

At Intersection of Trauma and Disabilities: A New Toolkit for Providers

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Patty Shure, Director of Child and Family Services at Las Cumbres Community Services in Española, NM, recently recalled her work three years ago with a young toddler receiving care at the Conjunto Therapeutic Preschool at Las Cumbres. The treatment team believed that the child's developmental and speech delays were due to severe facial injuries she sustained in a car accident before she was a year old. Shure, a social worker who has worked for more than 22 years with children with disabilities and trauma, suspected that the girl's delays might also be related to unresolved traumatic grief over the loss of her mother, who had died in the accident. The family and the teaching staff were not convinced that her behaviors were a trauma reaction – until the grandmother, out driving with the child, had a minor fender-bender. When she jumped out of the car to inspect the damage, her granddaughter, though unhurt, started screaming and was “incon-solable” for more than an hour.

“That [event] was the clue for the family and the treatment team that, for her, the trauma was still very present,” Shure said. “It wasn't solely her injuries that caused her inability to communicate and articulate words.” The preschooler's situation illustrates some of the complexities of working with clients at the intersection of disability and trauma.

“Many clinicians say they would be willing to work with children who have developmental disabilities, if only they knew how,” said Diane M. Jacobstein, PhD, Clinical Psychologist/Senior Policy Associate, Georgetown University Center for Child and Human Development, Washington, DC. But until this year, no tools existed to help clinicians disentangle what might be symptoms of trauma from behaviors related to intellectual and developmental disabilities (IDD).

With the release of the toolkit, *The Road to Recovery: Supporting Children with IDD Who Have Experienced Trauma*, providers well-versed in trauma now have the tools to factor in a new understanding of IDD in their assessment and treatment. And, providers who work with children with IDD can widen their therapeutic lens to “think trauma.”

“This toolkit and its training materials fill an important need in the face of our current workforce crisis,” said Jacobstein, who was a member of the expert panel that developed the toolkit. “They will help therapists gain skills and confidence to serve children with disabilities who experience trauma.”

Developed by the NCTSN, the toolkit was funded by the Hogg Foundation for Mental Health in Austin, TX. The development panel was chaired by Susan Ko, PhD, UCLA/Duke NCCTS, and comprised of a wide range of nationally known trauma and IDD experts, including NCTSN members The Family Center at Kennedy Krieger Institute and DePelchin Children's Center. Following two initial rounds of pilot trainings, a train-the-trainer session took place in August 2015 in Redondo Beach, CA. Feedback from all trainings was then incorporated into the toolkit.

Daniel Hoover, PhD, ABPP, a Senior Clinical Psychologist at the Kennedy Krieger Institute's Center for Child and Family Traumatic Stress, Baltimore, MD, was one of the participants at the Redondo Beach session. “This is a very innovative toolkit,” he said. “There are so many myths out there about working with children and families who have IDD. You can talk about trauma and you can get some resources on IDD, but until now there has been nothing in the field that combines the two in such a comprehensive way.”



High Risk and Challenges

According to the Hogg Foundation, children with developmental disabilities are twice as likely as those without IDD to experience emotional neglect and physical or sexual abuse; twice as likely to be bullied; and three times as likely to be in families where domestic violence is present. Because these children and youth are at such high risk of trauma, any behavior that a teacher, pediatrician, or child welfare worker observes “could be an expression of trauma versus just something that comes along with their disability,” Hoover pointed out.

Christopher Beegle, LCSW-C, a Clinical Field Instructor at the Family Connections program, University of Maryland School of Social Work, noted that even trained clinicians may not realize that some of the children with whom they work have an intellectual or developmental disability. He said his participation in the Redondo Beach train-the-trainer session strengthened his understanding about tying in the developmental piece. “The toolkit raises awareness about keeping both frameworks – trauma and IDD – in mind when working with families.”

For example, in the toolkit's Module 2 on development and trauma, providers are reminded of the developmental complexities they must consider in addition to assessing for trauma. A child may have co-occurring medical, genetic, or developmental issues, communication challenges, or attention deficit issues. "This module brought up questions about how to structure sessions to best attend to the presenting developmental issues for the families and children we serve, to promote healing," Beegle said.

'A Culture Shift'

Colleen Horton, MPAff, MA, Program Officer for the Hogg Foundation, observed that, "One of the biggest challenges in working with children with IDD is the added time it takes to talk with caregivers, and then finding a way an individual child communicates best." Horton has been a prime mover in the IDD toolkit project. Her involvement stemmed from a congruence of factors. As the parent of a daughter with autism, she could not find appropriate services to help her daughter after a traumatic event. At about the same time, she was asked to join the NCTSN Advisory Board, and she became familiar with trauma toolkits for other populations. "I recognized that children with IDD comprised a population for which this information was missing, but very much needed," she recalled.

Too often, children and youth with IDD do not receive state-of-the-art mental health treatment, Horton noted. Reflecting the combined expertise of the trauma and IDD communities, the toolkit encourages a culture shift in a provider's own perception. "We want to get away from a focus on managing behaviors with compliance as the primary goal; and to look at the history and cause of behaviors, to determine if trauma has occurred, and if what we're doing is creating an environment that continues to produce trauma reminders," Horton emphasized.

Caregivers, Parents Are Pivotal Team Members

Hoover recently initiated the Horizons Program, a therapeutic clinic dedicated to treating traumatized children with developmental disabilities. He will be participating in a panel on the toolkit at the 2016 All-Network Conference. He praised the toolkit's incorporation of family members and caregivers, which underlines the message to clinicians to honor the family's expertise and to approach the family's perception and knowledge of their child from their point of view.

Anne Fogg, MA, LPC, who works at the Aurora Mental Health Center in Aurora, CO, concurred with Hoover, adding, "The parents of our clients are experts with their child's disability, but not necessarily with trauma. Having the resources and vignettes in this toolkit really helps people who don't have as much experience working with this population." Fogg has begun to use materials from the toolkit in individual sessions with families. She pointed to the board game adapted from the Life Course Game as an excellent tool for underscoring risk factors and protective factors to help families build on their own resilience.

"I cannot say enough good things about this toolkit," said Mayra Mendez, PhD, LMFT, Certified Group Psychotherapist, CAMFT Certified Supervisor at Saint John's Child and Family Development Center in Santa Monica, CA, who also participated in the Redondo Beach training. "The developers gave great thought to using understandable concepts in the PowerPoint slides." Mendez has already begun training clinicians at her agency, and last November she launched a training group for parents. The group was so successful that the parents requested she offer an ongoing series on coping with trauma – "not just the trauma of abuse or bullying," she said, "but the trauma of dealing with the world, because having a child with a disability is traumatic for the parents, too." Part of their traumatic stress arises from the need to negotiate resources for their children; and changing developmental phases also introduce new challenges. Mendez praised the structure of the IDD toolkit, which requires a skilled facilitator to help ensure that parents, when their emotions are triggered, do not "spin out of control." Parents need to keep coping, she emphasized: "That's the trick with trauma."

Changing the Lens

The toolkit also underscores the need to dispel common myths surrounding work with children with IDD – mainly, that these children cannot engage in mental health treatment. At Las Cumbres, Shure has begun training clinicians and school staff together and has observed that each group has pushed the other to expand their ability to perceive clues about possible trauma. "The most important thing is taking both trauma and IDD into consideration," Shure noted, "and not seeing kids through a lens of behavior alone."

Once the treatment team at Conjunto Therapeutic Preschool realized that trauma was affecting the young toddler's ability to speak, the team and the family began to work through that piece of the treatment process. The girl was able to make progress with the help of clinical services and speech therapy. When clinicians understand that they are not just seeing "willful behaviors," and design ways to support the child to work through his or her trauma, "you get to see change and you get to see hope," Shure said. "And that makes a huge difference."