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OBJECTIVES

- Increase understanding of differences of trauma responses of children with disabilities versus typically developing children
- Understand the increased risk for maltreatment and associated long-term effects
- Identify treatment options for youth with disabilities that have experienced trauma
- Recognize differences in needs of navigating services for children with disabilities



Data Disclaimer



- Definitions are important!
- Limited Research Available
- Shared language is needed
- Trauma-Informed care practices need to be tailored to service providers and organizations

Important Considerations

- Individuals and Families do well if they can
- The best way to support families is to avoid blame and shame
- Supporting and educating families prevents maltreatment
- True trauma-informed practice and research must recognize how systemic inequalities contribute to traumatic experiences.
- Multiple structural barriers in accessing services



Defining Disability in South Dakota

Medical

- Labels, provides criterion, and diagnoses
- Provides access to reimbursement, supports, and services

Educational

- Views disability through an eligibility lens
- Not all students with medical diagnoses of disabilities will be eligible for educational services

Social

- Highlights the barriers and prejudice that exclude people with disabilities
- Can provide sense of community

Etiology of Disabilities

- Varies greatly depending on the specific disease or disorder
- Most common etiologies resulting in physical and health disabilities:
 - O Genetic and chromosomal defects
 - Hereditary conditions
 - Random abnormalities
 - O Teratogenic causes
 - Infections
 - Drugs
 - Chemicals
 - Environmental agents
 - Prematurity and complications during pregnancy
 - Born before 37 weeks of gestation
 - Asphyxia (decrease of oxygen in the blood) during perinatal period
 - Acquired causes
 - Trauma
 - Child abuse
 - Infections
 - Environmental toxins
 - Disease
 - Multiple etiologies

Prevalence

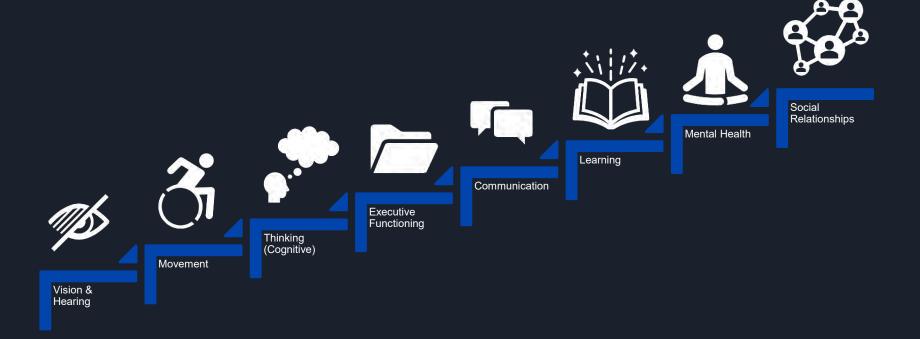
- According to the CDC, estimates in the U.S. show about 1 in 6, or about 17%, of children aged 3 through 17 years have one or more developmental disabilities
 - o ADHD
 - Autism
 - Cerebral palsy
 - Hearing loss
 - Intellectual disability
 - Learning disability
 - Vision impairment
 - O Other developmental delays

Defining Disability



Children in South Dakota		
	Total	Percentage
Special health care needs (2020)	37,957/210,872	18%
Special education (2021)*	22,220/140,826 (+1080)	15.78%
Children with disabilities (2017)*	8,400/243,600	9.5%
Total child population (2021)	220,429	100%

Disability Can Be...



Co-occurring

- "Dual Diagnosis" or "Comorbidities"
 - Mental illness and substance use disorder
 - Mental illness and intellectual/developmental disabilities (ID/DD)
- Autism and mental health (Gurney et al., 2006)
 - Depression or anxiety (38.9% vs 4.2%)
 Behavioral or conduct
 - Behavioral or conduct problems (58.9% vs 5.2%)

- Intellectual disabilities and mental health (Einfeld et al., 2011)
 - Comorbidity rates between 30-50% for children and adolescents
 - O 3 to 4x's more likely to experience comorbid health and mental health disorders

Signs and Symptoms of Trauma

Typical Signs of Trauma in Children

- Attachment- Difficulty trusting others or seeking help
- Physical- Increased medical problems (sensorimotor development problems, problems with coordination, etc.
- Affect Regulation Problems with emotion regulation
- •Behavioral- Poor impulse control, aggressive behavior, sleep disturbance, etc.
- Cognitive- Difficulty paying attention, processing information
- •Self-Concept- Low self-esteem, shame, guilt

Indicators for Children with Disabilities

- Developmental regression
- Social withdrawal or isolation
- Reduced self-care
- •Increase in being disorganized, dysregulated, aggressive, or self-injurious behavior

Responses to Trauma

- While children with and without disabilities experience similar physiological responses to traumatic events, they may exhibit different behavioral responses
- Children with disabilities tend to be "punished" more because of ableist expectations about how they should be behaving
- Children's responses to traumatic events are often discounted as symptoms of their disability (diagnostic overshadowing)
 - Higher levels of rumination
 - Lack of cognitive flexibility
 - Misunderstanding of social context
 - Internalizing alarm system



Effects of Maltreatment on Brain

Learning and Memory

Communication, Arousal, Emotion, Higher Cognitive Abilities

Motor Behavior and Executive Functioning

Behavior, Cognition, & Emotional Regulation



Threat Center & Emotional Response

ACEs Questionnaire

- Child maltreatment- physical abuse, emotional abuse, sexual abuse, physical neglect, and emotional neglect (Felitti, et al., 1998).
- Household Dysfunction- includes divorce/separation of parents/caregivers, witnessing domestic violence, and living with a person who suffers from a mental illness, substance abuse, or who is incarcerated (Centers for Disease Control and Prevention [CDC], 2019; Felitti, et al., 1998)
- Protective factors- relationships (one trusted adult), connection, and resources

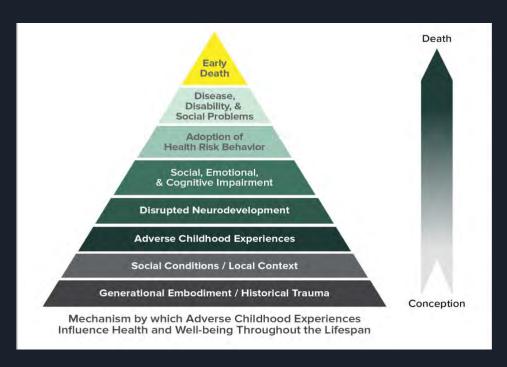
Adverse Childhood Experience (ACE) Questionnaire Finding your ACE Score 10 24 06

While you were growing up, during your first 18 years of life: 1. Did a parent or other adult in the household often ... Swear at you, insult you, put you down, or humiliate you? Act in a way that made you afraid that you might be physically hurt? If yes enter I 2. Did a parent or other adult in the household often ... Push, grab, slap, or throw something at you? Ever hit you so hard that you had marks or were injured? If yes enter 1 3. Did an adult or person at least 5 years older than you ever ... Touch or fondle you or have you touch their body in a sexual way? Try to or actually have oral, anal, or vaginal sex with you? If yes enter 1 4. Did you often feel that ... No one in your family loved you or thought you were important or special? Your family didn't look out for each other, feel close to each other, or support each other? If yes enter 1 5. Did you often feel that ... You didn't have enough to eat, had to wear dirty clothes, and had no one to protect you? Your parents were too drunk or high to take care of you or take you to the doctor if you needed it? If yes enter 1 6. Were your parents ever separated or divorced? If yes enter I 7. Was your mother or stepmother: Often pushed, grabbed, slapped, or had something thrown at her? Sometimes or often kicked, bitten, hit with a fist, or hit with something hard? Ever repeatedly hit over at least a few minutes or threatened with a gun or knife? 8. Did you live with anyone who was a problem drinker or alcoholic or who used street drugs? 9. Was a household member depressed or mentally ill or did a household member attempt suicide? If yes enter 1 10. Did a household member go to prison? Yes No If yes enter 1 Now add up your "Yes" answers: _____ This is your ACE Score

Disability in Correlation with ACEs

 Adverse childhood experiences are associated with longterm health conditions and longterm stress responses.





ACE Associated Health Conditions

Compared to children with 0 ACEs, those with 3+ ACEs...

- 2.3 times more likely to have a chronic disease
- 1.9 times more likely to have a developmental delay
- 5 times more likely to have ADHD



Mental Health and Maltreatment

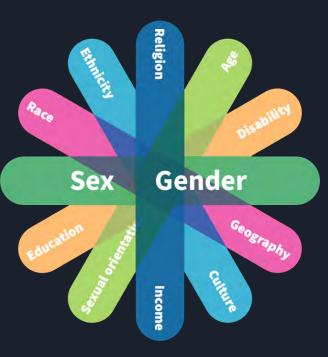
- The relationship between childhood disability and maltreatment is complex
- Causal relationship and direction of risk remains unclear
- Children with behavioral disorders have been found to be at the highest risk for maltreatment
- Symptoms of ADHD and maltreatment overlap = diagnostic confusion
 - Maltreatment deficits in emotion regulation and executive functioning
 - O ADHD concentration and attention difficulties, emotion dysregulation, disorganization, etc.
 - O Diagnosis of PTSD or Developmental Trauma be more appropriate?

Mental Health and Maltreatment

- Exposure to maltreatment can exacerbate ADHD symptoms
- Pre-existing ADHD involves interpersonal and regulation problems putting a child at greater risk for maltreatment or harsh parenting
- Given the heritability of ADHD, parent of a child with ADHD likely has
 ADHD and may be parenting in a dysregulated and impulsive manner
- Intergenerational trauma may be an important consideration for children with ADHD
- Systematic reviews suggest consistent association between ADHD and maltreatment across cultures
- Use of pharmacological stimulants
- Therapeutic approaches

Increased Risk of Maltreatment for Children with Disabilities

- Risk in home life vs. Service life (institutionalization, exploitation, seclusion and restraint, abandonment, medical trauma)
- Children with disabilities are 3 times more likely to be abused or neglected and more likely to be seriously injured
- 80% of children with ID experience one or more ACEs and
 20% experience four or more
- Differs by disability type
- Intersectional Identities- Disability



Service Availability

 Service availability and access to care are established barriers in healthcare for individuals with disabilities

- Even more true for mental health services
- When considering mental health and the known provider shortages nationally, access to services is an even bigger concern for those with disabilities, those living in rural areas, those living on our nine reservations, and especially those who find themselves at the intersection of one or more of these categories

Psychosocial Stressors

Physical Health and Stress

- Financial stress
- Increased need for supervision
- Increased physical and emotional strain on parents

Lack of Support

Social isolation

Family Functioning

- Feelings of grief about not having a "typically developing" child
- Time spend at appointments or providing in-home care

Poverty

- Live in high crime areas
- Poor-quality housing
- Lack of quality services

Risk Factors for Children with Disabilities

- Trained to be compliant to authority figures
- Dependent on caregivers for a longer periods of time for more types of assistance than a nondisabled child, and they are dependent on a larger number of caretakers
- Often unable to meet parental expectations
- Communication barriers
- More likely than other children to be placed in residential care facilities
- Sometimes more credulous and less prone to critical thinking than others
- Often not provided with general sex education
- Viewed negatively by society- seen as less than human

Maltreatment Rates in South Dakota (2020)

- In 34% of reports, it was determined at least one instance of maltreatment was substantiated or indicated
- About ½ of victims are under the age of
 3
 - o 81.5% qualify for birth to three services
- 25.5% of identified victims have a developmental delay or disability (only ages birth to 3)
- Similar to national data
 - % of children in foster care have a disability



Case Study

- Chronological age at date of evaluation: 1 year, 8 months (male)
- Child's pediatrician referred him to Birth-to-Three due a communication delay
- Motor development milestones met on time
- At 15-month well-child visit an autism evaluation was recommended
- Began receiving in-home speech therapy services 3months ago; 1x/week for approximately 45 minutes
- Child was born in an urban city of South Dakota
- Resides with his biological mother, his father, and an older half-sibling
- Conceived from a sexual assault, perpetrator is not involved in the child's life
- Induced delivery, full-term, with no complications throughout pregnancy, labor, or delivery, mother 30 years of age at delivery
- Denial of exposure to substances in-utero
- Normal birth weight (7 lbs. 13.6 oz)
- Mother: stay-at-home, caring for child full-time
- Father: home most weekends, away for work during the week
- Child only tends to interact or play with mother, not father or sister

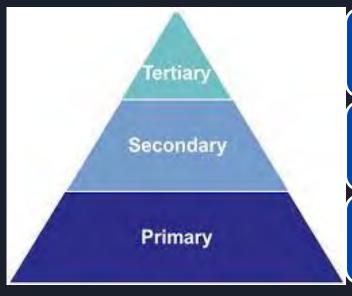
- Limited social exposure with peers, family has been isolated from their community since pandemic
- No pretend or imaginative play, interested in the sounds, movement, and lights of toys, loves to visually inspect his toys, especially the wheels of his toy cars
- Child flaps his hands when excited and grinds his teeth throughout the day
- Maternal extended family lives several states away, maternal grandparent killed in vehicular accident
- Paternal extended family lives in same town
- Perpetrator/biological father has known children, 1 with diagnosed ADHD, 1 with mobility impairments and is non-speaking due to agenesis of the corpus callosum (tissue that connects the left and right hemispheres is partially or completely missing)
- Mother received educational services growing up for ADHD and learning difficulties
- Maternal mental health history of depression and anxiety
- Concerns with large head and developmental delays
- Impression/Diagnoses: Autism Spectrum Disorder (ASD), Receptive and Expressive Language Disorder, Macrocephaly

Treatment Modalities and Collaboration

- Family Systems
- Instructional Programs
- Interactional Programs
- Early Intervention Services
 - Birth to Three Program
 - SD Early Childhood Enrichment Program
 - DayCare/Educational Program
- Recognizing Gaps
 - Over Reliance on Behavioral Management
 - Reluctance to treat youth with IDD due to lack of knowledge and expertise



Navigating Systems: Prevention



Tertiary- Focus on families where maltreatment has already occurred and seek to reduce negative outcomes of maltreatment and recurrence

Secondary- Populations that have one or more risk factors associated with child maltreatment. This is targeted for communities.

Primary- Directed at general population and attempt to stop maltreatment before it begins.

Prevention Strategies: Focus on Illness

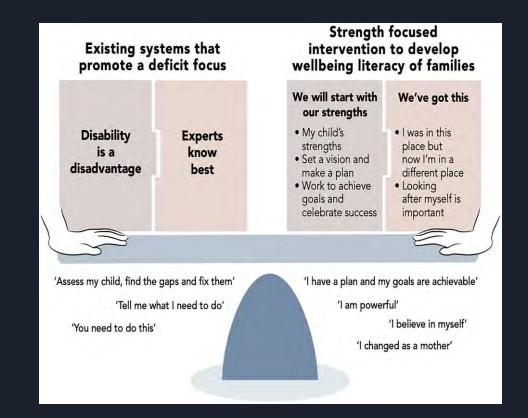


Prevention: Focus on Vitality



Working with Families

- Disability should be a primary focus, not an afterthought
- Take time to understand what works for families
- Take a strength-based approach
- Supports and services



Advocacy

- Limited disabilityspecific content in education
- Individuals and family members as advocates at individual, organizational, and community level

Spectrum of Prevention

Influencing Policy & Legislation

Changing Organizational Practices

Fostering Coalitions & Networks

Educating Providers

Promoting Community Education

Strengthening Individual Knowledge & Skills

If you have concerns...

- Psychologists
- Psychiatrists
- Developmental pediatricians
- Speech language pathologists
- Occupational therapists
- Mental health professionals
- Early childhood providers
- Disability-focused providers**

- Family/ caregivers
- Close support providers
- Teachers

SD Resources

- Parent Connection- Resources for Families with Disabilities | SD Parent Connection
- LifeScape LifeScape | Empowering people to live their best life (lifescapesd.org)
- Center for Disabilities- Center for Disabilities | University of South Dakota (usd.edu)
- Independent Living Choices Independent Living Choices Sioux Falls, SD (ilcchoices.org)
- Department of Human Services; Developmental Disabilities SD Department of Human Services
 - O Family Support 360
 - O Strengthening Families
 - Respite Care
 - o Choices
- Disability Rights Disability Rights South Dakota Formerly SD Advocacy Services (drsdlaw.org)
- IDD-MH guide; diagnostic considerations- Introduction | Center for START Services
- NCTSN-Intellectual and Developmental Disabilities | The National Child Traumatic Stress Network (nctsn.org)
- Child Welfare Information Gateway; Disability- Search Results Child Welfare Information Gateway

Questions?

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