

# WHEN DISABILITY IS A DISGUISE



Addressing the mental health  
needs of people  
with intellectual and  
developmental disabilities

## How Intellectual and Developmental Disabilities Can Obscure Mental Illness

The mental health needs of individuals with intellectual and developmental disabilities (IDD) are often overlooked or ignored. There are many reasons for this, but the primary one is that the disabilities overshadow the possible mental health conditions. Caregivers and family members who are accustomed to seeing the individual through the lens of the disability can misinterpret behaviors that may be associated with mental illness, distress, or past trauma. It's a natural reaction, and one that can come from a place of deep love and concern. Unfortunately it means that individuals with IDD often don't get the state-of-the-art, compassionate, comprehensive mental health treatment they deserve. As a result opportunities for improving behavioral health and recovery can be lost.

### The Reality of Trauma

Trauma is not the only cause of mental health challenges in people with IDD, but it's among the most significant. Adults and children with intellectual disabilities experience abuse, neglect, institutionalization, abandonment, bullying and other types of traumatic abuse and neglect at rates much higher than the general population. A 2013 report by the Spectrum Institute found that 70 percent of respondents with disabilities reported that they had been a victim of abuse and of those 90 percent had experienced such abuse on multiple occasions.<sup>1</sup> Other studies show that children with disabilities are two to ten times more likely to be victims of child abuse compared to children without disabilities.<sup>2</sup>

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### Where We Are Now

Professionals in the IDD field have historically relied on behavior management strategies to address challenging behaviors with limited consideration of the possible impact of past abuse, neglect, bullying, institutionalization, or a number of other traumatic events often experienced by this population. Likewise, professionals working in the mental health field often lack expertise and experience in working with people with IDD. Both sides of the equation are working against recovery.



# AMELIORATING UNNECESSARY SUFFERING INCREASING RATES OF RECOVERY IMPROVING PRACTICES WITHIN BOTH THE IDD AND MENTAL HEALTH FIELDS

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## How We Can Respond: Trauma-Informed Care

Over the past two decades a body of well-researched and widely-accepted set of practices known as trauma-informed care has been developed specifically to help populations with a high incidence of trauma, including those involved in the child and family welfare, juvenile justice, and criminal justice systems. Trauma-informed care has received little attention as an approach to supporting those with IDD, a population historically having one of the highest rates of abuse. A trauma-informed approach toward working with people with IDD holds enormous promise for ameliorating unnecessary suffering, increasing rates of recovery, and improving practices within both the IDD and mental health fields.

## Additional Resources

While there are few resources available on trauma-informed care specifically for individuals with IDD, the first step to recognizing the importance of trauma-informed care is to understand the connection between trauma, development and behavior. The following resources may be helpful.

National Child Traumatic Stress Network (<http://www.nctsn.org/>)

National Center for Trauma-Informed Care (<http://www.samhsa.gov/nctic/>)

Trauma-Informed Behavioral Interventions: What Works and What Doesn't, Karyn Harvey, PhD.

Positive Identify Development: An Alternative Treatment Approach for People with Mild and Moderate Intellectual Disabilities, Karyn Harvey, PhD.

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- 1 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.
  - 2 Hershkowitz, I., Lamb, M. E. and Horowitz, D. (2007), Victimization of Children With Disabilities. American Journal of Orthopsychiatry, 77: 629–635. doi: 10.1037/0002-9432.77.4.629

Traditional behavioral approaches have long dominated the care of individuals with IDD. Karyn Harvey, Ph.D., has worked with adults with IDD for over 25 years and currently serves the ARC Baltimore as its Assistant Executive Director of Quality, championing the clinical perspective that perhaps we are misunderstanding many behavioral issues when the core of these issues is the expression of emotional trauma or other mental health challenges. Much of Harvey's research and publications detail the lives and struggles of those individuals she has worked with in her practice. The following are two abridged accounts by Harvey that illustrate some of the ways that trauma manifests in behavior.

## Trudy

Trudy, a woman I counseled, had been stable for several years when she experienced a psychotic episode. She began yelling, attacked her very docile housemate, and threatened staff with a knife. Trudy was then hospitalized. She stabilized in the hospital, was released, and went home. Once at home she became psychotic again, responding to voices she appeared to be hearing, threatening staff, and trying to hurt both staff and her housemates. She was re-hospitalized again. This cycle continued over a 4-month period with four separate hospitalizations. Finally the truth came out. A weekend staff member had an abusive husband who was coming over and getting into altercations with his wife. The residents were witnessing their fights. Trudy has been triggered and possibly re-traumatized by the altercations and by the threats that this man had been making toward his wife. The wife, of course, tried to hide that this was occurring at the residence. Trudy's psychosis was, in fact, a trauma response. She felt safe in the hospital and was thus able to regain her sense of safety. As soon as she reentered the home, however, she again felt unsafe and would demonstrate a fight-or-flight response. Trudy finally became stable when she was placed in another home. Even though the staff member was removed and her husband never returned, Trudy continued to have behavioral difficulties at that home. When she moved to another home, she finally felt safe.

Individuals cannot begin the recovery process if they do not feel safe in their own homes. There are a variety of reasons why people with IDD might not feel safe: housemates who have bullying tendencies, staff who are not engaged or predictable in their action, visitors who are not expected and known, and new dynamics in the home that provoke memories of neglect, abandonment or abuse. Part of feeling safe is knowing that basic needs can be met, that there is no threat of harm, and that there is someone who will listen.

***Trudy's psychosis was, in fact, a trauma response.***

# Charles

Charles was a man who appeared shaken, as though he had fought in at least two wars. He had a shell-shocked look about him: hollow and haunted. He had a diagnosis of schizophrenia and moderate intellectual disabilities. Charles had spent a great deal of his life in state psychiatric hospitals. By his own account he had been both physically and sexually abused by other patients and by staff. He would recount story after story of abuse. He even experienced flashbacks.

One day in the clinic I heard screaming from the waiting room. I came out of my office to find Charles huddled in a corner, shaking. I asked him what was wrong. Charles pointed to a staff person who was there with another individual with IDD. "It's him! It's him!" he screamed. We had to remove this staff person from the waiting room immediately and make sure that Charles was nowhere near him. Slowly, Charles stood up and returned to his chair after about 15 minutes. He was still shaking.

Eventually we learned that the staff member looked just like someone who was abusive to Charles at a state hospital where he'd once lived. Charles was convinced that our staff member was the same person, and as he hadn't felt safe anywhere near the staff person in the state hospital, the same was true when he thought he had encountered his abuser in our clinic waiting room. The implicit memory of horrible abuse had been triggered. Charles was in fight-or-flight mode and tried his best to escape into a corner of the room.

It took a long, long time to comfort him. An important part of comforting him was helping him to feel grounded in the present. He believed he was back at the hospital and at the mercy of sadistic staff. We were finally able to bring him back to the present, and he was able to relax. His session was, nevertheless, an outpouring of the abuse that had occurred. We had to make sure that Charles never again encountered that staff person. We also had to make sure that he never lived with residents who had aggressive tendencies. Now he is living with staff around whom he feels safe, and he is far away from his previous setting. He has two patient and caring housemates and is on the long road to recovery.

***An important part of comforting Charles was helping him to feel grounded in the present.***

# RECOMMENDATIONS:

- 1. Increase awareness of the mental health needs of individuals with intellectual and other developmental disabilities (IDD).**
  - a. Create a mental health unit at the Department of Aging and Disability Services (DADS) to provide technical assistance and training statewide.
  - b. Require coordination of services between DADS and the Department of State Health Services (DSHS) for individuals with IDD experiencing mental health conditions.
- 2. Expand awareness and the use of trauma-informed care (TIC) for individuals with IDD.**
  - a. Require basic TIC training for all staff in state supported living centers (SSLCs), intermediate care facilities for individuals with IDD (ICFsIDD) and community group homes. This should include management, supervisory staff, mental health professional staff, training staff and direct care workers (similar to requirements in Child Protective Services system).
  - b. Offer TIC training to families and other caregivers through regional workshops, conferences, webinars, etc.
- 3. Develop crisis behavior intervention services for both children and adults with IDD.**
  - a. Develop crisis intervention teams at local authorities to provide supports and services to assist individuals and families when an individual with IDD is experiencing a mental health crisis. Crisis respite, intensive in-home support and other crisis intervention services should be available.
  - b. Ensure crisis teams are trained in both TIC and person-centered practices.



**4. Address the workforce shortage of professionals with the expertise and experience to serve the mental health needs of people with IDD.**

- a. Require a training component for mental health professionals relating to the mental health needs of the IDD population. This should be included in professional training for psychiatrists, social workers, psychologists, licensed professional counselors, and psychiatric nurses.
- b. Require school districts to offer professional development opportunities for special and regular education teachers on trauma-informed care for students with IDD.
- c. Require mental health awareness training for IDD professionals (previously known as qualified mental retardation professionals, QMRPs).
- d. Fund psychiatric residencies, as well as social work and psychology internships at local authorities (focus on the mental health of individuals with IDD).

**5. Identify and promote the use of state-of-the-art mental health treatment for individuals with IDD.**

- a. Require SSLCs, ICFsIDD, managed care organizations and providers of home and community-based services to have mental health treatment and services available to residents and consumers (not just behavior management plans). This should include a variety of services such as psychiatric services, medication management, counseling/therapy, in-home training and mentoring, care management and more.
- b. Require IDD providers to coordinate positive behavior supports and person-centered planning with mental health assessments and services/supports when appropriate.
- c. Make non-traditional services available such as WRAP – Wellness Recovery Action Plan Training for People with Development Distinctions (Mary Ellen Copeland).
- d. Require managed care health plans to make the same mental health services available to those with IDD as is available to all other members.



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