An Unseen Population: IDD and Trauma

Colleen Horton, Hogg Foundation for Mental Health
University of Texas-Austin

The Scope of the Problem

Children with IDD exhibiting challenging behaviors often do not receive state-of-the-art mental health treatment; instead the focus is often on managing their behavior with compliance as the primary goal. Caregivers and family members who are accustomed to seeing their child through the lens of the disability can misinterpret behaviors that are in fact symptomatic of mental illness, distress, or past trauma. *Overshadowing* is the term used when an individual's disabilities prevent professionals and other caregivers from looking beyond the disability and assessing for possible mental or physical illness. In attributing challenging behaviors solely to the disability, opportunities for recovery are missed. Cultures of care in both residential and community or family settings have historically been similar with a goal of reducing maladaptive behaviors by removing antecedents and replacing undesirable behavior with behaviors deemed "appropriate." While positive behavior management can be effective in changing challenging behaviors, if underlying trauma and other mental health issues are not addressed the likelihood of positive outcomes is greatly reduced.

While the mental health needs of children with IDD are often overlooked or ignored, individuals with IDD experience trauma from physical abuse, sexual abuse, exploitation, neglect, seclusion and restraint, institutionalization, abandonment, and bullying at rates higher than the general population. A 2010 Bureau of Justice Statistics report provides evidence that people with intellectual disabilities were the victims of violent crime at a much higher rate than the general population. Highlights included:

- Adjusting for the varied age distributions of persons with and without disabilities, the violent crime rate against persons with disabilities was 40 violent crimes per 1,000 persons age 12 or older, which was double the violent crime rate for persons without disabilities (20 per 1,000).
- Among the types of disabilities measured in 2008, persons with cognitive disabilities had the highest risk of violent victimization.[i]

Additionally, a 2013 report released by the Spectrum Institute, *Abuse of People with Disabilities: Victims and Their Families Speak Out,* reveals frightening statistics. The report was the result of a national survey conducted in 2012 with 7,289 respondents including individuals with disabilities, family members, advocates, service providers, therapists, social workers, law

enforcement and child welfare workers. People with disabilities or family members of people with disabilities comprised 67.6% of the respondents. Some of the report findings include:

- More than 70% of people with disabilities who took the survey reported they had been the victims of abuse.
- More than 63% of parents and immediate family members reported that their loved one with a disability had experienced abuse.
- More than 90% of people with disabilities who were victims of abuse said they had experienced such abuse on multiple occasions.
- Nearly half of victims with disabilities did not report abuse to authorities. Most thought it would be futile to do so. For those who did report abuse, nearly 54% said that nothing happened. In fewer than 10% of reported cases was the perpetrator arrested.
- When therapy is provided to victims with disabilities, the therapy is helpful. Unfortunately, about two-thirds of victims were not referred to a therapist.[ii]

Trauma is not the only cause of mental health challenges for people with IDD, but it's among the most significant. Ignoring the impact of trauma on individuals with IDD creates environments where challenging behaviors are often ineffectively met with physical, chemical, or mechanical restraint intended to control behaviors. These interventions are not only ineffective, but they may also re-traumatize the individual, causing further psychological harm.

Professionals in the disability field have historically relied on behavior management strategies to address challenging behaviors with limited consideration of the potential for underlying trauma or mental illness including the possible impact of past abuse, neglect, or other traumatic events often experienced by this population. Likewise, professionals working in the mental health field often lack expertise and experience when working with individuals with IDD. This skill shortage was recognized in a 2008 NADD article, *Graduate Training in the Mental Health Needs of People with Intellectual Disability: Preparing the Next Generation.*[iii] The article stated:

> It appears that the limited treatment availability for dually diagnosed persons in the U.S. is due, in no small measure, to the lack of a systematic, federally supported plan for the care of these individuals. A further and equally critical factor is the apparent absence of academic training in graduate programs (Rush, Bowman, Eidman, Toole, & Mortenson, 2004; VanderSchie-Bezyak, 2003; Werges, 2007). Butz, Bowling, and Bliss (2000) conducted a review of the published literature on the efficacy of psychotherapy with dually diagnosed persons. They concluded that there is a growing body of literature on the topic, but that psychologists need to be better informed about this work. Few professional psychologists receive adequate preparation in the area of mental health in ID, and many feel unprepared to treat individuals with dual diagnoses

(VanderSchie-Bezyak, 2003). It seems that the growth in research has yet to make its way into graduate academic training.

At the same time that the mental health needs of many individuals with IDD are not being appropriately addressed, interest in trauma-informed practices in a multitude of agencies and professions is expanding exponentially. The Substance Abuse and Mental Health Services Administration is just one federal agency that has devoted significant resources to trauma, including creating the National Center for Trauma Informed Care (NCTIC).

It is time that agencies coordinate efforts to address the mental health needs of individuals with IDD. This coordination should look past historic practices and existing organizational structure and develop new expectations that people with IDD will have a right to the same state-of-the-art mental health treatment as any other population.

Challenges/Barriers

Some of the continuing barriers preventing people with IDD from receiving appropriate mental health services include:

- Too few professionals (mental health and IDD) have an understanding of the impact of trauma on children with IDD and lack the skills and expertise to assess, diagnose and treat.
- Behavior management techniques are often used without consideration of the impact of trauma. Even positive behavior management may be unsuccessful if underlying trauma is not addressed.
- Misperceptions relating to the effectiveness of standard therapies and treatments for children with IDD.
- Lack of expertise in the treatment of children with IDD and co-occurring mental illness.
- It is often more difficult to assess and treat trauma in children with IDD. Professionals may not want to devote the time and resources needed.
- The historical paradigm of attributing behaviors to the disabilities and relying on behavior management is hard to break. The basic premise of trauma-informed care is asking "what happened to you" instead of "what's wrong with you." For children with IDD, we still too often view behaviors through the lens of "what's wrong with you" and focus on how we can fix instead of focusing on past trauma and searching for ways to help the children recover.

Top 3 Essential Messages

- Expand awareness of and expertise in the use of trauma-informed care, positive behavior support and person centered planning and how these three need to work together instead of in isolation.
- Identify and promote the use of state of the art mental health treatment for children with IDD including trauma-informed care, in-home modeling and mentoring.
- Address the lack of capacity in the current workforce to assess, diagnose and treat mental health conditions in children with IDD.

The Hogg Foundation partnered with the National Child Traumatic Stress Network (NCTSN) to develop *The Road to Recovery: Supporting Children with IDD Who Have Experienced Trauma.* This is a two-day train-the-trainer opportunity. The foundation has also awarded a grant to SafePlace in Austin, Texas, to provide the training in Texas. For more information or to obtain a schedule of upcoming trainings, please contact Michelle Schwartz at sschwartz@safeaustin.org.

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[i] [1]Harrell, E., Rand, M. (2010) *Crime Against People with Disabilities, 2008* Bureau of Justice Statistics, Office of Justice Programs, U.S. Department of Justice. Retrieved March 2014, http://www.bjs.gov/index.cfm?ty=pbdetail&iid=2019

[ii] [2] Baladerian, N. J.; Coleman, T. F.; Stream, J. (2013). *Abuse of people with disabilities – victims and their families speak out – A Report on the 2012 National Survey on Abuse of People with Disabilities.* Spectrum Institute Disability and Abuse Project.

[iii] [3]Razza, N.J. (2008) *Graduate Training in the Mental Health Needs of People with Intellectual Disability (ID): Preparing the Next Generation,* NADD Bulletin, Vol. XI, Number 2, Article 2.