Best Practices in Assessment and Treatment of Trauma for People with Intellectual and Developmental Disabilities Who Communicate Without Speech

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Introduction

Assault and abuse, including sexual assault, perpetrated against people with IDD (PwIDD) is a widespread issue not hindered by any country's borders, putting PwIDD at greater risk of trauma (Kildahl et al., 2020a; O'Malley et al., 2020; Rowsell et al., 2013). In addition to the heightened risk of assault and abuse, studies have revealed that PwIDD are more susceptible to trauma from life experiences they face as a result of their disability such as bullying, multiple placements, or loss of parents or caregivers (Daveney; Kildahl et al., 2020a; Kildahl et al., 2020b; McNally et al., 2021; Mevissen et al., 2012; Mevissen et al., 2016; Rowsell et al., 2013). Research also tells a story of inadequate assessment and treatment tools for PwIDD who have experienced trauma as a whole who seek to recover from the effects of their experiences (Daveney; Kildahl et al., 2020a; Kildahl et al., 2020b; McNally et al., 2021; Mevissen et al., 2012; Mevissen et al., 2016; O'Malley; Rowsell et al., 2013).

Most of the assessment tools available that have shown any success with PwIDD are only effective with those with mild to moderate IDD as they rely heavily on self-report (Daveney; Kildahl et al., 2020a; Kildahl et al., 2020b; Mevissen et al., 2012; Rowsell et al., 2013). However, within the IDD population, the most severely impacted people also usually communicate without speech, which leaves them with few tools for effective assessment.

While the scarcity of assessment tools for PwIDD seems alarming, the availability of treatment for PwIDD, especially those who communicate without speech, is even more grim. Despite the pervasiveness of sexual assault and other traumas among PwIDD, there is little research available to guide psychologists as they treat PwIDD, which leaves them to their own devices to adapt therapy to fit the individual client (O'Malley et al., 2020). Slowly, awareness is building that when modified appropriately, psychotherapy is an effective tool to use with PwIDD, especially cognitive behavioral therapy (CBT; McNally et al., 2021; Mevissen et al., 2016). While the use of psychotherapies among PwIDD is adapting, unfortunately, it is only shown to be effective with people who have mild to moderate IDD (McNally et al., 2021; Mevissen et al., 2016). Mevissen et al. (2012) describes the situation for people with more severe IDD who have PTSD symptoms being treated with an evidence-based treatment as "scarce."

The historical lack of assessment tools coupled with a lack of treatment options for trauma has left PwIDD who communicate without speech in a dangerous situation. Often parents, caregivers, and

therapists alike are left struggling to know how best to support and treat PwIDD who communicate without speech and have experienced trauma. Rowsell et al. (2013) indicated that in their study of people with severe IDD and trauma, no participant reported a therapeutic intervention that was successful. Additionally, the frequency and severity of emotional, physiological, and behavioral symptoms that indicated they were experiencing psychological stress eventually got better over time, but their psychological functioning remained impaired. This study demonstrates the need for effective assessment and treatment as a vital part of the wellbeing of PwIDD who communicate without speech who have experienced trauma.

Fortunately, research is beginning to grow in trauma assessment and treatment for PwIDD who are more seriously impacted by their disability. The recognition of how trauma symptoms present in PwIDD and the use of observational and input from family and caregivers has improved assessment for posttraumatic stress disorder (PTSD) and other trauma-related disorders for PwIDD who communicate without speech (Kildahl et al., 2020a; Kildahl et al., 2020b; Rowsell et al., 2013). Equally promising, recent research has shown that eye movement desensitization and reprocessing (EMDR) therapy is an effective treatment of trauma among PwIDD, including those who communicate without speech (McNally et al., 2021; Mevissen et al., 2012; Mevissen et al., 2016).

Definitions

According to Patel et al. (2018), IDD is a diagnosis given in childhood, yet it has effects that follow the person through their life after they become adults. Patel et al. break the severity of IDD into four categories: mild, moderate, severe, and profound. Each of the four levels of severity is broken down into categories of communication and language, basic skills, and supports needed. Earmarks of severe and profound levels within communication and language are differences in verbal and communication abilities. For the purposes of this paper, the term “people who communicate without speech” will be used interchangeably with PwIDD described in research as severely or profoundly impacted by their disabilities.

Assessment Challenges

While there is a lack of assessment tools for PwIDD, the nature of the disability also produces many challenges to diagnosing PTSD or other trauma-related disorders.

One of the more significant diagnostic challenges for PwIDD is communication. Diagnosing PTSD traditionally requires people to describe their experiences and answer questions asked by the clinician. However, those who communicate without speech may not be able to do either of these two tasks (Daveney et al., 2019; Kildahl et al., 2020a; Kildahl et al., 2020b).

Symptom presentation is another area of challenge when diagnosing PTSD. Often, symptoms of PTSD in PwIDD may present differently than in those without IDD and even differently between those with less severe IDD and those with more severe IDD (Daveney et al., 2019; Kildahl et al., 2020a; Kildahl et al., 2020b; Mevissen et al., 2016). Symptoms may present as challenging behavior such as disorganized behavior or aggression, self-injury, sleep problems—including nightmares, reenactments of the trauma, and a decline in adaptive skills (Daveney et al., 2019; Kildahl et al., 2020a; Kildahl et al., 2020b; McNally et al., 2021; Mevissen et al., 2012). Additionally, Kildahl et al. (2020b) indicate that people with autism and IDD who communicate without speech may have even more significant complexity with assessment and may see greater symptom variability on any given day.

A third complicating factor for diagnosing PTSD in PwIDD who communicate without speech is diagnostic overshadowing, or the mistaken attribution of symptoms to a diagnosis (Daveney et al., 2019; Kildahl et al., 2020a). For example, PwIDD who experience trauma and are reliving the experience may present with symptoms that looks like psychosis (Mevissen et al., 2016). If they are diagnosed with a psychotic illness rather than the PTSD causing the symptoms, this is diagnostic overshadowing. This can be an even more complicated factor when parents or caregivers are not aware of the trauma and do not know how best to attribute the symptoms they see (Kildahl et al., 2020a).

Assessment Best Practices

While the challenges to assessing trauma in PwIDD who communicate without speech may seem sizeable, recent research has shown evidence of certain practices that assist with assessment. Best practices include using multidisciplinary approaches that are thorough and trauma sensitive (Kildahl et al., 2020a; Kildahl et al., 2020b). Gathering historical information based on observations made from family, caregivers, and practitioners who work with the person will aid in answering the questions related to diagnosing trauma (Kildahl et al., 2020a; Kildahl et al., 2020b; McNally et al., 2021; Mevissen et al., 2012; Rowsell et al., 2013).

Matching Observations to Diagnostic Criteria

Assessment of trauma in PwIDD who communicate without speech is based significantly on observation of behaviors. McNalley et al. (2021) reports that several studies advocate using the Adaptive Behavior Scale to assess changes in adaptive behaviors of PwIDD who communicate without speech. They also note that one study recommends that when diagnosing PwIDD with PTSD practitioners consider the developmental level of the client and potentially include the criteria for diagnosing children, specifically when examining behavioral responses, reenactment of traumatic events, and arousal states. The following information highlights some of the behaviors associated with four of the diagnostic sections of the DSM-V as gathered from the research.

Reexperience. Examples of behavior associated with reexperiencing trauma include repeated phrases uttered at specific times such as shouting "no" repeatedly at bedtime (Kildahl et al., 2020a) or showing behaviors such as fear, resistance, or aggression at times associated with triggers (Mevissen et al., 2012).

Avoidance. Avoidance was observed in situations such as bathing, changing clothes, or not wanting to sleep in their bed or by not wanting to go to school or return home (Kildahl et al., 2020a; Mevissen et al., 2012).

Negative changes to mood and cognition. Reports of these behaviors included negative emotions such as sadness, hopelessness (including suicidal ideation), guilt, and shame as well as behaviors such as social withdrawal or deteriorating relationships with family or caregivers. People with limited verbal ability may have shown signs of negative self-image through behaviors such as repeatedly shouting "no" and their name (Kildahl et al., 2020a).

Altered arousal. States of altered arousal were observed in exaggerated startle response, aggression, restlessness, irritability and anger, and sleep disturbances—including difficulties falling asleep and waking during the night (Kildahl et al., 2020a; Mevissen et al., 2012).

Treatment Best Practices

The lack of evidence-based treatments for PwIDD who communicate without speech does not mean that therapists are not attempting to treat their clients. O'Malley et al. (2020) recommends the following approaches to working with PwIDD of all levels who have experienced trauma:

- use of art and drawing-based tools
- use of therapeutic approaches that are person-centered, flexible, and include creative adaptations to traditional methods
- nurturing trust
- validating the client's experiences
- being predictable and consistent with the client
- empowering the client, especially those who were assaulted by people in positions of power such as PwIDD living in congregate care

EMDR

Two methods of treatment for PTSD in PwIDD that are also recommended by the World Health Organization are EMDR therapy and trauma-focused CBT. CBT has been adapted for use with people with mild to moderate IDD who have experienced trauma (Mevissen et al., 2016). That study included no documentation for people with more severe IDD or those who communicate without speech.

However, research does show effective treatment for PwIDD who experienced trauma using EMDR across all disability ranges from mild to severe. (McNally et al., 2021; Mevissen et al., 2012; Mevissen et al., 2016). PwIDD who communicate without speech who have undergone EMDR have shown significant reduction in trauma symptoms and improvements in personal functioning (Mevissen et al., 2012). Specific improvements included disappearance of flashbacks and sleep disturbances; reduction of aggressive, obsessive, and avoidance behavior; and improved mood and social functioning (Mevissen et al., 2016).

Mevissen et al. (2016) offered suggestions for adapting EMDR for use with PwIDD. They suggest that activating the trauma memory and supporting the person during the desensitization and reprocessing process can be adapted based on the person's developmental age. They also suggest taking any co-occurring disorders such as autism into consideration. Some of the specific practical applications of the process itself include the therapist

- putting stickers on their fingers to facilitate tracking
- using buzzers to vibrate alternately between the person's right and left hands
- using alternating tones in headphones or speakers placed on either side of the person, or

- tapping on the person's hands or knees.

One of the advantages of EMDR therapy is the low number of sessions needed. Mevissen et al. (2012) specified the number of sessions of EMDR ranged from four to 17, indicating that this therapeutic method is efficient as well as effective. Additionally, there is no need for homework or practice outside the therapy, making this protocol even more beneficial for people with more severe IDD (Mevissen et al., 2016).

Last Word on Treatment

It would be remiss not to include an important note here concerning treatment of parents and caregivers. Parents and caregivers of adults who communicate without speech were often themselves traumatized by the abuse of their adult children, but they rarely were offered treatment for this secondary trauma. Treatment for PwIDD who have experienced trauma should also include treatment for family or caregivers who may be affected, as their wellbeing is inextricably tied to that of the PwIDD (McNally et al., 2021).

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