



Understanding Trauma and Supporting Healing in Persons with Developmental Disabilities:

**A summary report of the Trauma and Developmental
Disabilities Committee of Central West Region**

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Acknowledgements

This report and the project it describes are the result of a number of people who came together because of an interest and commitment to changing the way that people with developmental disabilities access and receive support for trauma. Two people in particular need to be acknowledged for their significant contribution to this work.

Melissa Otter is a self-advocate and trauma survivor who generously shared her time, her story and her expertise to inform and guide this work.

Dr. Lori Haskell, a leading psychologist in the field of trauma, provided invaluable leadership and education, teaching us how to look through a trauma-informed lens and understand the many ways that the experience of trauma influences the lives of people with developmental disabilities. **This report is based in part on Dr. Haskell's 2009 report; The Mental Health Needs of Persons with Developmental Disabilities and Abuse Related Trauma: Defining the Issues, Identifying the Challenges in which she documents in detail the initial work of the Trauma and Developmental Disabilities Committee of Central West Region.**

Introduction

This report is intended for an audience of service providers who are interested in understanding the impact of trauma on those with developmental disabilities and in applying trauma-informed approaches in their work with this population. This may include those working in the areas of developmental disabilities, health care, education, counseling, crisis services, mental health, elder care and justice.

The goal of this report is to introduce the effects of trauma on individuals with developmental disabilities and effective approaches to supporting people on their journey of healing. This is done through a description of the initial project and activities undertaken by the Trauma and Developmental Disabilities Committee of Central West Region¹, an overview of trauma theory and its application to those with developmental disabilities, an outline of practices to support recovery and healing from trauma for people with developmental disabilities, and a look forward to future directions.

¹Central West Region is comprised of Waterloo, Wellington, Dufferin, Halton and Peel counties.

This journey began with stories. Stories told by people referred to specialized services for challenging behaviours or a decline in their mental health. Stories buried deep within files, below multiple incident reports and behaviour management programs. Stories unspoken but transcribed in the scars left on bodies and souls. Stories of neglect, abuse, assault, fear, silencing, and coping.

The journey continues to be one of stories; stories of breaking silence, stories of hope, stories from people who can tell those who wish to help how to do so gently, respectfully and effectively.

Background

In April of 2005 Central West Specialized Developmental Services launched the Dual Diagnosis Service to address the needs of those with developmental disabilities who were experiencing mental health difficulties and/or exhibiting challenging behaviours. Within the first year a trend was identified – numerous individuals referred to the Dual Diagnosis Service had a history of trauma. Often these histories were not highlighted in the referral documentation, nor were they identified in the initial interviews with individuals and caregivers. Experiences of trauma would be buried in files or hinted at during conversations about school, family or institutional experiences. The focus was on current challenging behaviours and other difficulties, but there began to be growing evidence of a link between the present and the past.

Given the time-limited nature of the Dual Diagnosis Service, several individuals for whom this link had been made were referred to community services for trauma counseling. What they found was that service providers skilled in providing supports for people with developmental disabilities did not have training in trauma-specific approaches; and service providers for trauma survivors were not knowledgeable about how to adapt supports for individuals with developmental disabilities. This gap in training and services meant an absence of trauma treatment resources accessible to those with developmental disabilities within the Central West Region.

This lack of resources was identified to the then-coordinator of the Central West Community Network of Specialized Care, Arran Rowles, who initiated efforts to address the gap. A team of professionals from across the developmental and trauma service sectors was brought together, along with Dr. Lori Haskell, an expert in trauma treatment, to better understand the service needs of trauma survivors with developmental disabilities; determine the professional training needs of service providers with relation to trauma and developmental disabilities; begin to address these training needs via a cross sector conference; and to develop a set of recommendations to guide future planning. Although this team originally committed to just three consultation meetings, it

developed first into a longer-term working group focused on a single project, and then further transformed into an ongoing cross-sectorial committee dedicated to building community capacity to support people with developmental disabilities who have experienced trauma.

The overarching goal of the initial project was to identify the key components necessary to move towards the development of a continuum of care² within Central West Region for individuals with developmental disabilities experiencing the effects of trauma. This continuum of care was seen as needing to include both the developmental services sector and the trauma and mental health care sector, and to provide services for developmentally disabled survivors of trauma in the areas of assessment, psychoeducation, first stage trauma treatment, trauma processing, family support and education/training for service providers.

As part of her contracted services to the Central West Community Network of Specialized Care, Dr. Haskell conducted a telephone survey of trauma sector agencies. The results of this survey showed that while these agencies do serve individuals with developmental disabilities (with this population making up 2 – 7 % of clientele) the majority reported that they lack adequate knowledge to serve these individuals (Haskell, 2010). An additional survey of developmental and trauma sector service providers showed that there was a lack of developmental disabilities and trauma specific training for service providers across the region, and that services for trauma survivors with developmental disabilities were sparse to non-existent depending on the specific area within Central West Region. The biggest gaps in service were in assessment and trauma processing therapies as a few agencies within the region were able to offer access to some symptom management techniques and strategies. The original project culminated in a 2-day training conference in September 2009 attended by over 160 service providers from the developmental and trauma sectors from in and around Central West Region. The goal of this comprehensive training event was to build capacities among front-line service providers in both sectors through the following objectives:

- Provision of a conceptual framework to guide work with trauma survivors with developmental disabilities
- Explication of the differences between simple and complex psychological trauma
- Overview of developmental disabilities and considerations for providing trauma services to individuals with developmental disabilities
- Introduction to effective treatment interventions including specific tools and techniques
- Discussion of the impact of providing trauma services on workers

² A continuum of care is defined by The Canadian Council on Health Services Accreditation (CCHSA) as “an integrated and seamless system of setting, services, service providers and service levels to meet the needs of clients or defined populations”

Feedback from the conference was overwhelmingly positive citing the specific value of learning to look beyond behaviour and of having exposure to concrete tools for counseling. There was also consistent affirmation of the usefulness of bringing the two sectors together for training as well as for the networking opportunity it provided. There was clear acknowledgement of the need for further training in this area and the need to disseminate the training more broadly.

Following the success of the conference there was a period of reflection for the working group as we grappled with how to move forward. Dr. Haskell's final report provided several recommendations for continued action and the buzz in the community was that more work in the area of trauma and developmental disabilities was needed. The project was presented at the 2010 Ontario Association for Developmental Disabilities annual conference where it was met with significant interest and requests for additional trainings. Several members of the original working group and the new coordinator of Central West Community Network of Specialized Care, Trevor Lumb, met a year after the September conference to form what is now the Trauma and Developmental Disabilities Committee of Central West Region.

The Impact of Trauma on People with Developmental Disabilities

A traumatic experience can involve a single event, or enduring or repeated events, that overwhelm an individual's ability to cope or to integrate the ideas and emotions involved in that experience (Klinik Community Health Centre (KCHC), 2008 p 16). Traumatic experiences often involve a threat to life or safety, but any situation that leaves the person feeling overwhelmed and fractured can be traumatic, even if it doesn't involve actual physical harm. It is the individual's experience of the event, not the event itself, which determines whether or not trauma has occurred.

The impact of trauma can pervade a survivor's entire being, particularly when the traumatic experience involves a trusted person or persons, or happens over a long period of time. In these cases "the survivor's beliefs about humanity and the goodness in people is destroyed. This profoundly affects their identity, resulting in negative effects in mind, body, soul and spirit." (KCHC, 2008 p 16).

Those individuals who have well developed coping skills, a strong support network and the opportunity to process the traumatic event, are often able to integrate the experience into their lives and experience relatively few lasting impacts (KCHC, 2008). However individuals with developmental disabilities often lack some or all of these factors. Without coping skills, strong supports and trauma resources, these individuals frequently experience significant and lasting effects of trauma; long after the actual event has passed. Survivors often develop harmful or negative behaviours in an effort to cope with the emotional and psychological impact of trauma.

Some of the effects of trauma include:

- Re-experiencing the same mental, emotional, and physical experiences that occurred during or just after the trauma.
- A pervasive sense of agitation, anxiety or panic
- Persistent and overwhelming anger (sometimes leading to aggression or self-harm)
- Chaotic or bizarre behaviour
- Use of self-protective strategies even when others do not perceive a threat
- Out of proportion reactions to normal changes or to moderately stressful, but not catastrophic, situations
- Sleep and eating disturbances

Some survivors of trauma will develop Post Traumatic Stress Disorder (PTSD)³, a condition characterized by intrusive memories or flashbacks, avoiding reminders of the traumatic event, and living in a constant state of “red alert”. Survivors who experienced severe, long-term trauma at the hands of caregivers who were neglectful, inconsistent and/or abusive may develop **complex** PTSD. Survivors with complex PTSD often struggle with chronic self-destructive behaviours, dissociation, poor self-perception, unhealthy relationships, and physical manifestations of emotional distress (Haskell, 2003).

Risk Factors for People with Developmental Disabilities

Research shows that people with developmental disabilities are at higher risk of physical, emotional and sexual abuse and neglect than the general population (Cottis, 2009; Mansell, Sobsey&Moskal, 1998; Ryan, 1994; Doyle&Mitchell, 2003; and Pitonyak, 2005). This population experiences social conditions that result in isolation, exposure to multiple caregivers for personal care, lack of sexual and rights education, compliance training, and limited access to augmentative/alternative communication strategies, all of which contribute to the vulnerability of individuals with developmental disabilities to abuse. Additionally people with developmental disabilities often experience frequent and/or unexplained moves, extended hospitalizations, invasive medical procedures, bullying and degradation, institutionalization, separation from primary relationships, physical restraint, confinement, and/or punitive behavioural modification

³ Due to a lack of trauma-informed assessment and diagnostic services accessible to people with developmental disabilities many victims of trauma will not be formally diagnosed with PTSD despite demonstrating the diagnostic criteria (Doyle & Mitchell, 2003). Others may experience significant effects from trauma, but not meet the criteria for a PTSD diagnosis – this does not negate trauma as a contributing factor in their current difficulties and behaviour.

techniques. These events can be experienced as traumatic and can result in trauma effects, or may trigger a trauma response in those who have had earlier experiences of abuse.

Trauma effects and PTSD often go unrecognized in people with developmental disabilities. This occurs for a variety of reasons. Caregiver turnover can be high for those living outside of their family home and institutional memory can be short – historical abuses get buried in files and are forgotten as staff change and individuals move to new situations. Challenging behaviours can be overwhelming for caregivers trying to support the individual, and efforts are focused on making things better in the here and now rather than delving into the past. Behavioural and psychiatric diagnoses are used to explain trauma symptoms and medication is used to ameliorate these symptoms. Alternatively behavioural symptoms are attributed to the person's developmental disability and alternate explanations are left unexplored. And in some cases known abuse or traumatic experiences are dismissed as having happened too long ago to still be having an impact on the individual, or individuals are viewed as not having the same capacity for PTSD as others due to their developmental disability.

Even when caregivers and health care providers recognize the impact that abuse or other trauma has had on a person other barriers to diagnosis and treatment of PTSD remain. There is a paucity of research in the area of trauma in people with developmental disabilities resulting in a lack of assessment instruments 'normed' for this population, and a limited understanding of psychiatric professionals regarding diagnosis of those who do not use traditional communication methods and/or manifest trauma symptoms differently than the typical trauma survivor. Most trauma in this population is complex trauma, however the current understanding of trauma in mental health fields does not encompass the multiple and chronic abuse experiences of people with developmental disabilities.

Trauma treatment methods have not been well researched with developmentally disabled survivors and there is a lack of treatment methods/materials adapted for use with this population. Mental health and trauma professionals are rarely trained to support individuals with developmental disabilities in trauma processing work and express that they do not feel comfortable or competent to do so.

When trauma effects and PTSD remain unrecognized and therefore untreated, people with developmental disabilities suffer. They are often taking significant amounts of psychotropic medications, have a collection of diagnoses, have a long history of behavioural modification programs and strategies, spend a lot of time in either seclusion or restraints and develop a reputation for being manipulative, aggressive, and non-compliant (Pitonyak, 2005). Support systems for these individuals become extensive and expensive, but remain largely ineffective as trauma symptoms persist.

Behavioural manifestations of trauma in people with developmental disabilities can include aggression (verbal and physical), self-harm, suicidal ideation, risk-taking, elopement, emotional dysregulation, inattention, impulsivity, regression, refusals, panic attacks, substance abuse, and somatic complaints. These manifestations are often met with efforts to control, subdue and modify behaviour by well-intentioned caregivers. Adapting a trauma-informed framework for care can help caregivers and service providers respond differently, and more effectively, to these symptoms.

A Trauma-Informed Framework for Providing Support

The National Center for Trauma-Informed Care defines trauma-informed care as “an approach to engaging people with histories of trauma that recognizes the presence of trauma symptoms and acknowledges the role that trauma has played in their lives...[it] seeks to change the paradigm from one that asks, "What's wrong with you?" to one that asks, "What has happened to you?"”(<http://www.samhsa.gov/nctic>).

A trauma-informed framework for care

- Views trauma related responses/behaviours as best efforts to cope with external events
- Recognizes that current problematic behaviours may have originated as legitimate and even courageous adaptations to cope with or defend against trauma.
- Validates adaptations as having a function and contributing to the individual’s survival of the trauma
- Identifies strengths and helps the individual build on these strengths to find new, healthier ways to cope in the present

In addition to a trauma-informed framework of care, those providing trauma specific services need to become educated in how to provide adapted supports to people with developmental disabilities. These individuals can benefit from trauma therapies used with the general population when modifications based on learning styles and strengths are incorporated into the delivery of therapy (Cottis, 2009; Razza&Tomasulo, 2005; Lemmon &Mizes, 2002; Mansell&Sobsey, 2001; McCarthy, 2001; Hollins&Sinason, 2000). The following suggestions may be helpful when adapting therapies and treatment tools for use with individuals who have a developmental disability:

- Ask the person what they would find helpful to assist them in participating in therapy
- Include trusted caregivers/support providers in some sessions and/or consult with care givers regarding useful communication and learning strategies for the individual (only with the person’s consent of course)

- If the person is accompanied by a caregiver ensure that you talk directly to the person and ask permission to talk with their caregiver about them.
- Use simplified language, speak slowly, and pause often to allow the person time to process and answer
- Make use of a variety of communicative and teaching tools (visual aids, modeling, written and pictorial information, role play, videos etc.)
- Avoid abstract expressions, slang and jargon
- Use examples that the person can relate to in their own life
- Be aware that people with developmental disabilities are sometimes “conditioned to please” and so may answer with what they think you want to hear. Help them to feel safe to express their own thoughts and opinions
- Avoid leading questions, and check for understanding of questions by rephrasing
- Engage with the person in ongoing evaluation of tools and techniques (what’s working? what isn’t?)
- Present one concept at a time
- Review and practice concepts often
- With the person’s permission, ask caregivers to assist with practice and review between therapy sessions

Practices to Support Recovery and Healing

There is a range of trauma-informed therapeutic services and supports required for individuals engaged in a journey of healing and recovery from trauma. These include assessment and diagnosis, safety and stabilization, psycho-education, development of symptom management skills, and trauma processing. Some of these remain less accessible to those with developmental disabilities while others can be implemented by caregivers and front-line service providers who commit themselves to a trauma-informed framework of care in the work that they do.

Assessment and trauma processing work are often the most challenging aspects of care to obtain for individuals with developmental disabilities. Assessment of PTSD resulting in a formal diagnosis can only be done by a psychiatrist or registered psychologist. As discussed above, diagnoses can be difficult to obtain for a variety of reasons, however they can be useful in helping the person and his/her caregivers understand what s/he is experiencing. It is important to note however that a diagnosis of PTSD is not necessary prior to implementing the other aspects of care. Trauma processing is another area in which a skilled professional such as a psychologist, mental health counselor or trauma therapist must be involved. While there are few of these professionals trained to work with individuals with developmental disabilities, their numbers are slowly increasing, and sometimes an offer from a developmental service provider to

provide the therapist with some informal education and support regarding developmental disabilities can result in the individual getting service.

Recovering a sense of safety and stability is an essential first step in healing. Safety includes ensuring the person's physical safety in their immediate environments; this can mean having a safe place to live, food to eat and people around them who contribute to their sense of safety. It is also important to help the person establish a sense of stability; this can be done by identifying and reducing triggers, developing a safety plan, ensuring predictability and consistency as much as possible in the person's daily routines, and building soothing and stress-reducing activities into each day.

Psycho-education refers to the process of working with the individual to help them understand the connection between traumatic experiences and current symptoms. Learning about fight-flight-freeze reactions, dissociation and flashbacks helps the person recognize that they are not 'crazy', and that what they are experiencing is usual response to trauma. This process gives a name to the experience and teaches the person that nothing is wrong with him/her; rather something wrong has happened to him/her. It is important that the person's responses to the trauma are normalized and that symptoms are reframed as adaptations to a very difficult situation. Psycho-education can also involve teaching about healthy relationships, learning strategies for the prevention of further victimization, identifying personal strengths and developing skills.

Related to psycho-education is the development of symptom management techniques to help the individual overcome distressing trauma responses and replace adaptations that are no longer effective with more functional coping strategies. Symptom management techniques will vary depending on the needs of each individual however they may include strategies for emotion recognition, affect/emotion tolerance and regulation, coping with triggers, grounding techniques for episodes of dissociation and/or flashbacks, facing fears, alternatives to self-harm, reconnecting to one's body, and/or learning problem solving strategies.

Creating safety, providing psycho-education and developing symptom management skills are areas that front-line support workers and other caregivers can support an individual through once they have learned the foundations of trauma-informed care.

How Trauma Service Providers Can Support Healing	How Developmental Service Providers Can Support Healing
Listen and believe	Listen and believe
Help the person to understand and cope with what has happened to them.	Ensure safety
Validate the person's emotions and adaptations.	Understand behaviour through a trauma lens.
Provide trauma-informed counseling and support, recognizing that counseling may need to go on for a long period of time or be revisited at intervals.	Help the person to understand and cope with what has happened to them.
Allow for flexibility re: timelines (i.e. shorter but more frequent sessions) and allow the individual's needs set the pace.	Validate the person's emotions and adaptations.
Arrange for additional supports to be provided to the person between counseling sessions to assist with recall, practice and application of skills learned.	Provide additional supports to the person between counseling sessions to assist with recall, practice and application of skills learned.
Find out about the person's communication and learning style.	Share information about the person's communication and learning style with the counselor (with the person's consent).
Teach coping skills and trauma processing using methods that are tailored to the persons abilities, including visuals, cues, practice, role play, and repetition.	Teach skills related to symptom management, coping, stress and anger management, problem solving, and healthy relationships using methods that are tailored to the person's abilities.
Teach caregivers about trauma, its impact, and how to best support someone coping with the effects of trauma.	Learn about trauma, its impact, and how to best support someone coping with the effects of trauma.
Promote personal empowerment, rather than external controls.	Provide supports that promote personal empowerment, rather than those that impose external controls.
	Support/promote healthy interdependence as a goal – developing supportive relationships with friends, family and community.
	Support connections to the community.
	Provide opportunities for, and encourage, peer-to-peer support through groups, friendships and other connections.
	If old patterns and behaviours re-emerge – don't panic, rather continuing using a hope-based approach, recognizing the cyclical nature of healing.

A Summary of the Committee's Activities and Future Directions/Next Steps

Since its formation, the Trauma and Developmental Disabilities Committee of Central West Region has continued to pursue the goal of building a trauma and developmental informed network of service providers. Following the September 2009 conference Dr. Haskell proposed a number of key recommendations that included:

1. A trauma-informed framework for conceptualizing the range of abuse-related trauma therapeutic needs for developmentally disabled individuals that is understood and broadly accepted in both the developmental disabilities sector and the family violence and trauma services sector.
2. Development of an integrated network of services that offer a continuum of treatment. Some services can offer the full range of services and treatment required, but others can focus on specializing in first stage trauma treatment, or can specialize in trauma processing therapies.
3. The requirement that all agencies need to be trauma-informed and DS informed, including hospital personnel
4. Additional training/education throughout Ontario to develop expertise concerning how to conduct trauma therapy with individuals who have developmental disabilities and abuse-related trauma, including specialized training in trauma therapies such as EMDR or neurofeedback training.
5. An annual conference in developmental disabilities and trauma for the region.
6. Integrated referral system so that referrals can be tracked.
7. The development of psycho-education materials on complex trauma that have been translated into simple language and concepts for use with individuals with developmental disabilities and their families.
8. Continuity on how people move through services. If an individual is not suited for one type of therapy, it is important that a referral is made to a more suitable service without needing to start over with wait list issues.
9. Work experience exchanges; workers from the developmental disabilities sector can work in trauma services and trauma service workers can work in developmental services sectors.
10. The development of a web-based resource library with easily accessible resources on treatment, assessment, articles, and other literature, in addition to the announcement of workshops and trainings.
11. Video conferencing for ongoing training and supervision. This could be facilitated through monthly video conferencing sessions that would have an educational component and a case presentation component.

In the period following the September 2009 conference the trauma committee's journey has continued with stories. Several new members have joined including one self-advocate who identifies as a trauma survivor and who has leant her story and expertise to the committee's purposes. There is an ongoing effort to include additional self-advocates and to have membership that represents each county and sector equally on the committee.

Providing training to developmental and trauma sector service agencies throughout Central West Region continues to be a key focus of the committee in order to increase the capacity of both sectors to meet the trauma-based needs of this population. This has included bringing together both sectors in formal and informal education settings for general training, in addition to case specific information aimed at building competency within a team supporting an individual with a trauma background. The committee also presented a second time at the Ontario Association for Developmental Disabilities (OADD) annual conference in 2011. This time attendees from across Ontario expressed interest in joining the work of establishing a continuum of care for trauma survivors with developmental disabilities in their own regions and new partnerships began. The momentum generated from this expanded provincial interest has lead to members of the committee meeting and planning with other regions to deliver workshops or establish trauma committees of their own.

Other efforts include expanding communication through the building of a virtual resource library. This library will be accessed by service providers who require literature, educational material, therapeutic resources and training tools in their work with developmentally disabled trauma survivors. The committee is also committed to the development of informational resources for physicians, psychiatrists and psychologists, and is currently creating and collaborating on resource materials for both service providers and those with a developmental disability to guide them through the continuum of care services.

There is a need to increase the number of trauma-informed/disability-informed service providers across sectors, and to facilitate collaboration between trauma services and developmental services, in order to ensure that the healing and recovery of people with developmental disabilities can be well supported in our communities. It is hoped that collaboration within the committee and between other regional committees will further the goal of developing a best practice model.

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