IDD and Trauma

Summary of The National Child Traumatic Stress Network
2021 Updates

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Prevalence

- About 1 in 6 youth between 3 and 17 years in the US have an intellectual or developmental disability
- Youth with IDD are more vulnerable to co-occurring behavioral, social, and emotional difficulties (70% have co-occurring diagnosis)
- Autistic children may be more **reactive to stressful events** and lack coping skills
- **Youth with IDD are more vulnerable to traumatic experiences**
  - Children with ID are 2.84 times more likely to experience victimization than children without disabilities
  - 2021 analysis of a national dataset of 26,572 parents/caregivers

    Brendli, K.R., Broda, M.D., and Brown, R. (2021). Children with intellectual disability and victimization: A logistic regression analysis. Child Maltreatment.

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Gaps in Care

Mental health needs for youth with IDD often go unmet

- Provider and parent misconceptions about both IDD and trauma
- Siloed service systems
- Child-specific challenges (e.g., language, cognition, self-regulation) that make it more difficult to report trauma or internal distress

If trauma is not recognized and treated, there can be significant long-term negative mental health impacts (e.g., anxiety, PTSD, and depression)

Increased Risk

Youth with IDD are at increased risk of experiencing:

- physical and emotional neglect
- physical and sexual abuse
- trauma secondary to restraint and seclusion (e.g., school, police)
- teasing, bullying, rejection, and exploitation (e.g., peers, social media)
- multiple changes in educational placements and school settings
- out-of-home placements & changes in residential placements
- changes in care-givers (e.g., home-care workers)

Compounded by discrimination due to race, ethnicity, language, and SES

Increased Risk

Youth with (severe) IDD have higher likelihood of experiencing pain, stress and fear from:

- chronic health conditions
- surgeries and invasive procedures
- appointments and hospitalizations
- health-related life disruptions

Medical trauma and symptoms may go unnoted due to:

- child's difficulty communicating experiences/distress
- perception of child being less credible
- misattribution of behaviors to ID alone (child's input dismissed or disbelieved)

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Behavioral Indicators

Communication via behavior – especially changes from baseline:

- developmental regression (e.g., toileting, communication, self-care)
- increased disorganized and dysregulation
- social withdrawal/isolation
- aggression, self-injury, irritability, sexual acting out
- eating (less/more) and sleeping (lethargy/insomnia, nightmares)
- panic, tearfulness, ”shutting down”/freezing
- new fears, avoiding previously enjoyed activities or people

Crisis stabilization

- Youth may need (trauma-informed) stabilization before more formal trauma treatment

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Silos of Care

Mental health services and IDD-focused services are usually provided in separate, parallel systems

- Mental health system reluctant to treat youth with IDD due to limited knowledge and expertise
- IDD field reliant on behavior management instead of treatments for trauma or mental healthcare
- Trauma providers may lack experience with IDD

Pressing need for collaborative service delivery, communication and sharing of resources

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Screening

Ask about trauma events and experiences

- Encourage youth's input as well as caregiver's
- Incorporate trauma symptom checklists

Public domain trauma screeners:

U of Minnesota's Traumatic Stress Screen for Children and Adolescents (TSSCA), 5-18 years (7 questions)

U of Washington's Child and Adolescent Trauma Screen (CATS), 3-6 years parent report & 7-17 years self report (15 min, DSM-5 aligned)

Child PTSD Symptom Scale for DSM-V (CPSS-V SR), 8-18 years (Spanish, self-report 10 min)

UCLA Brief Screen for Child/Adolescent Trauma and PTSD, 6-18 years (15 min, Spanish)

UCLA Brief COVID-19 Screen for Child/Adolescent PTSD, 6-18 years (15 min, Spanish)

Assessment Challenges

- Trauma-related symptoms can mirror behaviors seen in IDD
- Multiple sources of information over time are often needed
- Diagnostic “overshadowing” (i.e., over-attributing IDD) can result in failing to look beyond IDD
  - ignoring trauma as a possible contributing factor
  - other conditions going undiagnosed and untreated

Explore behavioral changes and always consider the possibility of associated trauma

Treatment

Trauma-informed treatment can be effective for this population, but more research is needed especially for children with severe IDD

Trauma Focused-Cognitive Behavioral Therapy (TF-CBT) can be adapted with fidelity

- session length and frequency (e.g., shorter more often)
- pacing of content (e.g., slower, breaks, time for non-trauma issues)
- caregiver involvement (e.g., more family sessions, calls between sessions)
- individualized teaching, repetition and skills rehearsal (e.g., concrete language, less reliance on cognitive strategies, checking for understanding)
- use of sensory aids and alternate modes of learning (e.g., visuals)
- measuring change in smaller and more gradual increments

Family/Caregiver Support

- Families need support to:
  - increase child's sense of safety
  - assure family stability
  - maintain the health and well-being of each family member

- Providers should share information about:
  - behavioral and emotional changes associated with trauma exposure
  - recovery process of their child, themselves, and the family
  - how to connect with supports and mental health care

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NCTSN

The National Child Traumatic Stress Network

Mission: to raise the standard of care and increase access to services for children and families who experience or witness traumatic events

https://www.nctsn.org

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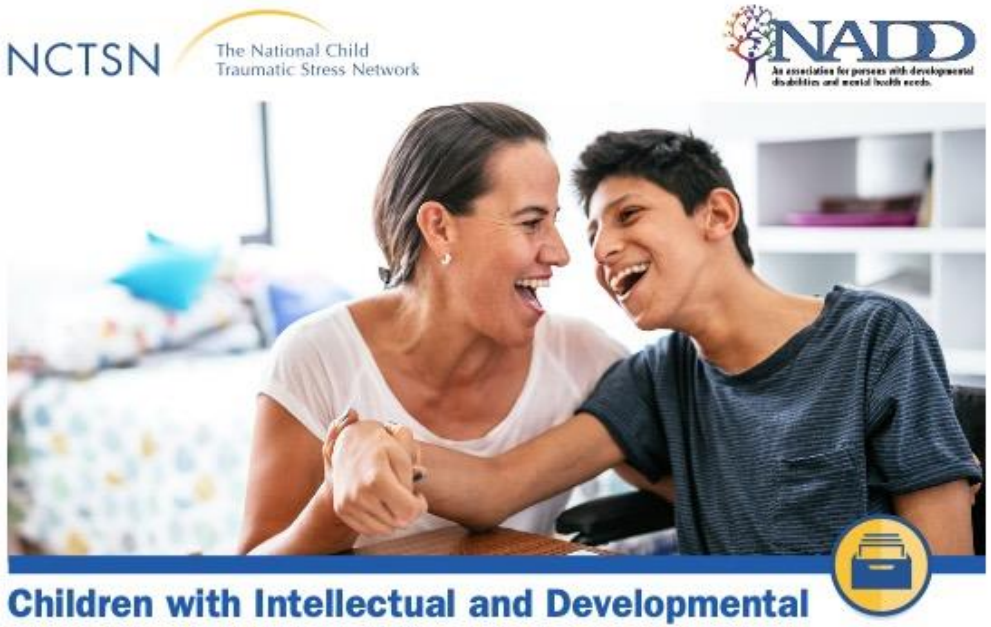

Children with Intellectual and Developmental Disabilities Can Experience Traumatic Stress

A Fact Sheet for Parents and Caregivers

The Intersection of IDD, Trauma, and Mental Wellness

Studies[1] indicate that children with intellectual and developmental disabilities (IDD) experience trauma and stressful circumstances or events at higher rates than children without these disabilities. For caregivers, including parents, family members, and others who support children with IDD, awareness of the impact of trauma on their children's mental health and wellness can greatly improve a child's opportunities for recovery from a traumatic or stressful experience. This fact sheet is designed to provide an overview of IDD and trauma and to:

- Help caregivers understand issues related to trauma and its impact on children with IDD and their families.
- Provide caregivers with information and resources that can help them improve the well-being of children with IDD who have experienced trauma.
- Help caregivers know the questions they should ask about traumatic stress and the treatments, services, and supports to expect for children and families.
- Promote awareness of the need to address the mental health and wellness of children with IDD.

With this guidance, we hope that caregivers will be able to better access services and advocate for their child.

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General Goals

- validate the trauma
- emphasize on child's and family's strengths
- build trusting relationships
- explore positive interests and activities
- establish safety around child's and family routines
- gain meaning from family's shared experience and growth
- establish ongoing supports for child and family

Trauma Informed Organizations

SAMHSA's definition of trauma informed organizations:

- Recognize the signs and symptoms of trauma in youth, families, staff, and others involved
- Realize the widespread impact of trauma and understand potential paths for recovery
- Respond by fully integrating knowledge about trauma into policies, procedures, and practices
- Seek to actively resist re-traumatization

References

- Brendli, K.R., Broda, M.D., and Brown, R. (2021). Children with intellectual disability and victimization: A logistic regression analysis. Child Maltreatment. https://doi.org/10.1177/1077559521994177
- Peterson, J. L., Earl, R. K., Fox, E. A., Ma, R., Haidar, G., Pepper, M., ... & Bernier, R. A. (2019). Trauma and autism spectrum disorder: review, proposed treatment adaptations and future directions. Journal of child & adolescent trauma, 12(4), 529-547.
- Trauma and Intellectual/Developmental Disability Collaborative Group. (2020). *The impact of trauma on youth with intellectual and developmental disabilities: A fact sheet for providers.* Los Angeles, CA, and Durham, NC: National Center for Child Traumatic Stress.
- Horton, C., Evans, N., Charkowski, R., D'Amico, P., Gomez, M., R., Henderson Bethel, T., Kraps, J., Vogel, J., and Youde, J. (2021)*Children with intellectual and developmental disabilities can experience traumatic stress: A fact sheet for parents and caregivers.* Los Angeles, CA, and Durham, NC: National Center for Child Traumatic Stress.
- Kerns, C. M., Newschaffer, C. J., & Berkowitz, S. J. (2015). Traumatic childhood events and Autism. *Journal of Autism and Developmental Disorders*, *45*(11).

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