



# Trauma and Children with Intellectual and Developmental Disabilities:

# **Taking Care of Yourself and Your Family**

Parenting is said to be one of the hardest jobs in the world. Parenting children with intellectual/developmental disabilities (IDD) can present even more unique challenges. When your child has also experienced a serious stressor or trauma, this can be even more challenging.

When you first learned that your child was diagnosed with IDD, you likely experienced various feelings. You learned to navigate those feelings with internal strength and support from others. Finding out that your child has also been through something extremely stressful - like being hurt by someone or seeing something very frightening - adds a layer of emotion that can make things seem too hard to handle. The strength and support you drew on when you learned the IDD diagnosis of your child will be important to use now. When you are parenting a child who is now showing reactions to trauma, it can feel overwhelming and leave you wondering how to help them recover. One important thing to remember is that stress has a similar impact on everyone's brains and bodies. Effective tools and treatments are available to help you and your child heal, no matter what diagnoses your child might have. Professionals are working to better adapt those tools and treatments especially for children like yours.

"After the trauma, it began to feel that parenting my son was too much. Then we found a provider who understood both autism and trauma. She helped us see that his behavior had changed because he was having a trauma response that added to his challenges from autism. She helped us recognize that, yeah, this is a really hard combination! Getting additional support that addressed both issues when we needed it really made a difference."

- Father of a child with autism



# As a Caregiver, Could I Also React to My Child's Negative Experiences or Traumas?

Definitely. Even if you have not experienced the traumatic event(s) yourself, knowing about your child's experience can be upsetting. The feelings you might have are quite common and are called secondary traumatic stress or STS. Our brains and bodies react similarly to both direct and indirect trauma. There are likely parallels between your child's reaction to the traumatic event and your own emotional response as you learned about what happened to your child. It's common to have physical and emotional responses as a part of STS. These are real and valid.

Each individual experiences STS in their own way. Common responses are:

#### **Physical Responses**

- Trouble sleeping
- Repeated thoughts or nightmares about your child's trauma
- Stomachaches
- Headaches
- Exhaustion

#### **Emotional Responses**

- Anxiety (feeling on edge and/or fearful)
- Overwhelmed (feeling drained and/or shutting down)
- Upset (feeling out of sorts, irritable, and/or angry)
- Concentration difficulties (having trouble focusing)
- Experiencing guilt



Even things that may not seem like a stress response, such as boredom, emotional numbness, body aches, etc., can be signs of STS. Any of these responses may indicate that you may benefit from seeking additional support for yourself.



# Taking Care of Myself During All of This Sometimes Feels Impossible!

When flying on a plane, you are instructed that in the event of an emergency, oxygen masks will drop down and you must put on your own mask before helping your child with theirs. By taking time to care for yourself, you are better able to help your child. Parents and caregivers of children with IDD typically already face demanding day-to-day responsibilities. The point here is that taking a few moments per day to meet your own needs is not selfish, it is actually critical for you and your child.

As parents and caregivers, your default may be set to, "I'll deal with my own needs later." In the past, think about how many times you were at home for hours and didn't eat or use the restroom. You may sometimes neglect emotional needs or avoid recognizing that you have needs of your own. The truth is, you do have the right to address your own needs. It can be helpful to take even a few minutes each day to try one stress management technique. It could also be a good time to consider accessing trauma-informed, mental health resources in your community. To find local options, a good place to start is with your primary care provider, community mental health center, or another trusted provider.

"When I thought about finding the time to take a break, clear my head, and do something just for me, I felt like it could never happen. But then I started to just do it once a day and built it into my routines. I started to feel better and calmer...at least for a while afterwards!"

A caregiving grandparent of a child with IDD



# **Self-Care Activities**

Here is an activity that can be practiced anywhere by anyone. It was designed by the NCTSN to be a fast, effective, in-the-moment technique for any person, whether they are a therapist, teacher, or caregiver. It gives one a good idea of what we mean when we say "Self-Care" (for example, we're not simply telling you to take a bubble bath). A full guide can be found at the NCTSN at: https://www.nctsn.org/resources/prn-to-promote-wellbeing-as-needed-to-care-for-your-wellness

Briefly, the activity is called "P-R-N." It stands for Pause-Reset-Nourish. By "Pause" we mean we want you to physically and psychologically pause, if only for a moment. Most days, caregivers have to operate in a constant rush and there is no time to pause. While it would be lovely to take a break for a half hour or more, this is usually not feasible. So all we ask is that you take a moment's pause to check how you are feeling on the inside; it takes just a few seconds.

"Reset" may take a slightly more time. The guiding goal for "Reset" is this: be kind to yourself. You are important. You can reset several ways, such as trying breathing techniques, connecting with a friend, or playing with your dog. Making several minutes for these healthy activities can be so worthwhile.



Lastly, the "Nourish" aspect challenges you to turn your focus to inward to help you remember your own strength and resilience, and remind you to take time to care for yourself. Strategies might include reminding yourself of a meaningful memory, enjoying a pleasant night with your family or friends, engaging with nature, or doing a faith-based practice. For "Nourish," the question you should ask yourself is: what do I need to nourish myself right now or plan to do so in the near future?

A final comment. Please do not feel pressure to do all three steps at the same time. Even if you just pause, you are engaging in an effective self-care activity. The goal of P-R-N is to have caregivers extend compassion towards themselves. You are such a critical part of how your family recovers from adversity, and this is one small tool that can help you see all the wonderful things others already see in you.



### What Are Some Other Self-Care Tools?

These are a few excellent books on the topic of caregiver self-care:

- Hijacked by Your Brain: How to Free Yourself When Stress Takes Over by Julian Ford and Jon Wortmann
   This book offers information about effectively managing stress, including another simple tool anyone can use to
   manage stress called the SOS method (Slow down, Orient to your core values, and Self-check).
- The Age of Overwhelm: Strategies for the Long Haul by Laura Van Dernoot Lipsky
   This book includes a number of great strategies for managing stress. You can also find podcasts and videos by Laura
   Van Der Noot Lipsky online where she shares her strategies.

There are smartphone apps you can download so stress reduction tools can be right in your hands. Find the below suggestions in your app store: (Note, some of these might have costs associated with them.)

- Headspace
- Woebot: Your Self-Care Expert (free)
- Daylio (free version available)
- Mindfulness Coach (which was made by the National Center for PTSD and the VA), free

To review, realizing that your child has had a traumatic experience can be distressing for you too and can potentially lead to developing secondary traumatic stress. P-R-N and the self care tools suggested are good starting points for responding to your own needs, which will help you better respond to your child's. Remember, in addition to the ideas in this fact sheet, there may be trauma-informed mental health resources in your community that can help you process and heal. Dealing with the effects of stress and trauma is a learnable skill. With your natural strength and resilience, healing is possible.

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