A Trauma-Informed Understanding of Children with Intellectual and Developmental Disabilities in a Child Welfare Context: A Facilitated Discussion for Oregon Citizen Review Board Members

Sarah Dababnah, Kathryn S. Collins, Emily Lee, Melissa H. Bellin, Molly H. Chinoy, Deborah P. Valentine

Learning Objectives

Define	Explain	Describe	Discuss	Construct
Define intellectual & developmental disabilities (IDD) and the use of respectful language	Explain the ways CRB members can better understand the needs of children with IDD in a child welfare context. Explain trauma-informed approach	Describe the relationships between IDD, child maltreatment & foster care	Discuss the impact of trauma on children with IDD & their needs. Discuss effective communication with parents with IDD	Construct service recommendations for children with IDD

2

Identity and Person-First Language

Person-first language emphasizes the person, not their disability;
for example:

- Instead of "handicapped," say "**person who uses a wheelchair," to emphasize abilities and not limitations.**
- Instead of "normal," say **"non-disabled person"** or "typical" in order to avoid characterizing people with disabilities as "abnormal."
- Instead of "birth defect," say **"born with ___" in** order to not imply a person is "defective" or broken.

Identity-first language, some individuals prefer identity-first language, for example:

- "An autistic person" (versus first-person language, "a person with autism").
- When possible, ask an individual with a disability their preferences. An individual's preference about how they want to be addressed is all that matters.

3

Defining Disability Broadly

A disability is a physical, mental, cognitive, or developmental condition that impairs, interferes with, or limits a child's ability to engage in certain tasks or actions or participate in typical daily activities and interactions.

- There are many definitions of disabilities.

- Disabilities vary in severity and need to be seen on a spectrum of impact to the child and family.

4

Five Categories of Disabilities and Other Health Conditions

Developmental
- These disabilities generally manifest during childhood and impacts personal, social, academic, or occupational functioning.
- Examples include: Intellectual Disability, Autism, AD/HD

Physical/Motor
- A physical condition that impacts a youth's motor function
- Examples include: Spina Bifida, Cerebal Palsy, Multiple Sclerosis

Visual or Hearing
- A visual difference that may impact educational performance or development; or hearing difference whether permanent or fluctuating that adversely impacts educational performance

Emotional Disturbance
- A mental or behavioral condition that is not explained by an intellectual, sensory, or health condition that is long term and impedes a child's functioning in their social environment.
- Examples include: Depression, Anxiety, Post Traumatic Stress

Medical Condition
- Conditions other than those noted above which require special medical care such as chronic illnesses
- Examples include: HIV/AIDS, Asthma, Cancer

A Focus on Intellectual and Developmental Disabilities (IDD)

- The National Institute of Child Health and Human Development (2012) defines IDD as "disorders that are usually present at birth and that negatively affect the trajectory of the individual's physical, intellectual, and/or emotional development."

- A developmental disability is an umbrella term that refers to a range of diagnoses, including intellectual disability.

- Individuals with a developmental disability do not necessarily have an intellectual disability. For example, only about 31% of children with autism also have an intellectual disability (Baio et al., 2018).

- Approximately 1 in 6 US children ages 3-17 years old (~17%) have a diagnosed developmental disability (Zablotsky et al., 2019).

6

IDD Definitions Vary by Source

- Lack of consistency between how government agencies and service organizations define IDD

- [Common examples of IDD](#) include Down Syndrome, Autism, Spina Bifida, Fetal Alcohol Spectrum Disorders, and Cerebral Palsy (CDC, 2019).

- Children with disabilities commonly receive school-based services through the Individuals with Disabilities Education Act (IDEA), which has its own definition of disability.

7

Individuals with Disabilities Education Act (IDEA)

- IDEA entitles children with disabilities a free and appropriate public education. It covers developmental delays (only for children up to age 9) and [13 categories of disabilities](#) (U.S. Department of Education, 2018) for children of all ages (up to age 21):
    1. Autism
    2. Deafness
    3. Deaf-blindness
    4. Emotional disturbance (e.g., anxiety and other mental health issues)
    5. Hearing impairment
    6. Intellectual disability
    7. Multiple disabilities (e.g., intellectual disability-blindness)
    8. Orthopedic impairment (e.g., cerebral palsy)
    9. Other health impairment (e.g., ADHD, asthma)
    10. Specific learning disability (e.g., dyslexia)
    11. Speech or language impairment (e.g., stuttering)
    12. Visual impairment
    13. Traumatic brain injury

- In order to receive services under IDEA, the child must fit into one of the above categories *AND* must need special education in order to make academic progress. A disability alone does not qualify a child for services under IDEA.

- Individual states provide guidance on how to define the above categories; thus, there are state-by-state variations on who qualifies. Visit Oregon's [IDEA website](#) to learn more.

8

Impact of IDD on Development

- An IDD may impact an individual's development and/or certain body systems.

- At times, there may be an overlap.

9

Causes of IDD

- For many IDD, the cause is **idiopathic** or **unknown**
  - Example: autism is suspected to result from a mixture of environmental and genetic causes, but scientists have not yet identified the precise cause.

- In some cases, the cause is known, and can result from a mix of one or more of the following factors:
  - **Genetic** (e.g., Fragile X, Prader-Willi, Williams, or Down syndromes)
  - **Environmental** (e.g., maternal or child lead exposure)
  - **Toxic exposures** (e.g., Fetal Alcohol Spectrum Disorders, which result from alcohol use during pregnancy)
  - **Preterm birth or low birthweight**
  - **Infections** (including maternal infections during pregnancy)
  - **Head trauma or other injuries**
  - **Metabolic issues** (e.g., high bilirubin levels in newborns can lead to kernicterus)
  - **Malnutrition**

10

Children with IDD in the Child Welfare System

Children with disabilities are:
- Three to Four times more likely to experience acute and chronic child maltreatment (Sullivan& Knutson, 2000)
- Two times as likely to be placed in foster care (Lightfoot et al., 2011) and permanently live in non-kin care (Romney et al., 2006)
- have a disrupted adoption (Slayter & Springer, 2011)

The systems serving children with disabilities and child welfare often do not align, due to:
- different definitions of "disability" (Liao et al., 2017)
- lack of training of service providers on people with disabilities (Lightfoot & LaLiberte, 2006)
- service differences (child welfare services are mandatory and meant to be short-term; whereas IDD services are voluntary and often longer-term).

11

Understanding Trauma and IDD

Children with IDD are at risk for multiple traumas:

-Three times more likely to be in families with domestic violence

-Four times more likely to be victims of crimes

-Two times more likely to be bullied

Several challenges exist to support children with IDD who have experienced trauma, including:

-Diagnostic overshadowing

-Inappropriate screening and assessment tools

-Lack of service provider training

-Assumptions made about children's ability to engage in treatment

-Fragmented services

12

6

Children of Color with Disabilities are Particularly Vulnerable

- Significant racial and ethnic health and diagnostic disparities for children with autism (Mandell et al., 2009) and other developmental disabilities (Magaña et al., 2012).

- Children of color, including Black and Native Americans, are overrepresented in the child welfare system (see Child Welfare Information Gateway, 2016 for more information and readings)

- A comprehensive approach is needed to address both individual and community risk factors (e.g., poverty) along with racial factors (e.g., worker biases) that lead to disparities in child welfare system involvement (see Putnam-Hornstein et al., 2013 for more information).

- The field needs to do more to understand the experiences of children of color with disabilities in the child welfare system.

13

The Importance of Identifying Foster Children with IDD

Understanding need for specialized supports

14

INFORMING FINDINGS

#3A

Has DHS ensured that appropriate services are in place to safeguard the child's safety, health, and well-being?
- Placement
- Safety
- Family contact
- Assessments
- Education
- Health
- Youth transition plan
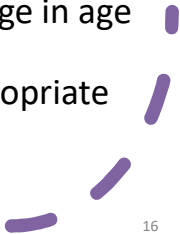- Cultural considerations

15

INFORMING FINDINGS

#3B

Has DHS taken appropriate steps to ensure that:

1) the substitute care provider is following the reasonable and prudent parent standard; and

2) the child has regular, ongoing opportunities to engage in age appropriate or developmentally appropriate activities?

16

INFORMING FINDINGS

#4

Has DHS made reasonable efforts to provide services to parents that make it possible for the child to safely return home?

- What services are provided?
- Are additional services needed?

17

INFORMING FINDINGS

#6

Have the parents made sufficient progress to make it possible for the child to safely return home?

18

How to ask questions about
IDD from the file and
during the review meeting?

Brainstorm:

1. Has there been an assessment and diagnosis
   completed by an appropriate professional?

2. Is the child receiving the proper
   accommodations in the school?

3. Is there evidence that the parents
   understand the disability?

4. OTHERS?

19

Case study: Monica

20

Think about …

How might DHS ensure that appropriate services are in place to safeguard Monica's safety, health, and well being?

- Assessments
- Accommodations
- ADA compliance
- School and education
- Community involvement
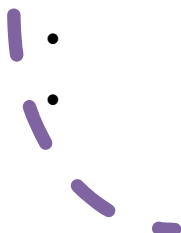
21

Examples of CRB recommendations

- An educational assessment be conducted as soon as possible
- A psychological assessment be conducted before the next CRB review
- The concurrent plan be evaluated recognizing a child's special needs
- Determine if the "diagnosis" is accurate
- Others?
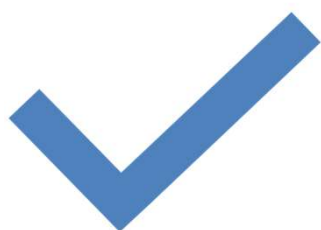
22

WRAP UP

- Feedback

- Next steps
-
-
-

23

References (1)

- Baio, J., Wiggins, L., Christensen, D. L., Maenner, M. J., Daniels, J.…Dowling, N. F. (2018). Prevalence of autism spectrum disorder among children aged 8 years—Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2014. *MMWR Surveillance Summaries, 67*(SS-6), 1–23.
- Centers for Disease Control and Prevention (CDC). (2019). Specific types developmental disabilities. Retrieved from https://www.cdc.gov/ncbddd/developmentaldisabilities/specificconditions.html
- Centers for Disease Control and Prevention. (2019). *Study to Explore Early Development (SEED)*. Retrieved from https://www.cdc.gov/ncbddd/autism/seed.html
- Child Welfare Information Gateway. (2016). Racial disproportionality and disparity in child welfare. Washington, DC: U.S. Department of Health and Human Services, Children's Bureau.
- Liao, M., Dababnah, S., & Park, H. (2017). Relationship between disabilities and adoption outcomes in African American children. *Journal of Child and Family Studies, 26*(9), 2438-2449.
- Lightfoot, E., Hill, K., & LaLiberte, T. (2011). Prevalence of children with disabilities in the child welfare system and out of home placement: An examination of administrative records. *Children and Youth Services Review, 33*(11), 2069–2075.
- Lightfoot, E. & LaLiberte, T. L. (2006). Approaches to child protection case management for cases involving people with disabilities. *Child Abuse & Neglect, 30*(4), 381-391.
- Magaña, S., Parish, S. L., Rose, R. A., Timberlake, M., & Swaine, J. G. (2012). Racial and ethnic disparities in quality of health care among children with autism and other developmental disabilities. *Intellectual & Developmental Disabilities, 50*(4), 287–299.
- Mandell, D. S., Wiggins, L. D., Carpenter, L. A., Daniels, J., DiGuiseppi, C., Durkin, M. S., . . .Kirby, R. S. (2009). Racial/ethnic disparities in the identification of children with autism spectrum disorders. *American Journal of Public Health, 99*(3), 493–498.

24

References (2)

- National Institute of Child Health and Human Development. (2012). Intellectual and developmental disabilities (IDDs): Condition information. Retrieved from https://www.nichd.nih.gov/health/topics/idds/conditioninfo/default
- Oregon Department of Education. (2020). *IDEA compliance and district resources.* Retrieved from https://www.oregon.gov/ode/rules-and-policies/Pages/Individuals-with-Disabilities-Education-Act.aspx
- Putnam-Hornstein, E., Needell, B., King, B., & Johnson-Motoyama, M. (2013). Racial and ethnic disparities: A population-based examination of risk factors for involvement with child protective services. *Child Abuse & Neglect, 37*(1), 33–46.
- Romney, S. C., Litrownik, A. J., Newton, R. R., & Lau, A. (2006). *Child Welfare, 85*(6), 965-984.
- Slayter, E. & Springer, C. (2011). Child welfare-involved youth with intellectual disabilities: Pathways into and placements in foster care. *Intellectual & Developmental Disabilities, 49*(1), 1-13.
- Sullivan, P. M. & Knutson, J.F. (2000). Maltreatment and disabilities: A population-based epidemiological study. *Child Abuse & Neglect, 24*(10), 1257-1273.
- U.S. Department of Education. (2018). *Sec. 300.8 Child with a disability.* Retrieved from https://sites.ed.gov/idea/regs/b/a/300.8
- Zablotsky, B., Black, L., Maenner, M., Schieve, L., Danielson, M., Bitsko, R., … Boyle, C. (2019). Prevalence and trends of developmental disabilities among children in the United States: 2009-2017. *Pediatrics, 144*(4), e20190811.

25