilities
Definition: The Center for Disease Control and Prevention defines Developmental Disabilities as a group of conditions due to an impairment in physical, learning, language, or behavioral areas.

- severe chronic disabilities that can be cognitive or physical or both.
- The disability appears before the age of 22 and is likely to be lifelong
- Some Developmental Disabilities are largely physical issues (cerebral palsy or epilepsy)
- Some Developmental Disabilities are both a physical and intellectual disability (Down Syndrome or Fetal Alcohol Syndrome)
Types of Developmental Disabilities

1. Intellectual Disability
2. Fetal Alcohol Effects and Fetal Alcohol Syndrome
3. Autism Spectrum Disorders
4. Attention Deficit Hyperactivity Disorder
5. Down Syndrome
6. Cerebral Palsy
What is an Intellectual Disability?

- **Definition:** The American Association of Intellectual and Developmental Disabilities (AAIDD) defines Intellectual Disabilities as the disability characterized by significant limitations in both intellectual function and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18 years.

- Previously known as Mental Retardation

- An Intellectual Disability is a type of Developmental Disability

- **Intelligence** is determined by IQ testing. A full scale IQ of 70-75 indicates limitations in intellectual functioning.
What is an Intellectual Disability continue

- Adaptive Behavior- AAIDD defines adaptive behavior as a collection of conceptual, social, and practical skills that are learned and performed by people in their everyday lives

**Types of Adaptive Skills:**

1. Conceptual Skills—language, literacy; money, time, number concepts, and self direction
2. Social Skills—interpersonal skills, social responsibility, self-esteem, gullibility, social problem skills, and ability to follow rules/obey laws and avoid being victimized.
3. Practical Skills—activities of daily living (personal care), occupational skills, healthcare, travel, use of money, safety, and telephone
Who should evaluate as part of the Multidisciplinary Team (MDT) process?

- **School Psychologist**- testing for IQ, Functional Behavioral Assessment (for those individuals with behavioral concerns), behavioral rating scales, and adaptive living skills testing.

- **Speech Language Pathologist**- Specific testing for receptive and expressive language is important. An individual may be able to say the words but do they understand what is being said.

- **Occupational Therapist and Physical Therapist** if determined necessary by the team or at parent’s request.

- **Assistive Technology**- this should be considered in order for the child/youth to live as independent as possible.
Important facts to remember with a youth with Intellectual Disabilities and Special Education:

1. It is important to **ALWAYS** have the child’s IQ and adaptive living skills evaluated every time there is a MDT reevaluation period. This information is considered when the parents or provider applies for Developmental Disability Services.

2. Many of these youth will graduate high school based on their IEP goals and not having met all of the graduation requirements. They also are served by the local public school system until the school year that they turn 21 years old.

3. Please do not refer to this category as Mental Retardation.

4. If a child “officially graduates” then the school no longer has to provide transition services until the child is 21 years old.
Fetal Alcohol Syndrome (FASD)

Definition: The Center for Disease Control (CDC) defines Fetal Alcohol Syndrome (FASD) as a group of conditions that can occur in a person whose mother drank alcohol during pregnancy. These effects can include physical problems and problems with behavior and learning.

Behavioral and Intellectual Disabilities for individuals with FASD:
1. Difficulty with learning.
2. Low IQ
3. Poor reasoning and judgment skills
4. Difficulty with maintaining attention to task
5. Higher than normal level of activity (Hyperactivity)
6. Speech and language delays
Fetal Alcohol Effects

- Definition: *About Parenting* defines Fetal Alcohol Effects (FAE) as a neurological impairment that can affect a child who has been exposed to alcohol in the womb. The child with FAE is not as impaired as children with FAS and they usually lack the distinctive FASD facial features and have normal IQs.

- The youth with FAE can have more difficulties in school and the community than those with FASD because they appear “normal,” but because they still have brain damage they may be perceived by adults as capable of functioning more like a neuro-typical youth.
Fetal Alcohol Syndrome Facts

- Fetal Alcohol Syndrome includes a characteristic group of defects including small head and brain, facial abnormalities, and defects of the organs.
- Alcohol is broken down more slowly in the immature body of the fetus than in the adults body.
- FAS is the most common known non-genetic (non-inherited) cause of Intellectual Disabilities in the United States
- As many as three babies in 1,000 will have FAS, although the rate in some populations may be much higher.
Fetal Alcohol Syndrome Facts Continued

Symptoms of Fetal Alcohol Syndrome

- Small head, small jaw, small, flat cheeks
- Malformed ears
- Small eyes, poor development of optic nerve, crossed-eyes
- Upturned nose, low bridge
- Small upper mouth structure and teeth
- Caved-in chest wall
- Extra fingers, abnormal palm creases
- Excessive hair
- Undergrown nails
- Incomplete or lack of development of brain structures, heart murmurs, and heart defects
- Incomplete development of the genitalia
- Irritability during infancy turning into hyperactivity in childhood
- Poor coordination
Fetal Alcohol Syndrome and Special Education

Who should evaluate as part of the MDT process?

- **School Psychologist** - IQ testing, adaptive skills, and behavioral rating scales. A Functional Behavioral Assessment may be necessary if there are behavioral concerns in the school environment.

- **Speech Pathologist** - Specific testing for receptive and expressive language is important. An individual may be able to say the words but do they understand what is being said.

- **Occupational Therapist and/or Physical Therapist** - the involvement of these professionals may depend on the limitations the child presents to the MDT professionals and family.
Fetal Alcohol Syndrome and Special Education

Youth with a medical diagnosis of Fetal Alcohol Syndrome will likely be supported in Special Education as a child with an Other Health Impairment.

**Other Health Impairment:**

- **Definition:** To qualify for this verification, a child **must have** limited strength, vitality or alertness with respect to the educational environment due to a chronic or acute health problem which adversely affects the child’s education and developmental performance. Examples include: Attention Deficit Hyperactivity Disorder, epilepsy, heart conditions, Tourette’s syndrome, Hemophilia, or Leukemia.
Fetal Alcohol Syndrome and Special Education

Important information to consider with Other Health Impairments:

- The medical doctor (MD only) that is treating and/or diagnosed the child will need to provide written documentation of the child’s diagnosis. This diagnosis **NEEDS TO** be signed by a **MD** - Either a Medical doctor or the child’s Psychiatrist.

- The child’s medical or mental health condition has to be shown to have a negative impact on their education and the child is in need of Special Education services and supports.

- Schools may be inclined to have the child in the Special Education verification category of Emotional Disturbance.
Autism Spectrum Disorders Medical Diagnosis

- **Medical Definition of an Autism Spectrum Disorder:** The Mayo Clinic defines an Autism Spectrum Disorder as a serious neurodevelopmental disorder that:
  - impairs a child’s ability to communicate and interact with others
  - includes restrictive repetitive behaviors, interests, and activities
  - these issues cause significant impairment in social, occupational and other areas of functioning

- Diagnosis now included in Autism Spectrum Disorders are Autism, Asperger’s Syndrome, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder Not Otherwise Specified.

- A “Spectrum” Disorder means that each individual will have a range of symptoms and severity
Autism Spectrum Disorder Continued

To qualify for special education services in the category of Autism Spectrum Disorder, the child must have a developmental disability which:

1. Significantly affects verbal and nonverbal communication and social interaction;
2. Is generally evident before the age of three years;
3. Engagement in repetitive activities and stereotyped movements, resistance to environmental change or change in daily routine, and unusual responses to sensory experiences; and
4. That adversely impacts the child’s educational performance.....(Key to the verification)
Autism Spectrum Disorders and Special Education

Who should evaluate as part of the MDT process?

**School Psychologist:** conduct an IQ Test;
- testing of adaptive functioning;
- Autism Rating Scales completed by teachers, parents, and other caregivers;
- Functional Behavioral Assessment if the child demonstrates behavioral concerns in the school environment;

**Speech Pathologist:**
- Specific testing for receptive and expressive language is important. An individual may be able to say the words but do they understand what is being said.
- The assessments completed should answer the question - how does this child learn - visually, auditorily, kinesthetically, or a combination of ways.
Autism Spectrum Disorders and Special Education continued

Occupational Therapist:
- A Sensory Profile should be completed by the parent(s), teachers, and other caregivers.
- Assessment of the child’s fine motor skills will also be assessed

Assistive Technology:
- If a child is nonverbal or limited verbal skills, an AT Specialist should evaluate and identify alternative methods of communication for the child. ie-IPAD, Dynavox

Important fact to remember: A youth may receive a medical diagnosis of an Autism Spectrum Disorder and not receive and Educational Verification of an Autism Spectrum Disorder. This doesn’t mean the child does not have an Autism Spectrum Disorder.
## Habilitation versus Rehabilitation

**Habilitation**

- Services that help a person learn, keep, or improve skills and functional abilities that they may not be developing normally.
- Supports and services are typically lifelong.
- Designed to support an individual in the least restrictive environment possible and individuals also benefit from access to “neuro-typical peers.”
- Services and supports are seen as “training and educational.”

**Rehabilitation**

- Services that help a person improve skills that have been lost after a stroke, injury, illness, or other cause.
- Services and supports are typically temporary.
- Other people in the environment may or may not be aware of the individual’s condition.
- Services and supports are seen as “treatment/therapy.”
Community Assessments for Persons suspected of having a Developmental Disability

- Psychological Assessment
  1. Vineland Adaptive Behavioral Scales
  2. IQ testing
  3. Functional Behavioral Assessment (observation in school and home environment if possible)
    - Identify the antecedents
    - Identify the function of the behavior
  4. Autism Diagnostic Observation Schedule- (for youth suspected of having an Autism Spectrum Disorder)
  5. Autism Rating Scales- (for youth suspected of having an Autism Spectrum Disorder) rating scales should also be completed by parent or primary caregiver
  6. Trauma Screen and potentially a Trauma Assessment
Community Assessments for Persons Suspected of Having a Developmental Disability continued

- Medical testing:

1. **Genetic Testing** to rule out genetic or chromosomal conditions
   - University of Nebraska Medical Center Munroe Meyer Institute of Human Genetics

2. **Fetal Alcohol Syndrome Diagnostic Clinic**
   - University of Nebraska Medical Center Munroe Meyer Institute
Trauma and Developmental Disabilities

**Trauma facts:**

- Individuals with Intellectual and Developmental Disabilities are two times more likely to experience emotional, neglect, physical, and sexual abuse than non-disabled peers.
- Three times more likely to be in families with domestic violence.
- Four times more likely to be victims of a crime.
- Two times more likely to be bullied.
The Importance of Family and/or Caregiver Engagement

Helpful Hints:

■ Recognize the multitude of emotions and struggles families face when raising a youth with a disability.

■ Don’t be afraid to ask what it has been like for the parent(s) to raise their child with an Intellectual or Developmental Disability- DON’T ASSUME

■ Recognize that the child may have parent(s) who also have limitations.

■ Help identify with the parent(s) the informal supports and/or family members who have had an active role in the child’s life.

■ Have knowledge of what supports are in the community and communicate those to the family-especially support groups.
The Importance of Family and/or Caregiver Engagement

- Utilize family and/or peer support services in the community to assist family members. Family members are more likely to be less defensive with parents who have “been in their shoes.”

- Attend Individual Education Program (IEP) meetings for the child and empower parent(s) to be advocates for their child’s educational services. Parents are their child’s expert.

- The youth is on probation but the keys to his/her success in learning and utilizing new behaviors starts with the adults in his/her life.
Additional Helpful Hints for Juvenile Justice Professionals

- Have a copy of and be familiar with Rule 51 (Nebraska Special Education Regulations)
- Request a copy of the youth’s Multidisciplinary Team Report and Individual Education Program report and thoroughly understand the strengths and deficits for the youth. The child’s attorney should also have knowledge to this information.
- A youth’s is reassessed every three years for the MDT and their IEP is rewritten at least every year. Both the MDT and IEP can be updated more often with additional information.
- Know what providers work with individuals with Intellectual and Developmental Disabilities in your community. Don’t be afraid to ask providers about their experience working with this population.
- If youth have coexisting conditions - Intellectual/Developmental Disabilities and Mental Illness, the Intellectual/Developmental Disability is ALWAYS the primary diagnosis.
- Understand how to assist parents with applying for Developmental Disability services. *Nebraska Department of Health and Human Services Division of Developmental Disabilities Eligibility Referral form on DHHS DD Public Site and fax to 402-471-8792. http://dhhs.ne.gov/developmental_disabilities/Pages/aDDIF-Eligibility.aspx
Support Groups and Community Resources

- The Arc of Nebraska - 402-475-4407
- Disability Rights Nebraska 1-800-422-6691
- PTI Nebraska 1-800-284-8520
- Autism Family Network 1-402-421-0874
- Autism Society of Nebraska 1-800-580-9279
- Fetal Alcohol Syndrome Education Program 1-308-234-2754
Questions

- Thank you for attending today's break-out session on Intellectual and Developmental Disabilities. If you have additional thoughts or questions please do not hesitate to reach out to Tricia Kingsley at tricia.kingsley@nebraska.gov