Choosing Trauma-Informed Care for Children with Intellectual and Developmental Disabilities: A Fact Sheet for Caregivers

We live in a world where all children can experience challenges with their mental health, including those caused by trauma. We know all children can heal after trauma; this includes children with intellectual and developmental disabilities (IDD). Sometimes recovery from trauma requires partnership with child- and family-focused mental health care providers. As a caregiver, you play a large and important role in your child’s treatment and recovery, so you should know that help is available for your child and family. It might be time to seek help from a mental health provider if you are aware that your child has experienced trauma, or you notice concerning changes in your child’s behavior or mood that suggest a traumatic experience may have occurred (see Understanding Trauma Responses in Children with Intellectual and Developmental Disabilities and When to Seek Help). This is especially the case if these changes leave you feeling overwhelmed.

"After my nephew was in a car accident, our behavior specialist helped us realize that he needed to be supported in gradually feeling safe getting into the car again. They helped us understand his reactions to the trauma, rather than focusing on quickly reducing his challenging behaviors when near cars."

- Uncle of a child with IDD

Children who have experienced trauma typically need help learning to cope with and process the experience. Look for a provider who can offer trauma-informed care and has experience working with children who have IDD. If none can be found, try to locate a provider in your community who is open to learning how to support your child, you, and your family in treatment. This fact sheet poses questions you are likely to have as a caregiver seeking and selecting a provider. In addition, it offers guidance on what to expect and listen for from prospective providers.

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How Can I Find a Mental Health Care Provider for My Child?

Begin by looking for licensed mental health care providers in your state. These are professionals such as psychologists, psychiatrists, social workers, and counselors. Turn to your care network for suggestions or referrals for providers in your community. For example, ask other caregivers, your child’s school staff, or professionals you are already working with (such as your pediatrician or nurse, speech therapist, or Applied Behavior Analysis (ABA) therapist). Specify that you are looking for someone both experienced in trauma treatment and who is knowledgeable about IDD. Often, there are parent groups or local/national organizations that can help you. If you cannot find a provider with this experience in your community, look for a provider who is open to learning how to support you and your family. Many providers who have not worked directly with children with IDD already have the needed skills. If they are willing to modify their methods to work with your child and family, your child can begin their road to recovery.

“We had a great relationship with our first therapist, but they had no experience with trauma, so little progress was made. Once we found a trauma-informed therapist, my daughter’s behavior and mood improved and we received great strategies for dealing with meltdowns as they occurred.” — Father of a daughter with IDD

What Should I Ask the Mental Health Care Providers I Contact?

Remember, you are a key partner in your child’s recovery, so it is vital that you feel empowered as you choose a provider. A good way to proceed is to prepare for an initial conversation with a provider that will help guide your decision.

What approach do you use to treat children who have experienced trauma?

Listen for a provider who:

- Outlines a process for screening for trauma exposure, assessing trauma responses, and developing treatment recommendations.
- Describes likely treatment options. They might mention trauma-focused interventions by name. If so, you can write them down and learn more about them on your own. The NCTSN has a list of evidence-based trauma interventions (visit https://www.nctsn.org/treatments-and-practices for more information).
- Collaborates with other providers working with your child. Trauma therapists often partner with caregivers, schools, and others to meet the child and family’s needs.

What is your comfort, willingness, and experience in treating children who have IDD?

Listen for a provider who:

- Describes how they will meet your child at their level and needs (for example, use of language your child understands, use of visual supports). Because your child’s involvement in the evaluation process is important, this should include the intake as well as therapy.
- Shares ideas for how they would learn and incorporate your child’s interests and strengths to engage your child in treatment.

“After my daughter’s trauma, we approached more than a dozen therapists who informed us that ‘we don’t provide services to individuals with IDD.’ Finally, one psychologist told us she had never worked with someone with IDD but was happy to try. She came to recognize that my daughter was obsessed with stuffed animals – they were her friends and her ‘safe place.’ The psychologist would bring stuffed animals to their sessions and the animals would talk to each other. That allowed my daughter a strong sense of safety and empowerment. It was simply a different way to communicate.” — Mother of a daughter with IDD
How Will I Know if My Child Is Getting the Trauma-Informed Care They Need?

After completing some initial assessments with your family, the therapist should choose an evidence-based treatment and discuss what it might include with you and your child. Each treatment is a little different, and the roles you and your child have will vary. Regardless of the treatment, your provider should:

- Ensure communication and treatment are tailored to your child’s skills and abilities.
- Help you understand trauma’s effects on your child’s thoughts, feelings, and actions.
- Offer you support, including information on how trauma may impact your family.
- Explain how you and your child can work together to address trauma-related challenges and process the traumatic experience.
- Plan with you for safety when needed.
- Explain how caregiver coping and support are essential for your child’s recovery.

When your child is receiving trauma-informed treatment, providers should routinely check in with you and your family about the progress they are seeing. During these conversations, they might explain changes in scores on assessments. They should ask you and your child about signs of progress you see towards the treatment goals and ask about any setbacks your child might experience. They should note progress seen by teachers or other providers. With this information, your family and the provider can adjust goals, strategies, or treatments together.

“After identifying a therapist and working through the initial evaluation process, my son’s treatment was progressing well. Then, as the anniversary of the traumatic event approached, our son’s behavior changed. Working with our therapist, we learned that this change was a reaction to the trauma reminders associated with the anniversary. They helped us to understand that this was a temporary setback and that the work we had been doing gave our family tools to navigate this tough time together.”

– Foster mom of a son with IDD

What Does Partnership in Trauma-Informed Care Mean?

Seeking help and support in caring for your child is a positive step in protecting your mental health and reducing the stress that your child may be experiencing. You can partner with your mental health provider by sharing your child’s strengths and interests; this will help the provider build a relationship with your child. Depending on your child’s needs and the treatment selected, you may be involved directly in their sessions. Trauma-informed care should include a partnership where providers, caregivers, and children work together. For example, your role might include serving as a link between the trauma therapist and others involved in your child’s care. Consistency is often an anchor for children with IDD. Having all team members respond in the same manner across all environments (home, therapy, school) can greatly assist a child’s progress. You’ll want to know, for example, if team members notice changes in your child’s behavior or if they can help support the coping strategies your child is learning.

As a caregiver, you have an essential voice and role in that partnership. Alongside you and other team members, mental health providers should:

- Partner with you to help set the stage for treatment by learning your child’s strengths and interests, which helps them build a relationship with your child.
- Prepare you and your child for what to expect during sessions.
- Describe how caregivers and other team members can support the work of therapy between sessions, including at home and at school.
- Listen and take into account your current concerns.

- Work with you on reactions your child might show before or after sessions. (For example, your child could be more talkative after sessions or perhaps will want quiet and calm).

- Provide you with strategies to use at home and ways to reinforce what was learned in sessions. (For example, this might include strategies to help you manage your own reactions to support your child.)

Consider switching providers if you feel your child isn’t making progress, or if the provider is not able to adjust treatment to meet your child’s needs. When your child has reached their treatment goals, the provider should prepare you with the tools to continue to support your child at home. They should also prepare you to advocate for any needed supports at school and in the community. Finally, they should help you with strategies to sustain the recovery gained during your partnership.

This fact sheet is a part of a series for parents and caregivers. It is meant to help you in supporting your family’s needs and their recovery from trauma. The series also includes Trauma and Children with Intellectual/Developmental Disabilities: Taking Care of Yourself and Your Family; Understanding Trauma Responses in Children with IDD and When to Seek Help; and Children with Intellectual and Developmental Disabilities Can Experience Traumatic Stress: A Fact Sheet for Parents and Caregivers. Please visit these other fact sheets for more information.

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