A Call for Trauma-Informed Services for Individuals with Developmental Disabilities and Challenging Behavior

--Elia Vecchione, Ph.D.

Purpose

This paper aims to provide research findings that support trauma as a significant factor in the development of challenging behavior for people with developmental disabilities. It is based on research findings that necessitate a call for trauma-informed treatment that promotes recovery from traumatic experiences and diminishes challenging behavior. A brief review of trauma-informed stage treatment is included.

Developmental Disabilities, Trauma, and Challenging Behavior Research

People with developmental and intellectual disabilities have alarmingly high rates of traumatic experiences. They are more likely than non-disabled people to be exposed to adverse experiences, traumatic events, be sexually abused, victims of crime, bullied and abused. Exposure to the DD service system alone nearly doubles the risk of abuse. One study noted the elevated rate of traumatic experiences in individuals receiving inpatient treatment for challenging behavior. These experiences and the increased difficulty in coping with them due to developmental disabilities increase the prevalence of stress-related disorders, including PTSD and other mental health problems. These experiences often result in challenging behavior.

Despite the increased risk of PTSD, trauma remains underdiagnosed and undertreated in this population. This may, in part, be due to the lack of widespread use of trauma assessment and the availability of trauma-informed care. It may also be due to diagnostic overshadowing, where clinicians/support people attribute the behavior to the disability and ignore the traumatic experiences. Trauma reactions may also present differently in this population. Trauma and abuse are often expressed behaviorally and emotionally, not cognitively, in people with developmental disabilities. Key signs of abuse often present as a deterioration in adaptive skills and behavior following the trauma and often get labeled as bad behavior rather than as a response to traumatic events.

People with developmental disabilities who have challenging behavior are often subject to multiple placements, sudden changes in these living arrangements, separation from parents, family, and friends, loss of rights and privileges, hospitalization, institutionalization, incarceration, and other traumatizing experiences. Their perceptions of traumatic events may be altered due to several differences in how they respond due to sensory processing issues,

intellectual capacity, verbal skills, coping strategies, social support, and previous life experiences. Their response to trauma may also be exacerbated by the responses of the service delivery system to their behavior. More often than not, the service delivery system responds to challenging behavior, even though it is driven by traumatic experiences with consequences. Consequences are intended to increase the person's motivation to behave differently but may re-traumatize the person.

People with developmental disabilities may lack the coping skills to understand and respond to traumatic experiences. People with developmental disabilities who receive services depend more on others for their care and often have limited emotion regulation skills, cognitive challenges, and an inability to identify risk. They also may be unable to communicate their distress to others to help them cope with their experiences. This often results in alterations to their nervous system, mistrust of service providers, and explosive and avoidant behavior.

Trauma increases symptoms of psychological distress and challenging behavior in this population. Research shows that individuals with developmental disabilities who have experienced traumatic life events in adulthood and childhood had a significantly higher risk of aggression, self-injury, and other behavioral problems. Challenging behavior can be mediated through PTSD symptoms and can cause stress-related difficulties, depressive symptoms, mental health problems, psychosis, personality disorders, and aggressive behavior. The most effective and compassionate way to view and treat individuals with challenging behavior is with trauma-informed care.

Trauma-Informed Care

Trauma-informed care is a fundamental concept in mental health treatment and needs to be incorporated into the service delivery system for people with developmental disabilities and challenging behavior. It is based on the following ideas:

1. Knowledge of the emotional, physiological, and neurological impacts of trauma changes the way we perceive and engage with others. When we have been the victim of an overwhelming experience, our sense of safety in our body, relationships, and world is compromised. When we meet trauma-induced behavior with compassion and a desire to validate and heal - rather than to judge or condemn – we provide the opportunity to recover from those experiences and, in the process, improve behavior.

2. Negative systemic responses to trauma, such as providing consequences for trauma-induced behavioral re-enactments, further marginalizes traumatized people. It dismisses the effect of past experience on current behavior. Trauma responses are physiological reactions to past experiences that allowed people to survive in a world that engendered fear, lack of trust in others, and was overwhelming. They can be re-traumatized by a service system that doesn't understand them, reacts to their behavior punitively, and drives further challenging behavior.

The tenets of trauma-informed care (based on SAMHSA guidelines) are services that:

1. Establish safety: Trauma takes away our feelings of safety. Treatment must help people feel safe in their bodies and in their relationships and give them real-life experiences of safety in the world.

2. Focus on relationships: As Pat Ogden said: "Trauma occurs in relationships and must be healed in relationships." Trauma causes people to lose faith in the ability of others to help them resolve their distress and may even cause them to view others as dangerous. Treatment must re-establish "reaching out" as the primary response to the distress so that "acting out" and "checking out" (challenging behavior) is no longer necessary to maximize survival and minimize suffering.

3. Create a large relational safety net: Traumatized people withdraw from relationships and the world because they have experienced danger in their lives and relationships. A focus of their treatment must be to build a broad relational safety net that offers multiple people they can reach out to when distressed or in need.

4. Operate through collaboration and establish mutuality: People who express their traumatic experiences through challenging behavior are often subject to inhumane reactions and treatment, such as isolation and restraint. These experiences reinforce the power differentials inherent in the service delivery system and exacerbate their trauma. Collaboration and mutuality re-establish safety in relationships and engender a sense of personal agency in the world.

5. Give people voice and choice in order to build a sense of agency: Trauma causes people to feel a loss of control. Re-establishing their agency in the world by helping them feel in control empowers them to react to threats and adversity without their behavior deteriorating.

6. Decrease stereotypes and biases about challenging behavior: Challenging behavior is often labeled as manipulative or attention-seeking when it is simply a learned response to their experiences. Labeling learned responses to distress as "bad behavior" is a never-ending source of shame, humiliation, and suffering.

All supports, and services we provide to this vulnerable group of people must be trauma-informed and incorporate these basic values. Trauma-informed care requires a Stage of State model.

The Stage Model: Regulate, Relate, Reason

Treating trauma without a stage model is unethical.

-Robert Kinscherff

Trauma-informed care requires a stage model in order to facilitate recovery from traumatic experiences and ameliorate challenging behavior. In fact, according to Robert Kinscherff, Director of the Center for Law, Brain, and Behavior at Harvard, it is unethical to provide trauma treatment without a stage model. It should be clear from the above summary and research findings that challenging behavior can be driven by traumatic experiences and should be treated as such.

Pierre Janet originally developed the stage model treatment for trauma over 140 years ago. Stage model treatment typically involves three stages designed to target different states of the body and different brain areas. Each stage has different goals. Stage one typically targets the dysregulation of the nervous system, a hallmark of trauma. Stage two treatment targets building trust in relationships, which is often decimated by traumatic experiences. Stage three treatment involves helping people reason through both current and previous experiences.

Bruce Perry, MD, Ph.D., initially developed the Regulate, Relate, Reason model. It is a hierarchical model that establishes the need to help people regulate their bodies first, allowing people to be calm with others and build trust in relationships. With a calm body and a trusting relationship, people can reason. Without a calm body and trusting relationships, they cannot. So, attempting to reason with a dysregulated person, or using future-oriented consequences to address challenging behavior when a person is dysregulated, may cause more of the behavior we are attempting to address.

Dr. Perry's model is also based on basic brain science. Different parts of the brain drive different behaviors. Stage one treatment is about regulating the brainstem, which regulates blood pressure, heart rate, arousal level, and other physiological mechanisms which drive dysregulation and challenging behavior. Stage two treatment aims to regulate the amygdala or mammalian alarm system, often triggered by interpersonal interactions and turns on challenging behavior. Stage three treatment depends upon the brainstem and amygdala being regulated, which then allows the frontal lobes, or the thinking part of the brain, to come online so that people can be reasoned with.

The stage model establishes regulation and building relationships as the treatment's primary goals, allowing people to reason. Typical treatment of challenging behavior does not incorporate the need for regulation and building relationships as the building blocks of recovery. More often, treatment is based on the direct, threaten, punish model and the use of

consequences as the primary means to address challenging behavior. Evidence-based trauma treatment requires a Stage model to support people with developmental disabilities, traumatic experiences, and challenging behavior.

Conclusions

Even though there are higher rates of traumatic experiences among people with developmental disabilities, they remain largely undiagnosed and untreated. Rather than receiving trauma-informed care, their behavior is often responded to with consequences. The most ethical and compassionate approach to supporting people with developmental disabilities who are challenged by their behavior is through trauma-informed treatment. Trauma-informed care requires a stage model, and people with developmental disabilities who are challenged by their behavior have the right to such treatment. It would be unethical and inhumane to provide treatment in any other way.

Bibliography

Clark, A., Crocker, A. G., & Morin, D. (2016). Victimization history and aggressive behaviour among adults with intellectual disabilities: The mediating role of mental health. *International Journal of Forensic Mental Health*

Cook, S., Hole, R., Trauma, Intellectual and/or developmental disability, and multiple complex needs: A scoping review of the literature

Hall, J. C., Jobson, L., & Langdon, P. E. (2014). Measuring symptoms of post-traumatic stress disorder in people with intellectual disabilities: The development and psychometric properties of the Impact of Events Scale-Intellectual Disabilities (IES-ID). *British Journal of Clinical Psychology*

Keesler, J. M. (2020). Trauma-specific treatment for individuals with intellectual and developmental disabilities: A review of the literature from 2008 to 2018

Kildahl, A. N., Helverschou, S. B., Bakken, T. L., & Oddli, H. W. (2020a). 'If we do not look for it, we do not see it': Clinicians' experiences and understanding of identifying post-traumatic stress disorder in adults with autism and intellectual disability. *Journal of Applied Research in Intellectual Disabilities*

Kildahl, A. N., Helverschou, S. B., Bakken, T. L., & Oddli, H. W. (2020b). 'Driven and tense, stressed out and anxious': Clinicians' perceptions of post-traumatic stress disorder symptoms expressions in adults with autism and intellectual disability. *Journal of Mental Health Research in Intellectual Disabilitie*s

Levitas, A. S., & Gibson, S. F. (2001). Predictable crisis in the lives of people with mental retardation. *Mental Health Aspects of Developmental Disabilities*

Mason-Roberts et al., (2018). Multiple traumatizations and subsequent psychopathology in people with intellectual disabilities and DSM-5 PTSD: A preliminary study. *Journal of Intellectual Disability Research*

McGlivery, S. (2018). *The identification and treatment of trauma in individuals with developmental disabilities*. NADD Press

McNally, P., Trauma experiences of people with intellectual disability and their implications: a scoping review Journal of Applied Research in Intellectual Disabilities

Murphy, G. H., O'Callaghan, A. C., & Clare, I. C. H. (2007). The impact of alleged abuse on behaviour in adults with severe intellectual disabilities. *Journal of Intellectual Disability Research*

Nunez-Polo, M., H., Integrative Therapy Focused on Trauma for People with Intellectual Disability (TIT-ID): A Therapeutic Answer to Abuse and Intellectual Disability Experience in the Individual and Family

O'Callaghan, A., & Murphy, G. (2003). The impact of abuse on men and women with severe learning disabilities and their families. *British Journal of Learning Disabilities*

Peckham, N. G., Howlett, S., & Corbett, A. (2007). Evaluating a survivors group pilot for women with significant intellectual disabilities who have been sexually abused. *Journal of Applied Research in Intellectual Disabilities*

Resilient Futures: Resilient Futures is a non-profit that provides trauma-informed care

Rittmannsberger et al. (2020) The association between challenging behaviour and symptoms of post-traumatic stress disorder in people with intellectual disabilities: A Bayesian mediation analysis approach. *Journal of Intellectual Disability Research*

Rittmannsberger, D., Kocman, A., Weber, G., & Lueger-Schuster, B. (2019). Trauma exposure and post-traumatic stress disorder in people with intellectual disabilities: A Delphi expert rating. *Journal of Applied Research in Intellectual Disabilities*

Roswell, A. C., Clare, I. C. H., & Murphy, G. H. (2013). The psychological impact of abuse on men and women with severe intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*

Substance Abuse and Mental Health Administration (SAMSHA) (2014). *Concept of trauma and guidance for a trauma-informed approach SAMSHA trauma and justice strategic initiative July 2014*. U.S. Department of Health and Human Services, office of policy, Planning, and Innovation.

Skelly, A. (2020a). Trauma exposure and the importance of attachment in people with intellectual disabilities. *Bulletin of the Faculty for People with Intellectual Disabilitie*s

Vecchione, E., (1993) Stress and behavioral adjustment in individuals with mental retardation Masters thesis

Wilcox, P., News, Trauma and Developmental Disabilities

Excerpts from the Research Literature

1. Prevalence: People with Developmental disabilities have alarmingly high rates of trauma

    *People with DD are at an increased risk of adverse experiences

    *People with autism/DD are more frequently exposed to traumatic events and more vulnerable to the development of PTSD

    *Rates of sexual abuse may be more than double the non-dd population

    *People with DD are four times more likely to be victims of crime

    *Exposure to the DD service system increases the risk of abuse by nearly 80%

    *People with ID have ten times more risk of suffering abuse than persons without ID

    *Individuals with developmental disabilities are at increased risk for PTSD

    *Having a disability can be a trauma in itself

2. Assessment:

    *Trauma is a significant underlying factor in the multimorbidity of people with intellectual disabilities

    *People with intellectual and developmental disabilities are at increased risk for PTSD

    *Key signs of abuse indicated by the deterioration of adaptive skills and behavior immediately following the abuse

    *Trauma and abuse expressed behaviorally and emotionally, not cognitively

    *There are appropriate assessment tools for diagnosing trauma

    *Trauma is underdiagnosed and undertreated in the DD population

    *The Impact of Events Scale-Intellectual Disability (IES-ID) was developed specifically for evaluating the traumatic experiences of individuals with DD

3. Factors Associated with having a disability can cause traumatic responses:

    *Multiple placements

    *Sudden changes in living arrangements

    *Exclusion from bereavement

*Bullying experiences

*Loss of rights

*Separation from parents, family, friends

*Perceptions of traumatic events may be altered due to several differences, including sensory processing issues, intellectual capacity, verbal skills, coping strategies, social support, and previous life experiences

4. Coping factors that may make people with intellectual disabilities more vulnerable to trauma:

*Dependence on others

*Limited emotion regulation skills

*Cognitive challenges

*Inability to identify risk

*The level of the person's intellectual disability influenced how symptoms of trauma were expressed

5. Behavioral expressions of trauma in individuals with DD:

*Trauma more likely to be expressed in behavior

*May induce deterioration of adaptive skills

*Aggressive behavior can be a symptom of trauma

*Trauma causes symptoms of altered arousal

6. The case for trauma-induced challenging behavior:

*Significantly higher rates of outwardly directed aggression are mediated by mental health experiences

*Adverse or abusive life events are linked to PTSD, stress-related difficulties, and depressive symptoms

*A history of traumatic life events was linked to mental health presentations, psychosis, personality disorders, and aggressive behavior

*Challenging behavior can be mediated through PTSD symptoms

*Individuals with dd experiencing traumatic life events in adult and childhood had a significantly higher risk of aggression, self-injurious behavior

*Trauma caused increased symptoms of psychological distress

*Trauma increased challenging behavior

7. Treatment:

*Evidence-based treatment is effective for treating trauma

*Trauma treatment and trauma-informed care need to be offered to people with DD

*Behavioral treatments may cause traumatic reactions

8. Essential Components of Trauma-Informed Care:

1. Establishes safety
2. Focuses on relationships
3. Creates a large relational safety net
4. Operates through collaboration and establishes mutuality (levels of power differential)
5. People have a voice/choice and; a sense of agency
6. Decreases stereotypes and biases about challenging behavior (attention, manipulation)