

Chapter 8

Working in a Trauma-Informed Way with Clients Who Have a Developmental Disability

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People with developmental disabilities are far more likely to be victimized than the general population, yet have fewer resources to deal with these experiences. Their response to the trauma may also be different. Therefore, trauma-informed practice with this population requires certain modifications. The goal of this chapter is to demystify the tailored approach to trauma-informed care for people with developmental disabilities. It addresses the types of trauma they may experience, the impact of cognitive impairments on how they may report trauma and how to apply a trauma-informed approach in work with people who have developmental disabilities.

In general, developmental disability refers to impairments in cognitive functioning accompanied by impairments in adaptive skills that emerge in the developmental period (prior to age 18). The term developmental disability¹ allows for inclusion of individuals whose IQ might be a little higher but who nevertheless have significant cognitive and functional difficulties. People with fetal alcohol spectrum disorders and autism spectrum disorders (ASD) are also considered to have developmental disabilities. Individuals with ASD may have ways of understanding and interpreting their social and non-social world that are different than those of neurotypical individuals.² They may experience

1. Diagnostic criteria for mental retardation in DSM-IV: Intellectual functioning markedly below average (IQ below 70–75, or two standard deviations below the mean); impairments in at least two areas of adaptive functioning; onset before age 18. (The term “mental retardation” will be replaced by “intellectual disability” in DSM-5.)
2. For more about “social stories” among people with ASD, see www.thegraycenter.org.

relatively minor events, such a falling off a bicycle or losing an object of attachment, as traumatic. Their difficulties in communicating and interacting socially and their behaviours associated with ASD will affect how they communicate and process their experiences.

Working with individuals with developmental disabilities who have experienced trauma often requires working with caregivers (family members or paid staff), and depending on the source of trauma, recognizing that abuse is not the only type of trauma the person may have experienced. The involvement of caregivers can be crucial, as many people with developmental disabilities do not live independently and may need others' assistance for transportation, decision-making and implementing treatment strategies. If it is safe to do so, it is these caregivers who can provide information about personal and clinical history, significant relationships, dreams and goals or preferences.

The following vignette illustrates key elements of trauma-informed practice involving a person with a developmental disability and those who work with her.

Tracy is 34 years old but looks and acts like a teenager. She has moderate intellectual disability and attention-deficit/hyperactivity disorder. She was admitted to hospital because her group home placement broke down due to her aggression. On one occasion, she entered a bedroom of another resident at night and started to punch him. Her records indicate that she experienced physical and emotional abuse and severe neglect in her family home. She was sexually assaulted by a stranger when she was 19, but her family refused the offer of counselling at that point. More recently, after Tracy left home, her sisters disclosed that they were sexually abused by their father and suspected that Tracy, too, might have been abused. Group home staff wanted Tracy to engage in psychotherapy, but following the initial evaluation, the therapist felt that she would not be able to tolerate it. Behavioural approaches were unsuccessful and staff continued to request individual therapy to help with challenging behaviours: Tracy was highly reactive, impulsive, intrusive and pushy, and at times of distress, she would become combative and verbally and physically aggressive, display sexualized behaviour and speak in a deep masculine voice.

In hospital, Tracy presented with high anxiety and agitation, excitability, need for attention and exaggerated display of somatic complaints, including leg or

stomach pain and difficulty swallowing. Given her dramatic presentation, somatic complaints might have been easily dismissed as attempts to engage staff, particularly since she would settle in response to staff reassurance; however, medical examination revealed underlying medical conditions. Further observations identified triggers to her agitation that seemed to be directly related to her experience of neglect and trauma: triggers included doing something incorrectly, such as spilling her drink; being criticized, ignored or dismissed; being sent for time out; perceiving unfairness or rejection; noticing attention being given to someone else; hearing other people breathing loudly or making “noises”; and having her family visit her. Attempts to talk with Tracy about those issues led inevitably and rapidly to behavioural escalation. The intervention approach was shifted from therapy and behavioural contingencies (i.e., providing consistent consequences for specific behaviours, such as cancelling an outing if she was verbally aggressive to staff) to a focus on staff understanding and being sensitive to Tracy’s experiences, both past and present. To support Tracy, staff had to keep the present impact of her history of trauma at the forefront of all interactions and acknowledge and validate her experiences. That was particularly important given the neglect and secrecy she had experienced with her family.

A trauma-informed plan of care was developed that emphasized the role of staff in addressing Tracy’s trauma-related behavioural difficulties. It included:

- educating staff about the effects of trauma on Tracy, her triggers and the importance of validating her experiences and how to tailor the teaching of self-soothing skills using visual aids
- creating a safe environment through recognizing and minimizing situations and responses that might be retraumatizing, such as sending Tracy for time out when she was upset about attention given to another client
- providing choices and increasing opportunities for positive experiences
- assisting Tracy to use calming strategies, employing specially tailored comic strips that illustrate deep breathing
- establishing a working relationship with Tracy’s family
- developing a support network beyond paid staff; for example, encouraging Tracy to attend her local church.

Tracy’s story illustrates how helpful trauma-informed practice can be, regardless of whether clients are able to describe their experiences as related to trauma. The therapeutic team’s awareness of how trauma may be expressed is critical to

trauma-informed services. With this awareness, the team can support the client by using creative approaches to applying the practices of creating safety, providing opportunities for relational connections and teaching skills.

The Nature of Trauma for People with Developmental Disabilities

In addition to issues such as sexual abuse, as illustrated by Tracy's story, there are other sources of trauma for people with developmental disabilities. Clinicians may not always consider the types of trauma that affect them and how their response to trauma may be different.

Abuse

People with developmental disabilities are more likely to experience emotional, physical and sexual abuse and life-threatening neglect than the general population. As in Tracy's case, this abuse is more likely to be perpetrated by someone they know rather than a stranger. They experience high rates of bullying and teasing by peers in youth and even in adulthood. One in three is sexually abused before age 18 and women are at higher risk than men of being victimized and revictimized. People with developmental disabilities who have been sexually abused may display sexualized behaviour (including sexual threats or accusations) under stress. Some individuals with developmental disabilities remain at lifelong risk for repeated trauma: acquiescence, social naiveté, poor judgment and social skills and a reluctance, fear or inability to disclose abuse make them more likely to experience traumatic events. Higher-functioning individuals may repeatedly place themselves in abusive or exploitive situations because of a desire to present as normal or to have relationships with "normal people."

Loss through Separation, Abandonment or Death

Loss can be experienced by being separated from or abandoned by family—being placed in a foster or group home or institution—or from the death of a

parent. In these situations, the person with a developmental disability is often removed from the family home and placed in the care of strangers. This means the person loses not only his or her parent, but a way of life and his or her possessions. Women with mild developmental disabilities, as with other women, may experience trauma when they give birth to children they are unable to care for, or when children are removed from their care. They may continually re-experience the loss of the mother role through exclusion from the child's life, for example, being denied participation in significant events such as birthdays due to concerns about their behaviour.

Natural Disasters, War, Displacement and Accidents

Caregivers, and sometimes clinicians, can wrongly assume that people with developmental disabilities are not aware of, or that they can be sheltered from, the psychological impact of a natural disaster, war, displacement or accident. Even when individuals are clearly aware of their circumstances, it might be difficult to determine their actual understanding and experience of the trauma. For example, a young woman with a mild developmental disability whose parents and several siblings were killed during Rwanda's genocide when she was 14 repeatedly expressed the desire to "go back home." When looking at the impact of these events, the clinician may find it helpful to consider how a similar situation might affect a young child who is reliant on a caregiver who has been harmed or killed.

Hospitalization

There are several factors to consider in relation to hospitalization and trauma. People with developmental disabilities experiencing mental health issues are generally hospitalized for difficulty managing aggression or for displaying self-injurious or severely disruptive behaviour. These behaviours are often precipitated by or exacerbated by significant life events in the preceding months and indicate the person's difficulties in dealing with them. Being admitted to hospital can be very traumatic, particularly if it involves the use of force and police. The hospital environment itself can be traumatizing for people with developmental disabilities.

FACTORS THAT CONTRIBUTE TO HIGH RISK OF (RE)TRAUMATIZATION IN HOSPITAL

- use of intrusive interventions such as time out, seclusion, mechanical and chemical restraints
- being assigned to or being restrained by a staff member of the same sex as an abuser
- witnessing others being restrained
- being assaulted or witnessing assaults by co-patients (not feeling safe)
- separation from family (caregivers)
- separation from familiar environment and routines
- prolonged admissions
- not understanding reason for hospitalization and not knowing for how long (forever)

WAYS TO MINIMIZE THE RISK OF (RE)TRAUMATIZATION IN HOSPITAL

- Assign same-sex staff to assist with personal hygiene (two staff if needed).
- Use least restraint policy: understand escalation continuum and use prevention; allow person to select preferred mode of restraint when required.
- Address vulnerability: Separate female bedrooms from male bedrooms.
- Debrief incidents that involve or are witnessed by the individual.
- Avoid hospitalization or keep it to a minimum.
- Facilitate caregiver contact and visits.

Impact of Cognitive Impairments on Reporting Trauma

People with developmental disabilities have a range of cognitive impairments that affect their ability to understand what has happened to them and to communicate the trauma to someone else. Impairments may occur in these areas:

Concrete thinking: People with developmental disabilities may have difficulty identifying their emotional or internal experience. They may actually not realize that what happened to them was traumatic or wrong, and that they could talk to someone about it.

Communication issues: They may not have words to explain their experience and may express it through their behaviour instead, or express it in ways that are misunderstood by others.

Individuals with developmental disabilities may experience their own thoughts or memories as voices. Their reporting of voices telling them upsetting things or telling them to do things may be misdiagnosed as psychotic.

Attention and memory issues: They may not be able to recall significant details of a traumatic experience, such as the names of people or places involved. Or they may confuse details and provide inconsistent information at different times, so that people do not believe them.

Concept of time: They may not be able to report when things happen and their report might be confusing, with remote events being reported as recent.

HOW SERVICE PROVIDERS CAN COMPENSATE FOR CLIENTS' COGNITIVE DIFFICULTIES

- Be explicit about interventions.
- Provide clear explanations, using:
 - concrete language
 - short sentences
 - visual aids (drawings, photos)
 - frequent repetition.
- Check for understanding (ask clients to explain in their own words).
- Allow time for processing.
- Provide engaging and fun activities.
- Repeat information over several sessions.
- Record sessions so the client can listen or even view them again.

A Trauma-Informed Approach with People Who Have Developmental Disabilities

This section applies and adapts the principles of trauma-informed practice articulated by Elliot et al. (2005) to the realities of people with developmental disabilities.

Recognize the impact of victimization and trauma on the person's behaviour and coping strategies. The person's childhood history may be unknown. Bizarre or disturbed behaviour might signal that the person is re-experiencing trauma or extreme distress, or that she or he is trying to self-soothe in the best way possible. It can be important, as in Tracy's situation (see p. 110), for the service provider to consider unrecognized trauma as an explanation for disturbed behaviour and to seek to understand it.

QUESTIONS ABOUT TRAUMA FOR SERVICE PROVIDERS TO CONSIDER

- When did the trauma occur?
- What is the nature of the trauma?
- What symptoms has the individual experienced?
- What support and treatment have been received?
- Is there a previous history of trauma? (McCarthy, 2001)

Note: These questions are not intended to be posed directly to the client; rather they are questions for service providers to keep in mind.

Identify recovery from trauma as a primary goal. Recovery from trauma should be a primary goal of treatment, as it would be with any other population. Specialized services—for developmental/dual diagnosis and trauma—need to be integrated into treatment. Furthermore, trauma work with this group extends beyond the individual with a developmental disability; when it is safe to do so, caregivers need to be involved, as their support can be critical to the recovery process. Caregivers may need education about trauma in general and about issues specific to the person in their care to better understand the person's behaviour and their own comfort level and ability to assist the person.³

Empower the individual. Be aware of a tendency that people with developmental disabilities have to acquiesce to caregivers or treatment providers. Recognize that they might feel that they did something wrong and may get in trouble if they reveal abuse. It is important to teach about privacy in interaction (e.g., not talking about sensitive or private topics in public places, checking with the person whether information he or she revealed may be shared with caregivers) and that saying no or refusing things does not mean the person is being unco-operative.

Maximize choices and control over recovery. People with developmental disabilities may have little sense of self-agency. They may not have skills to identify and express preferences and might need to be taught in small steps.

3. For more information about supporting a person with a disability who is experiencing posttraumatic stress disorder, see www.dimagine.com.

Provide them with situations where they can choose and assert preferences (e.g., what to wear or eat, where to go). Emphasize opportunities for positive experiences such as engaging in fun activities or fostering relationships with supportive others.

Create an environment that is safe, respectful and accepting. Take time to understand how the person communicates. Include people the person feels safe with, even in the therapy itself. Carefully consider the choice of therapist. This includes considering gender-specific services (i.e., a female therapist for a female client), or specialized dual diagnosis services, particularly if a diagnosis of psychotic spectrum disorder is being considered.

Create a predictable and consistent environment. Be aware of clients' current living circumstances: if they live somewhere they do not want to be and which is interpersonally stressful, they may need help to recognize and deal with that.

Emphasize strengths and resilience over pathology. See the person as someone to be admired rather than as a problem to be solved, recognizing his or her resilience in the face of impairments and traumas (Wilson & DuFrene, 2008). Identify and focus on relative strengths or the things the person enjoys doing.

Minimize possibilities for retraumatization. It is important to work with caregivers whose role is to protect the person from revictimization. Recognize that the person may be at risk in any placement—in the community as well as in an institutional setting (jail or hospital).

Be culturally competent and competent around the “culture” of developmental disability. In addition to being sensitive to the person's racial and cultural background, it is important to appreciate the different ways trauma might be expressed by people with developmental disabilities. Use your creativity to modify your interactions and treatment interventions to compensate for the cognitive impairment. You may have to adjust your expectations about what is helpful; take cues from the person about what type of interactions he or she finds supportive.

Solicit input from clients with developmental disabilities directly. Soliciting client input is an important aspect of providing trauma-informed services for any population. Even if it is more difficult to obtain input from people with

developmental disabilities, try to find ways to elicit feedback and consider it, even if it is limited (e.g., using simplified visual analogues of rating scales—smiling/upset faces). We recognize the possible importance of including caregivers, but not at the cost of excluding the person with the disability from being central and sharing his or her own perspective and experience of the services.

Monica is 40 years old and lives semi-independently with limited hours of support. She was admitted to hospital because of concerns about her aggressive behaviour, for which she was criminally charged. In contrast to her relatively high cognitive and adaptive abilities, Monica presented in a very childlike way in her speech and emotional reactions. In hospital, she described hearing the voices of her dead parents. She heard her mother, who had abused, neglected and later abandoned her, telling her to hurt herself or damage things. Monica was very distressed by hearing this. The voice of her father, on the other hand, was very protective, telling her mother to “shut up” or telling Monica to ignore her.

The main intervention was to explore Monica’s experience of the voices and “give” her power over them. In a concrete way, she decided to use a visual aid to help her contain the voices—she would “lock her mother (the voice) in a closet.” This helped her to stop paying attention to her mother’s voice and stop getting distressed by it.

Conclusion

The concept of trauma should be viewed very broadly in developmental disabilities; it is important to understand what is traumatizing for the person. Given the high probability of trauma in the lives of people with developmental disabilities, all interventions should be trauma sensitive, emphasizing coping, safety, choice and having a voice. It is also crucial to involve caregivers and help them understand the person’s behaviours in relation to trauma. The presence of trauma should become part of the clinical formulation, provide a framework for understanding the person’s experiences and be taken into account when planning supports and interventions. Hospitalization should be carefully considered because it will likely (and potentially unavoidably) be traumatizing.

References

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