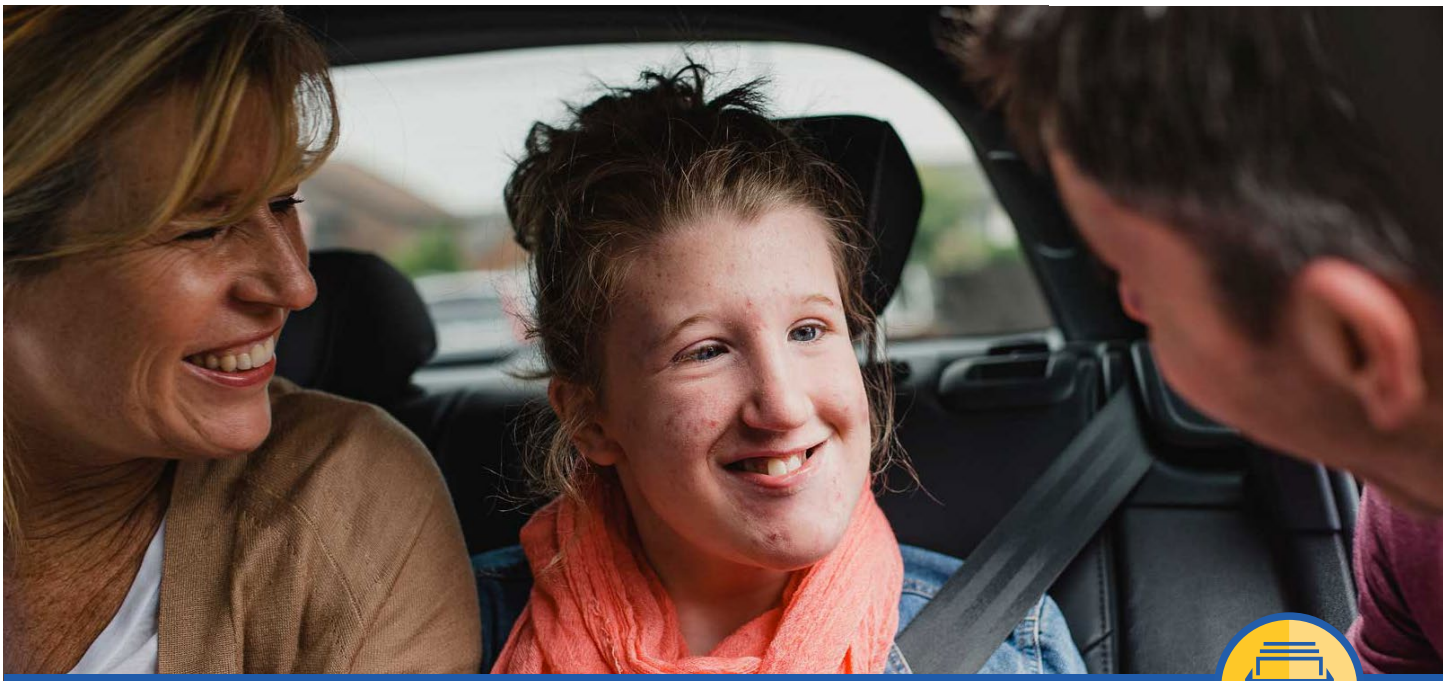
NCTSN The National Child Traumatic Stress Network

NADD An association for persons with developmental disabilities and mental health needs.



# The Impact of Trauma on Youth with Intellectual and Developmental Disabilities: A Fact Sheet for Providers

Approximately one in six youth between the ages of 3 and 17 in the United States have an intellectual or developmental disability, as signified by major delays or difficulty in functioning in one or more key developmental areas. These areas may affect thinking and learning, language, motor skills, behavior, and adaptive functions such as self-care, communication, and social skills. Intellectual and developmental disabilities (IDD) affect functioning throughout a person's lifetime. They leave children and youth more vulnerable to a range of behavioral, social, and emotional difficulties, and to co-occurring medical and mental health disorders. In particular, youth with IDD are at risk for traumatic experiences in the home, school, and community and sometimes in conjunction with their frequent healthcare encounters.

Early intervention in childhood may reduce the impact of some types of disabilities. However, gaps in services for children are leaving their mental health needs grossly underserved, especially with respect to trauma-informed care. There are many reasons for this, including provider misconceptions about IDD and trauma, siloed service systems, and specific challenges (e.g., deficits in speech, language, cognition, etc.) that may make it more difficult for children and youth with IDD to report traumatic experiences or internal distress. We developed this fact sheet for professionals across diverse practice settings (health, behavioral health, school, child welfare, juvenile justice) to increase understanding of trauma in youth with IDD. The overarching goal is to reduce service gaps and promote recovery and resilience.

**Terms of IDD**

Intellectual disabilities (ID) are conditions in which there is significant, persistent impairment in both thinking skills and everyday adaptive functioning such as self-care, communication, and social skills.

Developmental disabilities (DD) are disabilities with a pervasive impact, such as Autism Spectrum Disorder, cerebral palsy, Down syndrome, brain injury, and intellectual disabilities; DD may also be more focused in impact, such as a specific learning disability.

Youth with intellectual and developmental disabilities (IDD) are more vulnerable to a range of behavioral, social, and emotional difficulties throughout life, and many have co-occurring disorders, including those related to trauma exposure.

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## 1 IDD and Trauma

Children with IDD are at increased risk for various types of traumatic experiences. These experiences include physical and emotional neglect, physical and sexual abuse, as well as trauma secondary to restrains and seclusion, and other interventions used to contain a child who is presenting with behavior that is a danger to themselves or others. Children with IDD are also more likely to experience changes in educational placements and school settings, out-of-home placements (at times accompanied by parental loss) and changes in residential placements if placed outside of the home. As a result, they are more likely to experience disruptions in social supports. They are also at heightened risk for teasing, bullying, rejection, and exploitation by peers and social media. This risk is further compounded for individuals vulnerable to discrimination due to their race, ethnicity, language, and socioeconomic status. Children with more severe IDD are likely to experience a higher number of health-related procedures, as they often have chronic or comorbid conditions that necessitate surgeries, other invasive procedures, and frequent healthcare appointments. Such disruptions may put children with IDD at risk for medical trauma. Nonetheless, trauma exposure and symptomatology are believed to be underreported for several reasons. As noted, some children may be unable to communicate their experiences or distress to caregivers and professionals, who may themselves have limited understanding of trauma and trauma-related symptoms, and may attribute trauma-related behavior to the developmental condition alone. Such misattribution may delay or prevent needed services and contribute to or compound a youth's functional difficulties.

## 2 IDD, Communication, and Trauma-Related Behavior

Behavior is a form of communication for all children. Youth with IDD may have difficulty with cognitive processing, reasoning, problem solving, and coping skills, as well as language and communication challenges, will often communicate their needs through their behavior. The more severe the IDD, the more likely they are to use behavioral indicators versus verbal expressions in the home, at school, in the medical examining room, or in the therapy office. Providers should be alert to behavioral indicators such as developmental regression, social withdrawal or isolation, reduced self-care, increase in disorganized and dysregulated behavior, aggression, and self-injury.

***Crisis stabilization and management***

For some youth with IDD, the first sign that a trauma has occurred may be a significant regression in skills or escalation of behavior difficulties. Youth experiencing these changes will often need stabilization interventions before more conventional trauma treatment can take place. However, it is critical that such interventions be trauma-informed as well, and implemented by trauma-informed providers.

## 3 IDD and Systems of Care

Mental health services and IDD-focused services have traditionally been provided through separate and parallel systems of care – a siloed approach, rather than collaborative service delivery involving shared recognition, accountability, and decision-making. The lack of intersystem planning and coordination has resulted in obstacles to mental health and trauma-informed care, within both the mental health and IDD sectors.

- In the mental health system, there may be reluctance to treat youth with IDD such as Intellectual Disability or Autism Spectrum Disorder; this likely stems from both the providers' lack of knowledge that children and youth with IDD can benefit from trauma treatment, and the providers' lack of expertise in implementing the appropriate care.

- In the IDD field, the tendency is to rely on behavior management instead of approaches that would better help youth process and recover from traumatic experiences.

- In the trauma field, providers often lack familiarity or experience working with children and youth with IDD.

Overcoming these obstacles within each sector requires greater understanding of the trauma-related needs of children and youth with IDD. Across sectors, there is equally pressing need for improved communication, collaboration, and sharing of resources by providers and systems.

**The Trauma-Informed Agency**

The Substance Abuse and Mental Health Services Administration (SAMHSA) has defined trauma-informed programs, organizations, and systems as those that:

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

## 4 Screening and Assessment

The screening and assessment of trauma exposure is an essential component of a comprehensive mental health evaluation and plan for all children and youth with IDD. Providers should seek consultation when needed for interpreting prior cognitive or neuropsychological assessments in order to understand each child's developmental status, cognitive readiness, communication level, and need for assistive communication. Due to intellectual, language, or communication deficits, assessment of trauma in youth with IDD is rarely considered in assessment or clinical care. Moreover, when trauma is considered, providers tend to rely on caregiver reports to the exclusion of the youth's input. There is a pressing need to incorporate trauma event and symptom checklists into screening and assessment protocols. Health care providers should strive to begin by just "asking the question." It is also important to include reports from multiple informants when possible, including the child or youth with IDD if possible, and, to the extent they are available, to use trauma measures that are adapted to self-report by children and youth with IDD.

## 5 Diagnostic Considerations

The differential diagnosis of trauma-related disorders in youth with IDD has been problematic because many trauma-related symptoms can mirror behavior seen with IDD. Diagnostic "overshadowing" refers to the process of over-attributing an individual's symptoms to a particular condition (in this case, IDD), resulting in key co-morbid conditions being undiagnosed and untreated. Due to this overshadowing, professionals fail to look beyond a child's disability and overlook additional factors such as exposure to trauma. To overcome these biases, providers are encouraged to look carefully at behavior changes in particular, and should verify the changes with caregivers across multiple settings. If there is documented behavior change, providers should look at events surrounding the change and consider trauma as a possible contributing factor, particularly if evidence support this view.

## 6 Treatment

Standard trauma-informed mental health treatments can be effective for most youth with IDD and trauma exposure (although more research is needed for those with severe difficulties). A growing number of providers with experience delivering evidence-based trauma interventions are already treating youth with IDD by making flexible adaptations with fidelity to the original trauma protocol. The degree of support that clinicians may need depends on their understanding of IDD issues and trauma care, as well as their comfort and confidence in tailoring treatment to this population. Some adjustments reported as helpful focus on:

- Session length and frequency (shorter sessions, more frequent sessions); length of treatment (more sessions), and slower pacing of content.
- Parent or caregiver involvement including increased time in child sessions; increased time in parent/caregiver sessions; family sessions that include the youth, siblings, and parents; and between-session communications.
- Treatment content such as repetition and rehearsal of skills; use of sensory aids, use of individualized teaching materials; alternative modes of expression such as art; and measuring change in smaller and more gradual increments.
- Treatment structure including increased structure; more session (movement) breaks; use of enhanced engagement strategies (e.g., play rewards); more time on non-trauma-related issues; concrete presentations; plain language; simplified and reduced reliance on cognitive strategies as well as checks for understanding.

**"We Needed Help as Much as Our Daughter Did"**

Parenting a youth with IDD can be extraordinarily stressful. Against a background of day-to-day stressors, caregivers cope with social burdens such as stigma associated with IDD and mental health; emotional strain from worry about the future; excessive demands on the family unit and family members; strain on the marriage; and financial pressure. With the added element of traumatic stress, families will need support for increasing the child's sense of safety, assuring family stability, and maintaining the health and well-being of each family member.

Caregivers and families need to be validated on their unique struggles, and to understand how essential they are to the child's effective assessment and treatment. This is the case for all children with traumatic stress but particularly for those with IDD. Providers rely heavily on parent or caregiver reports of the youth's experiences and functional changes. In support of caregivers, providers should offer them education on how they can help with the recovery process of their child, themselves, and the family. Further, providers may need to educate families about the behavioral and emotional changes associated with trauma exposure, and connect them with sources for individual support or mental health care.

## 7 Resilience and Recovery

The recovery process is unique for each individual with IDD and trauma. The process is best reinforced by validation of the trauma, support of the youth and family, and reliance on childrens' and families' existing strengths. Using a trauma-informed approach by trying to determine "what happened" to the child instead of "what's wrong" with the child is a helpful first step. Parents, teachers, and clinicians may need to work extra hard in building or rebuilding a trusting relationship; moreover, clinicians should advocate for the individual to have more time with caregivers who have established trusting relationships. Exploring special talents, interests, or activities of the youth or family, and ensuring increased time in these activities, may help to lessen the impact of trauma and hasten the recovery process. An emphasis on child and family routines and rituals is another step toward validation and normalization. Helping the youth and family to gain meaning out of their shared experience and recovery is critical for the youth and family to heal.

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