The Mental Health Needs of Persons with Developmental Disabilities and Abuse-Related Trauma: Defining the Issues, Identifying the Challenges

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PART I -- PROJECT INTRODUCTION AND OVERVIEW

EXECUTIVE SUMMARY

Persons with developmental disabilities and abuse-related trauma issues[1] represent an extremely vulnerable population. This population has high needs and faces a range of difficulties and challenges in receiving appropriate service and/or treatment for their abuse-related trauma. These difficulties exist largely because these needs go unrecognized, and are therefore left unmet and untreated.

These difficulties are further compounded by the relative absence of resources and training available for those service providers best situated to provide this treatment. Put differently, although there exists a skilled body of professionals and service providers working with people with developmental disabilities, most of these providers, despite their expertise in understanding developmental disabilities, have not received specialized training in trauma treatment. Similarly, those mental health professionals and service providers trained to provide trauma treatment typically have not been educated about the specific needs and particular issues facing people with developmental disabilities. *The training and service delivery gaps, therefore, exist both within the field of those providing trauma treatment and within the field of those working with developmental disabilities.*

This report documents a project developed and undertaken to begin addressing these gaps. The project's specific focus was to outline both the educational and training needs of service providers in the Central West Network of Ontario, Canada, and to document the challenges which inhere in providing effective treatment and services to persons with developmental disabilities and abuse-related trauma issues.

A team of experts was drawn together to undertake this work, led and coordinated by Dr. Lori Haskell and Arran Rowles, Regional Coordinator, Central West Network of Specialized Care. The project concluded with a 2-day training delivered to a cross-section of service providers from the developmental disabilities and trauma mental health sectors.

One of the central goals of the project was to draw on the concept of a "continuum of care" for the provision of trauma related services to people with developmental disabilities. The Canadian Council on Health Services Accreditation (CCHSA) defines a continuum of care as "an integrated and seamless system of settings, services, service providers, and service levels to meet the needs of clients or defined populations." If a "continuum of care" is the best approach – differentiated treatment approaches based both on the service settings of the care providers and the specific needs of the population served – then the groundwork for the continuum to meet the needs of

[1] These issues of developmental disabilities and abuse-related trauma may also include (or manifest as) challenging behaviours.

persons with developmental disabilities and abuse-related trauma issues must first be laid.

This project aims to begin the process of identifying key components necessary to move towards developing such a continuum of care in order to deliver collaborative, abuse-related trauma services within the Central West region for individuals with developmental disabilities and mental health needs.

Not all agencies or services will be able to provide all services necessary in the lives of traumatized developmentally disabled people. The point of this project, however, is rather to develop a collaborative network of agencies and organization with information about their various services and programs offered and their capacities, in order to work towards the best continuum of care possible.

PROJECT PURPOSE

Persons with developmental disabilities and abuse-related trauma issues[2] represent an extremely vulnerable population. This population has high needs and faces a range of difficulties and challenges in receiving appropriate service and/or treatment for their abuse-related trauma. These difficulties exist largely because these needs go unrecognized, and are therefore left unmet and untreated.

These difficulties are further compounded by the relative absence of resources and training available for those service providers best situated to provide this treatment. Put differently, although there exists a skilled body of professionals and service providers working with people with developmental disabilities, most of these providers, despite their expertise in understanding developmental disabilities, have not received specialized training in trauma treatment. Similarly, those mental health professionals and service providers trained to provide trauma treatment typically have not been educated about the specific needs and particular issues facing people with developmental disabilities. *The training and service delivery gaps, therefore, exist both within the field of those providing trauma treatment and within the field of those working with developmental disabilities.*

This report documents a project developed and undertaken to begin addressing these gaps. The project's specific focus was to outline both the educational and training needs of service providers in the Central West region of Ontario, Canada, and to document the challenges which inhere in providing effective treatment and services to persons with developmental disabilities and abuse-related trauma issues. A team of experts (identified below in the report) was drawn together to undertake this work, led and coordinated by Dr. Lori Haskell and Arran Rowles, Regional Coordinator, Central West Network of Specialized Care. The project concluded with a 2-day training delivered to a cross-section of service providers from the developmental disabilities and trauma mental health sectors.

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This project aims to begin the process of identifying key components necessary to move towards developing such a continuum of care in order to deliver collaborative, abuse-

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related trauma services within the Central West region for individuals with developmental disabilities and mental health needs.

PROJECT OVERVIEW

Project Background

A few highlights to provide some background and context to the initiative for this project are highlighted in point form below:

- Central West Network of Specialized Care established in May 2006;
- Central West Specialized Developmental Services Dual Diagnosis Service established in Spring 2005;
- Trend identified – numerous individuals referred to DDS team for aggressive behaviours diagnosed with PTSD; and
- Gap identified – no trauma treatment resources in Central West region for individuals with dual diagnosis of developmental disability and abuse related trauma.

The Project's Overarching Goal

The overarching goal of the project, then, was to begin to address the gap in the provision of trauma treatment to people with developmental disabilities. Put differently, the goal was to begin to indentify the key components necessary to move towards developing a continuum of care for the delivery of collaborative, abuse-related trauma services within the Central West region for individuals with developmental disabilities and mental health needs.

Questions Guiding the Work

The project was undertaken to begin developing answers to these following questions:

1. What does an effective "continuum of care" for people with developmental disabilities and mental health needs require?
2. What do we need to know in order to develop a "continuum of care" to provide better services?

3. What resources are required to provide these services?

4. What are the education and training needs of the service providers?

5. What services are most capable and best situated to provide components of such a continuum of care?

The project addresses two major axes (or two major foci):

1. Identifying and documenting the unique mental health needs and challenges of the population of persons with developmental disabilities and abuse-related trauma issues (Phase 1 — "Defining the Issues" -— Project Conceptualization and Development); and

2. Identifying and documenting the educational and training needs of the service providers best situated to provide a "continuum of care" within the community of service providers from Mental Health, Developmental Services, Specialized Services, Family Counseling Services and Trauma Services within the Central West region. (Phase 2 -— "Beginning to Address the Issues and Challenges" — Recommendations on the Educational and Training Needs to Support a "Continuum of Care" for Persons with developmental disabilities and abuse-related trauma issues).

Project Objectives

The specific Project Objectives identified to achieve the project's overarching goal are outlined below. They included:

- Conducting a survey of the existing key research literature and available resources and programs already in place addressing the treatment needs of persons with developmental disabilities and mental health issues (and/or challenging behaviours);

- Conducting a needs assessment to identify the professional training needs of service providers;

- Establishing and collaborating with a "working group" to guide the development and implementation of an approach for such services to this population;

- Documenting the nature of the problem and the kinds of service approaches which can begin to most effectively address it;

- Developing a comprehensive Two Day Training Program with distinct modules aimed at integrating a theoretical framework to guide the work with trauma

survivors with developmental disabilities, and to develop skills towards the provision of effective treatment;

- Delivering the educational components of the Two Day Training Program aimed at laying the groundwork to enhance the capacities of service providers to serve the needs of individuals with a dual diagnosis who are dealing with issues pertaining to abuse-related trauma; and

- Developing a set of recommendations, delivered in a final report, to guide the provision of collaborative care, treatment approaches, and any needs for ongoing professional education in support of this "continuum of care."

The Project Team

This project was guided by the work of a consultant, Dr. Lori Haskell, who worked in collaboration with a cross-sectoral working group formed specifically for the project.

The team members and their affiliations are provided below:

Dr. Lori Haskell
Arran Rowles
Karen Klee
Donna Lee
Anne Hougham
Casey Cruikshank
Christine Rickards
Darina Vasek
Gail Marr
Jillian Carlyle
Heather Field
Jannette Thompson
Mary Dempsey
Nicole Pietsch
Tamara Vukelic

Some research assistance was provided to Dr. Lori Haskell for the purposes of the report by Kate Leslie, Caitlin Mary-Faith Turner and, in particular, Jennifer Del Vechio.[3]

[3] Kate Leslie provided excellent research and writing assistance on the section on disability and language, and Caitlin Turner provided excellent research assistance compiling bibliographic resources.

Overview of the Report

This report provides an overview of a project undertaken to begin to address the gap in the provision of trauma treatment to people with developmental disabilities and mental health needs, moving towards the development of a "continuum of care" for the delivery of collaborative, abuse-related trauma services. This project took place within the Central West region of Ontario, Canada.

The report begins in Part I with an overview of the project's goals and objectives, and its development.

Part II of the report presents an analysis of the importance of language in understanding and speaking about developmental disabilities and the lives of the developmentally disabled.

Part III of the report presents a literature review of some of the key issues relating to developmental disabilities and mental health, including trauma.

Part IV of the report explains the significance of "complex trauma," and how it is distinct from simple post-traumatic stress. This part of the report also demonstrates the critical importance of recognition of complex trauma and its effects, particularly in the lives of people living with developmental disabilities.

Part V of the report discusses the development of an integrated network of services for a continuum of care for people living with developmental disabilities who are also dealing with trauma.

Part VI of the report concludes with some key recommendations aimed at moving this important work forward in the delivery of trauma-informed services for people with development disabilities and abuse histories.

Part II- UNDERSTANDING AND SPEAKING OF DEVELOPMENTAL DISABILITIES: THE IMPORTANCE OF LANGUAGE

I. Developmental Disabilities: Finding a Common Language

Language is a theme of struggle in the disability community, as it also is for other marginalized groups in society. Despite a growing awareness of the problems faced by disabled people in relation to integrating into mainstream of modern society, many significant barriers to full accessibility and community participation persist. Public ignorance and stereotyping is one of these barriers, and this attitude can contribute to a climate of exclusion and discrimination for people with disabilities.

However, one of the most insidious bases of discrimination against people with disabilities is found in everyday patterns of language use. This disabling discourse has the potential to be perpetrated by all speaking members of society.

II. Conceptual Models of Disability

Several conceptual frameworks have contributed to and influenced the concept of language in disability studies. The first, called the *medical model*, views disability as a characteristic of the individual, which is directly caused by disease, trauma, or other health conditions, and requires some type of intervention provided by professionals to "correct" or "compensate" for the problem. Although medicalization can have a role in managing some disabilities in certain contexts, "it easily slips into paternalism, echoes stereotypes of dependence, and/or reinforces the sick role for disabled people." In the medical model, disability is the problem, medical interventions are the solution, and the individual is the passive recipient of service.

In contrast, the *social model* of disability views disability as a socially created problem, and not as an attribute of the person. As such, disability has no inherent meaning, but is instead defined by any given community's understanding of the individual's role within that community. In the social model of disability, the problem is created by an inaccessible or inflexible environment brought about by the oppressive social milieu, and the solution called for is primarily political.

Finally, the third model is called the *independent living model.* This model challenges both the medical and social models of disability. In this model, the social construct of disability can reinforce the negative stereotypes of disabled people. For example, a physical barrier would be present when an individual who uses a wheelchair cannot access a building in the same way as someone who is able-bodied; it is demoralizing and dehumanizing to have to take a kitchen or service entrance instead. In the same way, attitudinal barriers can work to perpetuate stereotypes, which are often subtle and contagious. In the independent living model, the problem is dependence on professionals and others, with a locus in the medical and rehabilitative process itself. Changing attitudes and environments is the solution. Interventions include civil rights and advocacy, barrier removal, and consumer control over services. An individual with

a disability is not a "patient," but a "consumer". As such, the independent living model attempts to remove barriers and empower disabled people in creating control, flexibility, and choice in all aspects of life.

III. The relationship between language and identity

Language has the power to define a group's identity. Both overt and implied references to people with disabilities are integral to disability culture and identity. Disability policy consultant, June Isaacson-Kailes, explains, "[a] significant element in the struggle for basic human rights is what people call themselves…Disability culture is the commonality of the experience of living with a disability, and language is one of the keys to acknowledging this culture." As an example, rights-based groups have advocated a move away from the word "handicapped," which many felt associated disability with begging, to "people with disabilities," which is known as "people-first" terminology.

This relationship between language and identity is not unambiguous. "People-first" terminology, and even the word "disability," are controversial. "People-first" language has been criticized by disability groups and questioned academically as unwittingly weakening the impact of social constructions of disability by suggesting that disability is possessed by individuals rather than society, and suggesting that disabled people are the cause of their own oppression.

In reference to the word "disability," activist Bill Bolt in *Ragged Edge* argued:

> The name that we've insisted on for ourselves – the word 'disabled' – sends journalists into a tailspin. If we are 'disabled,' that is, 'without abilities,' then what is this demand for equal employment, journalists likely think. On the other hand, if we can work with only minimal special arrangements, then why do we need all kinds of government funds to live on?

Although the word "disability" has long been associated with suffering and weakness, it is so pervasive that disability rights groups continue to battle for a new understanding of the word. Disability studies scholar, Jenny Corbett, proposes that language must be continually challenged so that words such as "disabled" may be won by the "voice of enlightened modernity" in debates about political correctness, and thus old usages are redefined. This type of language challenging can explain how disabled activists justify using words such as "cripple" to describe themselves: by reclaiming such language, activists can take the image of their identity that creates fear and confusion in outside society and make it a source of "militant pride."

Furthermore, challenging the common usage of words and attempting to reassign their meanings is vital to demonstrate how language reinforces the dominant culture's views of disability. It is only when this occurs that society can see how even metaphoric use of disability terms stigmatize people with disabilities:

> When we use terms like "retarded,"' "lame," or "blind" – even if we are referring to acts or ideas and not to people at all – we perpetuate the stigma associated with disability. By using a label, which is commonly associated with disabled people to denote deficiency, a lack, or an ill-conceived notion, we reproduce the oppression of people with disabilities.

Even more subtle challenges to common uses of disability terminology can make a big difference in the social construct of disability. For example, altering from the stereotyping term of 'wheelchair bound' or 'confined to a wheelchair' to "an individual who uses a wheelchair" changes the focus from the chair to the person, emphasizing the active nature of the user and the positive way that wheelchairs increase mobility for a variety of activities.

While there are a number of factors that contribute to what is appropriate or favoured speech patterns, it is necessary to gain an enhanced sense of what is important in the eyes and ears of listeners, with and without disabilities. The most relevant criterion with which to judge the appropriateness of our language about disabilities is the reaction of disabled people themselves to the allegedly stigmatizing labels. Language patterns favoured by able-bodied individuals are often disfavoured by disabled people, who may find the adoption of solicitous language patterns ingratiating, even when no slight is intended by the speaker. The able-bodied community must create opportunities to empower disabled individuals to teach the rest of society the correct terms to use.

In conclusion, language is a powerful tool in shaping attitudes. Choosing terminology that shapes positive attitudes can go a long way in eliminating any prejudices and stereotypes that remain about disability. As a society, we have the ability to bring disabled people into the mainstream. Since able-bodiedness is a shifting and transitory state over the course of an average lifetime, realizing true equality and accessibility is not just important for those who currently live with a disability, but also for those who can be described as temporarily able-bodied: everyone.

IV. The International Classification of Functioning, Disability and Health

The *International Classification of Functioning, Disability and Health* (ICF) is the World Health Organization's (WHO) framework for measuring health and disability at both individual and population levels.[4] The ICF was officially endorsed by all 191 WHO Member States in the Fifty-fourth World Health Assembly in 2001. Unlike its predecessor, which was endorsed for field trial purposes only, the ICF was endorsed for use as the international standard to describe and measure health and disability.

[4] See World Health Organization website, at: http://www.who.int/classifications/icf/en/.

The ICF attempts to provide a coherent view of health states from a biological, personal, and social perspective, portraying human function and decreases in functioning as the product of a dynamic interaction between health conditions and contextual factors. The ICF identifies three levels of human function: body parts, the whole person, and the whole person in their complete environment. These levels, in turn, contain three domains of human function: body functions and structures, activities, and participation. The ICF acknowledges that "health" and "disability" are on a spectrum, and all human beings can experience a decrease in health, and thereby a degree of disability. In attempting to mainstream the experience of disability, the ICF shifts the focus from cause to impact.

The development of the ICF framework is an important advance with the potential to provide a universal, standardized language and framework that looks beyond disease to focus on how individuals live with their disabilities. If widely adopted, the ICF could create a common international language with the potential to facilitate discourse across international borders.

PART III - KEY ISSUES AND SELECTIVE OVERVIEW OF THE LITERATURE ON DEVELOPMENTAL DISABILITIES AND MENTAL HEALTH

Abuse and Post-traumatic Stress in the Lives of People with Developmental Disabilities

The pervasiveness of sexual, physical and emotional abuse is increasingly acknowledged in the general population. For people with developmental disabilities, however, there has long been a minimization of the magnitude of the abuse experienced, compounded by a significant lack of knowledge about the pervasive and traumatic effects of this abuse on developmentally disabled peoples' lives. Moreover, individuals with developmental disabilities have inadequate access to treatment, and confront a severe paucity of appropriately trained service providers.

It is now understood that people with developmental disabilities have high rates of childhood abuse. In fact, women with developmental disabilities have higher rates of sexual abuse than women in the general population (Furey, 1994). Sobsey (2001) reports that people with disabilities are twice as likely to experience abuse. Women with mild mental retardation in particular experience the highest levels of sexual abuse.

The complexities of the long-term effects of this violence, though, are not often fully recognized. The developmental, emotional, and psychological consequences of violence and trauma are often underestimated, and more often misunderstood. Yet it is imperative that those providing service to people with developmental disabilities with abuse histories be sensitive to the impact of trauma so they are able to ensure appropriate sources of help.

It's not enough, however, to merely identify abuse in the lives of people with developmental disabilities. *Front-line workers and service providers must also help these individuals, and their families and caretakers, to understand that seemingly unrelated mental health problems are often actually responses to — and attempts to cope with — the psychological and physiological disruptions caused by abuse-related trauma.*

Some of the signs of abuse-related trauma are anxiety, sleeplessness, depression, eating disorders, self-harming behaviour, and agitation. Since, in so many cases, people and their caregivers do not recognize the effects of abuse-related trauma, they struggle in their daily lives to cope with their distress, too often in hidden and untreated forms.

Key findings on PTSD and Developmental Disabilities

Some of the key findings from the literature on post-traumatic stress and developmental disabilities, sometimes also referred to as developmental disabilities in the literature, are presented below, in enumerated points.

1. Developmentally disabled individuals may be at a greater risk for developing post-traumatic stress disorder (PTSD) because they face an increased likelihood of abuse

While some researchers suggest that there is little empirical evidence in support, it is commonly believed that people with developmental disabilities are at a higher risk for exposure to traumatic abuse events than the general population.[5]

People with developmental disabilities are particularly at risk for neglect and physical, emotional, and sexual abuse, and this abuse is more likely to be perpetrated by multiple people and on a frequent basis.[6] One major reason that the developmentally disabled are especially vulnerable to abuse under these circumstances is because they often need to rely on many different caregivers in order to meet their daily needs. They may also fear that if they do not comply with their abusers, the support they require in order to function will be withdrawn from them.[7]

Once exposed to a traumatic event, those with developmental disabilities may have fewer internal and external resources at their disposal to process what has happened and to move forward. It is essential for developmentally disabled individuals to understand what happened to them in order to minimize the traumatic effect and the likelihood that PTSD will develop.[8]

2. Developmentally disabled individuals often manifest PTSD differently than what is typically recognized as PTSD in the DSM-IV

The DSM-IV diagnosis of PTSD requires exposure to a traumatic event involving actual or threatened death or serious injury to self or others causing intense fear, horror, or helplessness, in addition to persistent re-experiencing of the event.[9] The

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[5] Newman, E, Christopher, S & Berry, J. (2000) "Developmental Disabilities, Trauma Exposure, and Post Traumatic Stress Disorder", Trauma, Violence and Abuse 1: 154-170, at 154 ("Newman"). Newman asserts that there is insufficient empirical evidence to support that the learning disabled face more trauma in their lives. She believes the rates are inflated because there has not been an appropriate comparison group; Lemmon, p. 318.

[6] Doyle, C. & Mitchell, D. (2003) "Post-traumatic stress disorder and people with learning disabilities: a literature based discussion", Journal of Intellectual Disabilities 7: 23-33, at 28("Doyle"); Curry, M., & Navarro, F. (2002) "Responding to Abuse Against Women with Disabilities: Broadening the Definition of Domestic Violence" Health Alert 8: 1 – 5 ("Curry"): McCarthy, p. 164.

[7] Curry, p. 2.

[8] Doyle, p. 27; Lemmon, p. 318.

[9] Turk, J., Robbins, I., & Woodhead M. (2005) "Post-traumatic stress disorder in young people with intellectual disability", Journal of Intellectual Disability Research 49: 872 – 875, at p. 873 ("Turk"); Tomasulo, D. & Razza, N. () "Posttraumatic Stress Disorder", in Fletcher, R., Loschen, E., Stavrakaki, C. & First, M. (eds) *Diagnostic Manual-Intellectual Disability: A Clinical Guide for Diagnosis of Mental Disorders in Persons with Intellectual Disabilities*, pp.215 – 224. National Association for the Dually Diagnosed, at p. 216 ("Tomasulo").

diagnosis often requires sophisticated language skills of the patient and the ability to identify and communicate emotional states.[10] Research has illustrated that some people with developmental disabilities have these skills and manifest PTSD similarly to those without PTSD, commonly reporting flashbacks, sleep disturbance, intrusive thoughts, and nightmares, and feel more irritable, have an elevated startle response, and attempt to avoid reminders of the traumatic event.[11] However, people with more severe developmental disabilities often present atypically. The DSM-IV, however, does not recognize the manifestation amongst people with lowered intellectual ability.[12]

The DSM-IV events that classify as traumatic may not be appropriate with developmentally disabled individuals. A traumatic event for a learning or developmentally disabled individual may not fit within the traditional definition of a traumatic event — such as moving to a new home — even though it has resulted in a serious impact on the individual.[13] In addition, the characteristic of the event creating a feeling of "helplessness" is not very useful in a group of individuals that may have to rely on the assistance of others to meet most of their daily needs.[14]

Some people with learning disabilities may lack the intellectual abilities to communicate their subjective thoughts and feelings about an event. They would therefore not be able to communicate to their assessor that they are re-experiencing a traumatic event, or even that they were exposed to a traumatic event in the first place.[15] For those with communication difficulties, research on PTSD in children may be more appropriate.

Children tend to somatize their feelings. Some research shows that those with learning disabilities may do this as well.[16] Children rarely experience flashbacks, the iconic indicator of PTSD, and it has been suggested that flashbacks are uncommon amongst severely learning disabled individuals as well.[17] Some learning disabled individuals may have flashbacks, but are not able to communicate that experience. What they do communicate, rather, may be misunderstood as a psychotic disorder.[18]

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[10] Turk, p. 874.

[11] Mitchell, A. & Clegg, J. (2005) "Is Post-Traumatic Stress Disorder a helpful concept for adults with intellectual disability?", Journal of Intellectual Disability Research 49: 552 – 559, at p. 533 ("Mitchell").

[12] Curry, 27; Turk, p. 874.

[13] Lemmon, p. 320; Tomasulo, p. 219.

[14] Mitchell, p. 557.

[15] Mitchell, p. 553; Lemmon, V. & Mizes, J. (2002) "Effectiveness of Exposure Therapy: A Case Study of Postraumatic Stress Disorder and Mental Retardation", Cognitive and Behavioural Practice 9: 317 – 323, p. 318 ("Lemmon").

[16] Mitchell, p. 554.

[17] Mitchell, p. 553.

[18] Tomasulo, p. 219

The most common symptoms of PTSD in the general population are nightmares, jumpiness, and trouble sleeping.[19] On the other hand, the most common symptoms of PTSD amongst children are behavioural, such as, for example, repetitive play.[20] The learning disabled individual often manifests PTSD behaviourally as well, via aggressiveness and stereotyped behaviours, such as repetitive rocking and odd or bizarre behavior.[21]

3. PTSD is under-recognized amongst people with learning or developmental disabilities

There are several reasons why PTSD is under-recognized amongst learning disabled individuals. One of the main reasons is the diagnostic criteria of PTSD in the DSM-IV and its limited applicability for many learning disabled individuals as explained in the above. Additionally, it may more difficult to recognize that a traumatic event has even happened for a learning disabled individual, especially for those without well developed communication skills and when the event has happened long in the past, since some of the events most likely to cause PTSD, such as sexual abuse, occur behind closed doors.[22]

Another major cause of this under-recognition is that the behavioural manifestations of PTSD may be misinterpreted as merely part of the learning disability rather than a comorbid health problem.[23] For example, some people with PTSD attempt to avoid the stimuli that remind them of the traumatic event. A learning disabled person who tries to use this strategy may be labeled as non-compliant, which is interpreted as a behavioural consequence of their learning disability.[24]

Some do not believe handicapped people are even capable of the emotional complexity required to develop PTSD and to benefit from appropriate treatment for PTSD.[25] With beliefs like this existing amongst some in the therapeutic environment, it is no surprise that there is under-diagnosis of PTSD amongst the learning disabled.

A leading problem with the under-diagnosis of PTSD amongst the learning disabled is that a large portion of learning disabled individuals with PTSD never receive treatment. One study of fifty-four learning disabled individuals who had been exposed to sexual abuse, an all too common source of PTSD in the general population, found that only 39% of victims received treatment from a therapist.[26] Many of the victims exhibited

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[19] McCarthy, p. 164

[20] Tomasulo, p. 216

[21] Mitchell, p. 554; Tomasulo, p. 217; Doyle, p. 29; Sequiera, p. 454

[22] Sequiera, p. 451; McCarthy, p. 166; Turk, p. 872

[23] Lemmon, p. 18.

[24] Tomasulo, p. 219.

[25] Hollins, p. 35; McCarthy, p. 163; Curry, p. 4.

signs of PTSD. Studies have shown that people who are exposed to trauma are at a risk of developing learning disabilities and maturing more slowly. Accordingly, it would not be a stretch to assert that the disability level of people with learning disabilities who are exposed to trauma could be worsened if they do not receive appropriate treatment.[27] Unresolved PTSD symptoms amongst the learning disabled can lead to devastating consequences, including suicide.[28]

4. The manifestation of PTSD differs depending on the level of learning disability

Individuals with slight to moderate learning disabilities present with symptoms of PTSD similar to the signs and symptoms seen in the general population.[29] Those with more severe learning disabilities exhibit behavioural signs of PTSD.

5. Treatment used in the general population can be effective for those with learning disabilities with modifications appropriate for the individual's level of learning disability

Historically, it has been assumed by some practitioners that people with learning disabilities lack the emotional skills required to understand their predicament so to develop affective disorders because of their experiences.[30] Such practitioners may not recognize PTSD in an individual with a learning disability or may not believe that a learning disabled individual will benefit from treatment for his or her PTSD. This assumption is incorrect. The research illustrates that interventions for PTSD can be effective for people with learning disabilities, with appropriate modifications specific to the individual learning disability.[31]

When a traumatic event happens to a person with a learning disability sometimes the people around them try to shield them from the trauma by either avoiding talking about the event or giving the person misleading information, such as, for example, saying that a deceased parent has just "gone away."[32] As with individuals without learning disabilities, and maybe more so, it is important for the individual to be told what has

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[26] Sequeira, H, Howlin, P & Hollins, S. (2003) "Psychological disturbance associated with sexual abuse in people with learning disabilities", British Journal of Psychiatry, 183: 451-456, p. 453 ("Sequiera")

[27] Tomasulo, p. 215.

[28] DesNoyers Hurley, A. (1998) "Two cases of Suicide Attempt by Patients with Down's Syndrome" Psychiatric Services 49: 1618 – 1619.

[29] McCarthy, p. 164

[30] Hollins, S. & Sinason, V. (2000) "Psychotherapy, learning disabilities and trauma: new perspectives" *British Journal of Psychiatry* 176: 32 – 36, p. 35 ("Hollins"); McCarthy, J. (2001) "Post-traumatic stress disorder in people with learning disability" Advances in Psychiatric Treatment 7: 163 – 169, p. 163 ("McCarthy").

[31] Hollins, p. 35; Lemmon, p. 320; McCarthy, p. 167.

[32] Hollins, p. 33.

happened and to be able to talk about the event so that the traumatic event can be made more amenable to emotional processing and so that the patient can appropriately grieve.[33]

Cognitive behavioural therapy (CBT) has yielded positive results amongst learning disabled individuals with PTSD just as it has in the general population.[34] Depending on the level of disability, some modifications may be required of the traditional CBT approach. In one study, the therapist made several modifications including: a modified self report scale from 0 to 10 rather than 0 to 100; allowing the victim to use the past tense when relating the traumatic event (rather than using the present tense to explain the story as if it were occurring presently); and allowing a therapist to attend with the victim at the site of the original traumatic event because the victim was not sufficiently independent to do so on her own.[35] With these and other modifications, the patient's self reported and observed distress levels were lessened by the end of treatment.[36]

Communication with the patient is a very important factor of both the diagnosis of PTSD and its treatment. The therapist must be able to facilitate the discussion of a traumatic event, in addition to other elements, such as how it made the patient feel and how that patient currently feels.[37] This approach may help the patient comprehend what happened, and assists in better understanding and identifying his or her feelings and reactions.[38] Additionally, for those with limited communication skills, it may be helpful to interview caregivers.

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[33] Lemmon, p. 318; Hollins, p. 33.

[34] Hollins, p. 32; Lemmon, p. 319.

[35] Lemmon, P. 320.

[36] Lemmon, p. 322

[37] Mitchell, p. 557.

[38] Mitchell, p. 558.

UNDERSTANDING TRAUMA: NEW CONCEPTUALIZATIONS OF FORMS OF TRAUMATIC STRESS

Different Kinds of Post-traumatic Stress — Simple and Complex

In the past decade, there have been significant developments in the understanding of psychological trauma and its treatment. It has become increasingly clear that *simple post-traumatic stress* resulting from a one-time incident — such as a rape or a serious car accident — is markedly different from the complex set of responses that follows chronic, multiple, and/or ongoing traumatic events. Chronic childhood abuse or prolonged experiences of assault and violence in an intimate relationship results in an entirely different clinical picture.

Most of the literature addresses simple PTSD, and there is therefore a limited amount of literature in relation to the population of people with developmental disabilities. Single traumatic incidents tend to produce discrete conditioned behavioral and biological responses to reminders of the trauma, and the responses are outlined in the PTSD diagnosis (van der Kolk, date). Simple PTSD is primarily a neurophysiological disorder with effects on hippocampal volume as a result of an overaroused amygdala.

Chronic maltreatment or repeated traumatization, on the other hand, such as occurs in the lives of children who are exposed to repeated medical or surgical procedures, have pervasive effects on the development of mind and brain. Chronic trauma interferes with neurobiological development and the capacity to integrate sensory, emotional, and cognitive information into a cohesive whole.

Trauma researchers now recognize that the overwhelming experiences of neglect and ongoing emotional, sexual, and/or physical abuse have a pervasive impact on the developing brain, resulting in wide-ranging behavioral and neurobiological effects, including depression, attention disorders, various somatic illnesses, interpersonal problems, and impulsive and self-destructive behaviors.

Children who have experienced ongoing abuse, parental misattunement, and neglect *develop a view of the world that incorporates their betrayal and hurt.* An expectation that they will be harmed permeate their relationships. This expectation is expressed as negative self-attributions, loss of trust in caretakers, and loss of the belief that someone will look after them and make them feel safe. They tend to lose the expectation that they will be protected, and act accordingly. As a result, they are starved for connection with others, but withdraw from fear and are left feeling lonely and sad.

Early childhood neglect and abuse has a devastating effect on the child's sense of connection to others. These memories are implicit (there is no conscious recall), and are encoded differently than other memories because there is no language component. These individuals unknowingly *organize their relationships around the expectation or prevention of abandonment or victimization.* This can be expressed as excessive clinging, compliance, oppositional defiance and distrustful behavior. John Briere suggests that how we know ourselves implicitly is like watching a movie about ourselves rather than

writing the movie. We do not have a sense of recall of these early experiences; they are rather evoked or triggered. We can observe them unfolding, but we do not know of their existence beforehand.

For years, clinicians and researchers believed that acts of abuse were the largest contributors to trauma. This belief has shifted to an understanding that acts of omission create the worst traumas. The Minnesota developmental study (Sroufe, 2005) found that the biggest risk factor for later attachment difficulties and psychological trauma was the absence of someone to love or connect to you.

Experiences of neglect, parental misattunent, and emotional abandonment are not discrete events; they are processes. Neglect in childhood creates a significant trauma. The feeling of loss and abandonment results in immediate effects of pain and agony, and these experiences cannot be cognitively mediated because they are not knowable at a cognitive level, and therefore can only be mediated experientially.

A child requires secure attachment for psychobiological development. Parents are required to keep children safe, and also teach them how to handle adversity and emotional upset. Children who are neglected and abused experience overwhelming emotional pain without anyone to comfort them. As a result, they do not implicitly learn problem solving strategies or means to comfort or self-soothe. The emotional pain they carry exceeds their capacity to handle pain, and this combination of processes undermines the individual's ability to develop affect regulation skills.

Judith Herman (1992) explains that prolonged and repeated trauma occurs in situations where a person is captive, unable to flee, or is under the control of the perpetrator. These conditions render the person powerless and allow the perpetrator *ongoing coercive control.* Such conditions may be found in situations varying from prison camps, some religious cults, and conditions of war to some families or institutions, such as residential schools. This was the case for First Nations students in residential schools in Canada.

The result of this ongoing coercive control is psychological trauma that differs greatly, both in complexity and range of effects, from that resulting from a one-time traumatic event. As a result, a new diagnosis has been developed, called *Complex PTSD* in adults, and Developmental Trauma Disorder in children.

Although this new diagnosis has not yet been officially recognized in the *Diagnostic and Statistical Manual of Mental Disorders* (the most-used guide to diagnosing mental disorders, also referred to as "the DSM"), it is currently captured under the general DSM category of Disorders of Extreme Stress Not Otherwise Specified. This is an important development in understanding and treating trauma. Complex PTSD is expected to be included in the next revision of the DSM.

Psychiatrist, Bessel van der Kolk, argues that, without a diagnosis that accurately describes the vastness of the neurobiological and psychological adaptations required to survive living in a threatening and overwhelming environment, people are instead given a hodgepodge of labels for a what is mistakenly understood as a number of separate

conditions. For example, people are diagnosed with PTSD and attention deficit, or with mood disorders.

One of the outcomes of this type of piecemeal diagnosis is the type of treatment that is prescribed. When the emotional dysregulation of traumatized people is not recognized, the coping mechanisms they may adopt, such as self- harming, are given diagnoses such as bipolar disorder, treated exclusively with drugs and behaviour management (van der Kolk, 2009).

In the May 2005 *Psychiatric Annals*, van der Kolk wrote, "Because infants and children who experience multiple forms of abuse often experience developmental delays across a broad spectrum, including cognitive, language, motor, and socialization skills, they tend to display very complex disturbances, with a variety of different, often fluctuating, presentations." They therefore *anticipate and expect the trauma to recur*, and respond with hyperactivity, aggression, defeat, or freeze responses to minor stresses.

Reminders affect their cognition: they tend to become *confused, dissociated, and disoriented* when faced with stressful stimuli. They easily *misinterpret events* in the direction of a return of trauma and helplessness, which causes them to be constantly *on guard, frightened, and over-reactive.*

Moreover, these neurobiological and psychological changes are likely to interfere with sequential developmental tasks, creating new difficulties with each succeeding stage of development, and complicating the clinical picture as the child matures.

Herman (1992) outlines three broad areas of psychological disturbance that distinguish complex PTSD from simple PTSD. The first area involves the types of responses or effects, which are more complex, widespread, and persistent in complex PTSD due to the prolonged nature of the trauma. The second area involves the kinds of characteristic personality changes that accompany complex PTSD, including difficulties with relationships and identity. The third area relates to the survivor's increased vulnerability to further victimization, both in the forms of self-harm as well as harm perpetrated by others.

Trauma in a Bio-Psycho-Social Framework

Trauma can change a person's life when it leads to disruptions in emotion, consciousness, memory, sense of self, attachment to others, and relationships. Moreover, trauma does not merely affect a person's mind, but also affects their bodies as well Responses of the body are known as *physiological* responses. When children are abused by their own caretakers, or while sleeping in their own beds, they cannot fight or flee. They are often trapped both physically and emotionally by their attachment to the perpetrator, or else they are made powerless by their mistaken beliefs that they are to blamed for the abuse. Similarly, many adult women are trapped in relationships with abusive men — they may fear that their abusers will kill them if they attempt to leave.

When a person is trapped, his or her sympathetic nervous system is activated. As a result, they often have a surge of physiological arousal — with no outlet for this arousal — resulting in agitation, tension and anxiety.

Prolonged trauma increases and generalizes physiological arousal. Trauma survivors often complain that they are not able to establish a state of calm or comfort. Instead, they too often feel chronically anxious, agitated, and tense. This increased physiological arousal often results in insomnia, tension headaches, gastrointestinal disturbances, and back and pelvic pain.

Traumatic experiences, therefore, alter the functioning of the central nervous system. as well as general physiological functioning. In this way, trauma has both emotional and physical effects.

Trauma is best discussed in a framework that takes into account the physiological and psychological levels on which trauma is experienced, as well as the social context in which the trauma occurs. This is known as the *bio-psycho-social framework*.

In this bio-psycho-social framework, all responses to trauma are understood as attempts to cope with the stress of trauma. People adapt — mentally, physically, behaviourally, and socially — to traumatic experiences. The social context and circumstances that define and shape people's lives also shape the ways and means that they may adapt or cope with trauma.

Complex post-traumatic stress is multidimensional and pervasive because it is often the result of ongoing damaging and neglectful experiences, which are sometimes compounded by childhoods that lack consistent, predictable and attuned parenting. People experiencing complex post-traumatic stress have most typically experienced chronic and ongoing abuse, often in the context of intimate relationships.

Individuals who have experienced severe and frightening events as either children or adults can have complex post-traumatic stress, and yet not have simple post-traumatic stress. More typically, however, they suffer from both kinds of post-traumatic stress (Luxenberg, Spinazzola & van der Kolk, 2001).

Part IV: COMPLEX TRAUMA: A DEVELOPMENTAL FRAMEWORK FOR UNDERSTANDING TRAUMA RESPONSES IN THE LIVES OF PEOPLE WITH DEVELOPMENTAL DISABILITIES

Why Is it Imperative to Understand the Nature of Complex Traumatic Stress in the Lives of People with Developmental Disabilities?

Many of those who seek treatment in mental health clinics have histories of long-term emotional, physical, and sexual abuse. Many mental-health professionals, especially those lacking specialized education and training, have previously not understood that prolonged abuse experiences can cause a person to develop a spectrum of complex psychological trauma responses.

Individuals with developmental disabilities are at increased risk for abuse as compared to the general population (Gil, 1970; Mahoney & Camilo, 1998; Ryan, 1994). Maltreatment of children with disabilities is 1.5 to 10 times higher than of children without disabilities (Baladerian, 1991; Sobsey & Doe 1991; Sobsey & Vamhagen, 1989; Sullivan & Knutson, 2000; Westat, 1991).

Sullivan & Knutson (1998) reported from their study that sixty-four percent of the children who were maltreated had a disability. The most common disabilities were behavior disorders, speech/language, learning disability, and mental retardation. The most common type of maltreatment was neglect. Children with mental retardation were the most severely abused.

Immediate family members perpetrate the majority of neglect, physical abuse, and emotional abuse. Extra-familial perpetrators account for the majority of sexual abuse (Sullivan & Knutson, 2000). As well, more people with developmental disabilities (DD) receive care in institutional settings; the incidence of sexual abuse in such settings is four times higher than in the community.

Additionally, people with developmental disabilities have characteristics that result in greater likelihood to be abused. These characteristics include:

- Trained to be compliant to authority figures;
- Dependent on caregivers for longer periods of time;
- Can be quite accommodating, loves to please;
- Require more types of assistance;
- Require larger number of caretakers;

- Less able to meet parental expectation;
- Often isolated from resources to whom abuse reports could be made;
- Historically have not received education about their rights, relationship safety, or stranger danger;
- May have impairment in their ability to communicate or have impaired mobility so it is harder to get to a location to report;
- DD may result in the person experiencing cognitive and processing delays that make it difficult to understand that they are being abused; and
- Can be easier for perpetrators to manipulate them

Abuse and neglect have profound influences on brain development. The more prolonged the abuse or neglect, the more likely it is that permanent brain damage will occur. Not only are people with developmental disabilities more likely to be exposed to trauma, but exposure to trauma makes developmental delays more likely. In fact, "[t]he developing brain is exquisitely sensitive to stress." Persistent states of fear in children impair their capacity to benefit from cognitive, social, and emotional experiences (Perry, 2001).

Exposure to trauma can modify the child's ability to access different levels of brain functioning, resulting in changes in their perception of time, cognitive style, affective tone, ability to develop solutions to problems, and ability to respond to and understand rules, regulations, and laws (Perry, 2001).

People with developmental disabilities may also experience cognitive and processing delays that interfere with understanding of what is happening in abusive situations, and feelings of isolation and withdrawal due to their differences, which may make them more vulnerable to manipulation because of their increased responsiveness to attention and affection.

In addition, the effect of trauma is increased for people with developmental disabilities due to a predisposition toward emotional problems and impaired resiliency before the abuse occurs (Burrows & Kochurka, 1995). Possible reasons for this increased vulnerability to develop trauma and other mental health problems include the following: (Avrin, Charlton, Tallant, 1998)

- It is more difficult to cope with normal life stressors given the limited resources the client has available;
- There is an increased vulnerability to abuse in the home, since these children can be a challenge to raise and place a high level of strain on the family;

- Developmentally disabled children are more vulnerable to abuse in the community because of their poor judgment and lack of self-protective skills;

- An additional stressor for higher functioning clients is awareness of their intellectual deficit — they have many grief and loss issues associated with their functioning problems; and

- People with developmental disabilities experience greater difficulty in receiving help for mental health problems due to communication and processing problems.

Implications of Failures in Recognizing Complex Trauma

Despite the growing awareness of the nature and impact of trauma, it is still too often the case that traumatic effects, particularly relating to abuse, are insufficiently understood and under-recognized in people's lives. This failure is particularly acute in the lives of the developmentally disabled.

Given the very high rates of interpersonal violence, sexual assault, and childhood abuse and neglect experienced by many people with developmental disabilities, this failure has particular relevance for this population, and diminishes the likelihood that this population will receive proper and effective treatment.

There are a range of current challenges which exist in relation to meeting the needs of individuals with trauma and developmental disabilities. These challenges include the following:

- Untreated trauma will persist;

- Research knowledge in the area is limited;

- Little recognition that people with developmental disabilities can and do develop PTSD and are at greater risk;

- Self-reporting is limited;

- Behavioural presentation attributed to non-compliance, agitation, anxiety or other mood disorders;

- A justice system that often fails to accept the credibility of people with developmental disabilities;

- Less likely to receive appropriate treatment;

- Long-standing bias that people with developmental disabilities cannot benefit from verbal oriented therapies;
- Very few clinical resources have been developed;
- A serious lack of trained professionals who are comfortable in working with people who have developmental disabilities in order to help them process traumatic incidents;
- Most of the literature addresses simple PTSD;
- Simple PTSD is based on single traumatic event — this paradigm does not encompass the multiple abuse experiences of people with developmental disabilities;
- Chronic abuse results in complex PTSD;
- The disparate presentation of symptoms associated with complex PTSD results in clinicians not considering traumatic events as etiological factors since it is less obvious;
- Assessment and diagnosis not well researched or developed; and
- Instruments not normed/often not suitable for developmentally disabled clients

Therapies that focus on addressing the core disturbances of affect dysregulation, attention and consciousness, interpersonal skills and attributions and schemas show significant treatment gains in trauma survivors. Further refinement of these areas of psychological disturbance are described by van der Kolk in his articles published in the *Psychiatric Annals*. van der Kolk argues that effective treatment must focus on three primary areas:

1. establishing the person's capacity to regulate his or her internal states of arousal,
2. learning to negotiate safe interpersonal attachments, and
3. integration and mastery of the body and mind.

"Mastery is most of all a physical experience," van der Kolk writes. Mastery is:

> the feeling of being in charge, calm, and able to engage in focused efforts to accomplish goals. Children who have been traumatized experience the trauma-related hyperarousal and numbing on a deeply somatic level. Their hyperarousal

is apparent in their inability to relax and in their high degree of irritability. (Van der Kolk)

PART V - Developing an integrated network of services for a continuum of care for people with developmental disabilities and abuse-related trauma histories

In order to offer a comprehensive and unified understanding of severe abuse, neglect, and emotional misattunement in the lives of people with developmental disabilities, we must understand and apply the framework of complex trauma. This framework helps identify the range of treatment needs of this population that can be best addressed by a "continuum of care."

Such a continuum must include assessment, treatment, and program planning, as well as delivery of trauma informed treatment. The continuum of care is designed to illustrate the range of services and treatment required. By identifying the specific types of services required, this continuum provides some direction of the type of practitioner knowledge, skill development, and training in different treatment modalities required to offer the range of services and treatment required to offer comprehensive trauma informed treatment.

_____ Range of trauma informed therapeutic services required _____

Psychoeducation	Assessment	First Stage Trauma Treatment	Trauma Processing Therapy	Group Work	Forensic Assessment
Abuse prevention Sexuality Education Information on trauma and its effects on body and brain	Trauma Symptom Checklist for Children Traumagenic Impact Rating	Symptom Management Skills Grounding Techniques Sensory anchors Skills	EMDR Neurofeedback Body Therapies	Women's groups Substance Abuse/Self Harm Psychoeducation Groups (teaching coping skills)	Medication Assessment

The continuum of services for people with developmental disabilities and trauma must include the following domains:

- Trauma informed assessment -- careful diagnosis and the development of appropriate treatment approaches;

- Psycho-Education -- prevention, helping clients with developmental disabilities understand their experience of trauma;

- Group work –psychoeducation, coping skills, substance abuse, sexual assault;

- Symptom Management Skills (individual or group models);

- Trauma Processing Therapies (individual treatment modalities); and

- Working with Families and Community.

Not all agencies or services will be able to provide all services necessary in the lives of traumatized developmentally disabled people. The point of this project is rather to develop a collaborative network of agencies and organization with information about their various services and programs offered and their capacities in order to work towards the best continuum of care possible.

Brief Description of the different domains that are part of the continuum of treatment

This section of the report identifies the key elements of a continuum of care for people with developmental disabilities who are dealing with trauma responses.

Psychoeducation

Psychoeduation is a critically important element of trauma treatment. Psychoeducation is necessary for:

- Educating the client about the nature of trauma and its treatment

- Educating family members and caretakers; and

- Increased awareness and education for community members.

In the early or initial stages of trauma treatment, a critical component of focus should be educational and cognitive. This includes providing survivors with information about the immediate impact of trauma as well as its long-lasting after-effects.

Most clients need to understand how abuse and neglect shaped their development and responses as children, as well as their responses in adulthood. It is through this lens that they can reinterpret their lives in a way that is meaningful and coherent. Education about post-traumatic stress engenders hope in clients because if their problem "has a name," then it is understood and treated.

The pace and timing of introducing information regarding how people respond to traumatic events should be tailored to the individual client. Not all clients will want or

need this psycho-educational information, nor will all clients be ready for it, or at least not all of it.

The challenge for developmental disabilities services is to have clear explanations of abuse-related trauma and its after-effects. The therapist can then educate the client regarding the bio-psycho-social dimensions of post-traumatic stress, along with the physiological impact of having experienced traumatic events. Many survivors are emotionally constricted and have spent a lifetime minimizing their abuse. As a result, they may not even initially report having had abusive experiences. However, an informed therapist will be able to infer from the abuse history a client provides, and by their current responses and symptoms, that they very likely did have a psychically overwhelming experience, and that their psychological defences are still protecting them from fully acknowledging, and thereby healing, from that experience. In cases where clients had childhoods of neglect and deprivation, they most likely cannot name what they did not receive.

It is therefore crucial that therapists understand these concepts and be able to explain and draw on them in order to help survivors understand some of their typical and understandable reactions.

The challenge for trauma therapists providing this information to clients with developmental disabilities is to be able to translate the concepts and theories in a developmentally appropriate language tailored to the client.

Assessment and Diagnosis

Assessment and diagnosis are essential first steps towards providing trauma informed treatment to people with developmental disabilities. Diagnosing complex trauma in people with developmental disabilities , however, poses numerous challenges and complications. These challenges can seem like insurmountable obstacles, yet they do not need to be. For example, people who do not have the communication skills to describe their thoughts, feelings, and mood may be hindered in their abilities to express their reactions. As a result, observing changes in their behaviour must suffice for the purposes of discerning trauma responses.

Whether or not they exhibit symptoms of PTSD, children who have developed in the context of ongoing danger, maltreatment, and inadequate care giving systems are ill-served by the current diagnostic system. No single current psychiatric diagnosis begins to accurately capture the cluster of symptoms that research has shown to commonly occur in children exposed to interpersonal trauma.

Since complex PTSD is not yet recognized and has not been conceptually applied to people with developmental disabilities and abuse-related trauma, the use of inadequately conceptualized diagnostic categories can lead to a myriad of problems. These problems can include:

- no diagnosis;
- multiple unrelated diagnoses;
- an emphasis on behavioral control without recognition of interpersonal trauma;
- a lack of safety in the etiology of symptoms; and
- a lack of attention to ameliorating the developmental disruptions that underlie the symptoms.

In absence of a developmentally sensitive trauma-specific diagnosis for children, such children are instead diagnosed with an average of 3 to 8 co-morbid Axis I and II disorders (Putman, 2008).

Misdiagnosis is common especially when obsessions, insomnia, and anxiety are misunderstood. Flashbacks may be described as things the client has seen, heard, or sensed. Flashbacks may be reported as newly imagined experiences, and lead to diagnoses of schizophrenia, psychosis, or personality disorders.

The most common presenting symptom of trauma in the developmentally disabled population is aggression, as opposed to sleep problems, nightmares, and hyper arousal in non-disabled population. Since the trauma may manifest itself in changes in behaviour, this change in behaviour is often misdiagnosed and treated as challenging behaviour. Other presenting symptoms include disruptive/defiant behaviour, self-harm, agitation, sleep problems, and depressed mood.

The treatment outcome literature shows the necessity of undertaking an adequate complex trauma diagnosis.

Suitable instruments for diagnosing complex trauma in people with developmental disabilities include the following assessment instruments;

Trauma Symptom Checklist for Children (TSCC)

This assessment instrument can be used with adults with Developmental Disabilities. The items of the TSCC are explicitly written at a level thought to be understood by children eight years of age or older.

The TSCC is a self-report measure of post-traumatic stress and related psychological symptomatology in children aged eight to sixteen years who have experienced traumatic events, such as physical or sexual abuse, major loss, natural disaster, and witnessing violence.

The 54-item TSCC includes two validity scales (Underresponse and Hyperresponse), six clinical scales (Anxiety, Depression, Anger, Posttraumatic Stress, Dissociation, and Sexual Concerns), and eight critical items. (Briere, 1996).

The Inventory of Altered Self-Capacities (IASC)

The IASC is a fully standardized psychological test which measures seven types of "self-related" psychological difficulties, such as identity problems, affect dysregulation, and interpersonal conflicts. When arising from trauma, many of these altered self-capacities are considered to be part of complex PTSD.
A sixth-grade reading ability is required to complete the IASC. (Briere, 2000).

First Stage Trauma Treatment

Essential Components of First Phase Treatment:

The essential components of first phase treatment include:

- Establishing a therapeutic alliance;
- Promoting client safety;
- Addressing the client's immediate needs;
- Normalizing and validating the client's experiences;
- Educating the client about post-traumatic stress and treatment;
- Nurturing hope and emphasizing the client's strengths; and
- Teaching coping skills and managing target symptoms of PTSD (intrusive ideation, hyper-arousal, avoidance, dissociation).

The lives of many abuse survivors are complicated and even controlled by intrusive and persistent symptoms of trauma. In order to teach clients to manage these symptoms, mental health professionals must be knowledgeable and familiar with diverse therapeutic tools and strategies.

In first stage trauma treatment, a central therapeutic goal is to provide clients with the tools and knowledge they require in order to feel empowered and to learn skills to manage their own symptoms.

Therapists need to offer a theoretically contextualized approach to doing this work. That means that a clear, theoretical understanding of why any specific approach or technique is being used should be provided. Clients indeed gain immense relief from understanding the purpose of clinical techniques in therapy. Clients are also more likely to be willing and able to collaborate with the therapist on managing their traumatic responses.

Trauma Processing Treatment

Trauma Processing Treatment Modalities include:

- Cognitive Behavioural Therapy (cognitive processing therapy (CPT), prolonged exposure);
- EMDR (Eye movement Desensitization and Reprocessing Therapy)'
- Neuro Feedback Therapy; and
- Body Therapies (Sensorimotor Psychotherapy).

<u>Cognitive Behavioural Therapy</u>

Cognitive -Behavioural Therapy (CBT) is effective in helping clients improve functioning and in identifying the beliefs, feelings, and behaviours associated with the trauma responses. Overall functioning is improved through skills development and more adaptive cognitive appraisals of events that trigger intense responses.

Some specific CBT treatment approaches used for treating complex trauma include Skills Training in Affective and Interpersonal Regulation/Modified Prolonged Exposure (STAIR-MPE) and Dialectical Behaviour therapy (DBT).

CBT therapies include psycho-education about the etiology of clients' symptoms, as well as techniques and strategies to change these symptoms. For example, clients can learn relaxation skills to address states of hyperarousal. In fact, clients with developmental disabilities have responded well to cognitive behavioral therapies.

<u>EMDR (Eye movement Desensitization and Reprocessing Therapy)</u>

"EMDR is an approach to psychotherapy that is comprised of principles, procedures and protocols. It is not a simple technique characterized primarily by the use of eye movements. EMDR integrates elements from both psychological theories (e.g. affect, attachment, behavior, bioinformational processing, cognitive, humanistic, family systems, psychodynamic and somatic) and psychotherapies (e.g., body-based, cognitive-behavioral, interpersonal, person-centered, and psychodynamic) into a standardized set of procedures and clinical protocols. Research on how the brain processes information

and generates consciousness also informs the evolution of EMDR theory and procedure" (EMDR International Association, Webpage description).

EMDR has been successfully used on clients with developmental disabilities and trauma.

Neurofeedback

Neurofeedback is a technique in which the brain is trained in order to help improve its ability to regulate all bodily functions and to take care of itself. Research has found that the brain is highly adaptable and has great plasticity (Doidge, 2007). The brain therefore has an innate capacity to change, learn and improve performance.

With neurofeedback, clients learn how to control their brain waves. Once this is learned, clients have control over them indefinitely. Clients with developmental disabilities can learn to regulate their emotional states.

Body Therapies (Sensorimotor Psychotherapy)

Trauma not only affects the mind, but also the body. Often, clients need to learn to regulate bodily states that have been altered by enduring ongoing traumatic stress. Many clients with developmental disabilities, for example, will have difficulty describing the traumatic experiences they have experienced, and will not be able to form narratives of these events.

Many clients with complex trauma have a disconnection from their bodies, their physical patterns, and their psychological issues. Sensorimotor therapy is a method to address these disconnections. Sensorimotor Psychotherapy draws from somatic therapies, neuroscience, attachment theory, and cognitive approaches.

Such interventions help clients become aware of their bodily (somatic) responses, allowing these clients to recognize their function and then modify these responses to become a more adaptively functional, and maybe a useful, approach to take. Body therapies are useful with individuals with developmental disabilities.

Group therapy

There are many potential therapeutic factors associated with group therapy for trauma disorders. These factors include:

- It is a practical way to provide help to large numbers of clients;
- It is effective for teaching coping skills, and group members can reinforce the work by sharing what they find helpful;
- It helps break down the isolation;
- It helps normalize people's experience when others share their struggle;
- Groups are a good forum for psycho-education; and

- Women with mild developmental disabilities have been found to have extremely high rates of sexual assault, and group therapy is an extremely effective treatment modality.

Working with Family and Caretakers

Inclusion of caretakers and supportive others is essential in order to learn about various aspects of the client's functioning, including information about the client's receptive and expressive language. Gathering information from many sources in this manner helps identify treatment issues and clarify treatment progress.

Developing an alliance with the client's support systems will be enormously beneficial if they are able to support appropriate client coping and emotional problem solving. Caretakers and family members require education about complex trauma in order to strengthen their capacity to be supportive and also to provide ongoing feedback about what tools and techniques are working and what are not working.

Needs assessment to identify professional training needs of service providers best situated to provide a "continuum of care."

In order to meet the Community Network's goal of creating a sustainable system of specialized professionals and supports to offer individuals with a developmental disability and abuse-related trauma effective and seamless services, a needs assessment was carried out to determine what services existed. The survey focused on both the violence and developmental disabilities sector.

A program of education and training is imperative in order to increase system and service providers' capacity to care for people with developmental disabilities and mental health needs and/or challenging behaviour.

In order to establish a working group to guide the work on the trauma and developmental disabilities project, a phone-survey was conducted with sixteen sexual assault and family counseling centres in the Central West Region over a four-week period in June-July 2008. Survey respondents are listed in the appendices.

Respondents were introduced to the abuse-related trauma and developmental disabilities project, and were asked a series of questions about their experiences serving clients with developmental disabilities.

Agency members were asked about what current challenges they faced in doing this work.

A summary of feedback and themes is given below. In addition to this material, specific information regarding clinical services offered, multidisciplinary capacity, clinical specialties, service criteria, and catchment were collected.

Overall Findings:

The majority of the sexual assault and family counseling centres contacted agencies surveyed reported that they provided services to individuals with developmental disabilities.

The percentage of their reported caseload that included individuals with developmental disabilities was in the range of 2-7%. The majority reported that they lacked adequate knowledge to serve individuals with developmental disabilities.

Formation of a Working Group to Guide the development and implementation of an approach for services for this population.

Key stakeholders in the mental health, developmental, family counselling, trauma, and specialized service provider sector within the Central West region were invited to participate in the working group, and were offered the following description of the project:

> "The overall aim of this project is to move towards the development of effective and appropriate treatments for individuals who have both developmental disabilities and abuse related trauma. More specifically the project aims to engage providers from Mental Health, Developmental Services, Specialized Services, Family Counseling Services and Trauma Services to work collaboratively to develop a model which describes the appropriate continuum of trauma services for individuals. We hope to identify strategies to facilitate collaborative care, treatment and education. In addition, the project will include educational events to enhance the capacity of service providers to serve the needs of individuals with development disabilities who are also dealing with trauma issues.
>
> In the working group we hope to present a genuine opportunity for discussion, and the sharing of experiences and explorations of how to best address the complex difficulties faced by people dealing with the intersection of developmental disabilities and trauma. This intersection often undermines core psychological capacities, resulting in significant challenges for service providers.

Furthermore, there is too often a lack of information and training about the proper recognition and treatment of complex trauma generally amongst health and mental health service providers, let alone amongst those providing more specialized services for the developmentally disabled. In order to meet the needs of these populations as well as the needs of service providers, there must be specialized knowledge both of the complications surrounding complex psychological trauma and of the particular needs of those with a diverse range of developmental challenges.

Appropriate and effective treatment responses will require services with the abilities to do careful assessments as well services able to provide a range of treatment modalities. Unfortunately, there are very major gaps in providing appropriate and skilled treatment to these communities. As you can see, this project will necessarily engage us in confronting a range of complex problems. But it also provides an important opportunity to move this important work forward in progressing towards better understanding and serving the needs of developmentally challenged people dealing with trauma."

The first consultation meeting with stakeholders focused on developing a process to work as collaborators. Each stakeholder was asked the following questions:

- why each person is interested in coming together to focus on persons with disabilities and violence
- what each person's particular experiences have been in this arena
- what obstacles to providing support to persons with developmental disabilities have participants encountered and
- what strengths does each person believe they have to offer to support and serve people with developmental disabilities.

Additionally, the group worked to define the committee's goals. The committee was asked to consider and discuss the following questions:

- Is there a specific goal or action that the group could tackle together?
- What does the group want to achieve in the short term? The long term?
- Who else might we need or want at the table?
- What resources and technical assistance might we want to begin to take action on our identified goals?
- Where could we find those resources and assistance?

- How do we sustain our momentum and action-focus over time?

- How do we institutionalize change in our communities and organizations instead of relying only on specific individuals for change?

The original plan was for this working group to meet only three times, for 3 half day meetings, aimed at giving guidance and direction to the Consultant's work on the project.

However, on a volunteer basis, these dedicated professionals ended up meeting multiple times over the period of over a year, to play a greater role culminating in the development of a two day training workshop, as well as becoming co-trainers in the delivery of this workshop.

The committee meetings over the period of a year resulted in a dynamic and collaborative process. People from both the developmental services sector and the trauma services sector worked to combine experiences and expertise. An essential part of this project then, was the capacity building it entailed.

The outcome of the year long process of the working group was the development of a comprehensive workshop to enhance the capacities of service providers who provide counseling to individuals with developmental disabilities and abuse-related trauma.

This two day training conference is detailed further in the report, in the following section, which outlines the various modules.

A Comprehensive Workshop- Complex Trauma and Its Treatment to the Lives of People with Developmental Disabilities

The workshop on developmental disabilities and complex trauma that was developed to inform front line workers in South Western Ontario focused on the following four goals:

1. To offer a theoretical framework to guide work with trauma survivors with developmental disabilities;

2. To explicate the differences between simple and complex psychological trauma;

3. To discuss effective treatment interventions; and

4. To focus on the needs of trauma therapists and front line service staff as well as those of their clients.

Module One: Introduction to the Issues

The introductory module focused on the following issues:

- Why it is important to understand trauma in the lives of people with developmental disabilities (including gender differences and incidence of abuse)
- Defining developmental disabilities
- Identifying the prevalence of developmental disabilities in the general population
- Why people with developmental disabilities have an increased vulnerability for victimization
- The greater likelihood that people with developmental disabilities will develop traumatic responses
- Assessment and Diagnosis are essential first steps
- What are some of the challenges in doing this work?
- The need for a comprehensive theoretical framework
- Framework overview

Module Two: Why a Trauma Model is necessary.

This module focused on why a paradigm shift is necessary to address developmental disabilities and trauma in a non-pathologizing manner.

- Importance of a non-pathologizing approach to abuse related trauma and recovery
- A focus on adaptations
- Validation
- The critical importance of recognizing clients' resiliency and strengths

Module Three -A Conceptual Framework to Understand the Impact of Abuse Related Trauma on the Lives of People with Developmental Disabilities

This educational module addressed:

- Psychological Development (how we develop self-regulation)
- Attachment Theory
- Understanding the neurobiology of trauma
- Complex versus Simple Post Traumatic Disorder
- Affect Dysregulation
- Complications for people who developmental disorders and trauma
- Changes and losses
- Recognizing challenging behaviours-

- Understanding the function of these behaviours. Why are they challenging?
- Safety concerns for staff.

Module Four: Developing a Continuum of Treatment

This module dealt with:

- a continuum of services for developmental disabilities and trauma
- group exercise- a completion of an environmental scan of what services currently exist in each community
- Issue of Diagnoses
- Psycho-Education (a focus on prevention aspects and helping clients with developmental disabilities understand their experience of trauma)
- Symptom Management Skills
- Processing Trauma
- Working with Families and Community

Module Five - Case Study:
The application of tools and techniques used in trauma treatment with a young woman with developmental disabilities

Drawing on a specific and real case study, this module dealt with:

- Psycho-Education
- Strength building
- Symptom Management Skills- (grounding techniques)
- Understanding therapies that may be used
- How to help support clients while in therapy
- Working with Families and Community

Module Six -- Introduction to Developmental Disabilities

This model addressed the following:

- What do people need to know about developmental disabilities. Key information.
- Connection to intake, engagement issues
- Issues relating to Language
- Philosophical Differences

Module Seven -- Moving towards Trauma-Informed Services

This model asked:

- What needs to be considered (Making Links) in making our Services Trauma Informed?
- How do we develop collaboration?

~Group Exercise~

Case Scenario with Helen and Andrea was presented.
The focus was on how developmental disabilities would services need to change to support Andrea with her trauma behaviours and responses and how trauma services would need to change to be more informed about developmental disabilities.

What would it involve to develop trauma informed services for people with developmental disabilities?

Clips from the Film – "Her Name is Sabine"

The training also involved a view of segments from a film about a developmentally disabled woman in order to demonstrate the negative effects of institutionalization.

"Her Name is Sabine" is film made by actress, Sandrine Bonnarire, about her thirty-eight year old sister, Sabine, who, for most of her life, had undiagnosed autism and was institutionalized in a psychiatric hospital for five years of her life. The care she received while institutionalized resulted in an incredible decline in her psychological capacities. Sabine emerged from hospital overweight, depressed, and prone to abusive and aggressive episodes.

As the film description notes, "through remarkable family archival footage filmed over a twenty-five year period," the film is effectively able to depict Sabine's vibrant personality, numerous talents, and intense attachment to her sisters prior to her devastating five-year stay in hospital.

The film focuses on the group home that Sabine moves into and her long journey to recover basic behaviours, such as feeding herself, completing domestic tasks, and reconnecting to her sister. The film depicts the devastating effects of the kind of institutional care that fosters passivity and compliance at the cost of immense personal decline. The greatest harm was to Sabine's sense of attachment and security to her sister. Sabine's intense fear and anxiety after being abandoned for several years is

evident in her unrelenting requests for reassurance from her sister, along with intense, aggressive displays when she is faced with separation.

The film ends by showing the progress made in a small group home environment with caregivers that promote Sabine's agency and do not punish her for her inability to regulate her emotional states. The small group home instead offers empathy, a way for her to understand her intense reactions, and alternatives to using self-harm or aggressive hitting.

Module Eight -- Providing Trauma-Specific Services for People with Developmental Disorders

This module addressed:

- Treatment Stages (focus on Stage one treatment)
- Tools/Techniques
- Treatment Adaptations Required for developmentally disabled individuals
- Understanding the critical role of the therapeutic relationship
- Introduction to multi-modal, symptom-focused treatment
- Assessment approaches
- Cognitive and emotional processing of trauma memories
- Treatment of problems related to affect dysregulation, such as substance abuse, dissociation, and tension-reduction behaviour.
- Treatment of identity/self-disturbance, cognitive distortions, negative relational schemata
- New treatment approaches- Neural Feedback Training
- Creative Approaches-therapeutic stories

Module Nine - Vicarious trauma: The Impact of Our Work on the Service Providers

This module dealt with the topic of vicarious trauma, and the effects of doing trauma work on mental health professionals and other service providers.

- The emotional toll of working with traumatized people
- How does trauma work effect the helpers
- How can helpers process their reactions
- Developing a community of caring colleagues (for support & feedback)
- Importance of supervision and staff supporting one another

Environmental Scan from Two Day Training Conference

The domains of the continuum of services for clients with developmental disabilities and trauma served as the bases for survey questions with the participants at the two-day conference.

Participants were asked whether their provision of services were available in the following domains:

1. Assessment;
2. Psychoeducation;
3. Working with Families and Communities;
4. First Stage Trauma Treatment; and
5. Trauma Processing Therapies.

Environmental Scan Data

Participants were asked what training opportunities they had on trauma and the effects on clients with developmental disabilities. The following is an overview of their conclusions:

- The Wellington Area respondents (ten groups) all responded saying this was their first training but would like more;

- Dufferin Area respondents said it was their first training on developmental disabilities and first training on complex trauma;

- Halton Area respondents said this was their first training; and

- Peel Area respondents had no previous training on this issue but some on vicarious trauma.

- Waterloo

1. Participants were asked to identify the barriers to assessment of trauma for people with a DD in their communities. These included:

    Waitlist
    Few services
    Lacking in knowledge and awareness
    Failure to acknowledge or recognize trauma
    Lack of expertise
    Lack of assessments

Communication when language barrier exists (nonverbal no access)
Social stigma and judgment
Blame disability
Lack of alternatives
Rural areas face greater challenges
Unable to identify triggers
No consistency of care providers
Interpreters required
Transportation
Funding

Access to trained clinicians
Consultants were limited in time
Wanting to help but feeling a lack of skill set
Clear indications of a trauma
Lack of history taking
Priority of treatment is unmasking trauma
Discipline is missing
Behavioural challenges
No long term services
Funding
Education

3. Psychoeducation

The data on providing psycho-education indicates that few services are providing psycho-education with clients with developmental disabilities and trauma. However, psycho-educational efforts on prevention (social-sexuality education) are more common.

4. First Stage Trauma Treatment

Participants all reported that to varying degrees they did offer clients symptom management skills.

5. Trauma Processing

Very few services offered trauma processing therapies.

Discussion

It is evident from the environmental scan data that there are enormous gaps in services for clients with developmental disabilities and complex trauma. The biggest gaps appear to be in assessment and trauma processing therapies. Some agencies appear to be able to offer symptom management techniques and strategies.

The scan also revealed a general lack of training in this area, along with a distinct desire to learn more and to receive more information and skills development.

Feedback on Evaluations of Two Day Training

Day 1 Evaluations

Words most often used to describe this training on Day 1 were:

- profound;
- fascinating;
- informative;
- good;
- excellent;
- enlightening;
- intensive; and
- needed

Those from the Developmental Disabilities Services sector appeared to be taking away the key message that it is important to go beyond behaviour, and to look more deeply.

The trauma staff have identified that it is important to use concrete tools and be creative to make the counseling valuable.

All participants appreciated the depth of the content and how current it is. With respect to some of the challenges experienced, it is no surprise that participants felt that it was a lot of information to cover in a short time.

Things that they learned on day 1 and will use, included the following:

- There was certainly a theme that emerged with respect to the desire to have more time in the small groups to share and discuss with each other.

- Participants were pleased to be "grouped together" and wanted more time to connect with their table mates.

- There were many comments about the value and importance of the training and the need to share it more often and more broadly

Day 2 Evaluations

Words most often used to describe this training on Day 2 were:

- informative;

- good;
- excellent;
- enlightening;
- intensive; and
- needed.

Furthermore:

- 96% agreed or strongly agreed that we met all the Learning Objectives; and
- 85% agreed or strongly agreed that the Content and Format was helpful and flowed well.

Of those that disagreed, the majority were from the DS sector, and their thoughts included:

- that the afternoon flowed better than the morning;
- disappointed the section of Vicarious Trauma had to be shortened;
- too rushed, too much information;
- stained to hear speakers and movie; and
- found introduction to DD not necessary (brief would have been better).

The participants indicated that there were certain things that they learned from Day 2, and that they will use in the future. These things included:

- how to engage with clients without overwhelming them;
- importance of consent/capacity discussion;
- awareness, understanding, and recognizing the signs of abuse;
- conscious of words and actions having impact on clients including boundaries;
- networking and support, self-care; and
- tool box, stress thermometer, handouts, practical tools to use with clients with DD.

Ninety-six percent of the participants agreed or strongly agreed with the three questions in the "speaker review" area of the evaluation, and also that the speakers were clear in their presentation, knowledgeable about the subjects, and responsive to issues that came up.

Other general comments and questions included the following:

- Lori was a great speaker and kept their interest, liked that fact she incorporated real life experiences with concrete examples
- many appreciated the time and effort it took to put this together and thanked all the presenters, but felt that there was too much information for 2 days, too

rushed. This rushing takes away from the excellent material. Consider cutting some things out.

- missed breaks leave people un-focused even if the material is good.
- needed to be more interactive in the afternoon to stay focused
- upset vicarious trauma was rushed/shortened
- don't want presenters to just read power point slides but comment on them, gives examples, experiences instead, we can read slides ourselves later.
- liked the group work and would like more of it but in smaller groups with less people attending
- visuals were hard to see/hear at back of room but many enjoyed "Sabine" video
- needed more time to connect with table mates about their services
- liked that we provided opportunities for people to ask questions but acknowledged this took away from presenters time
- liked the "tool box & stress thermometer" and handouts to use later
- will there be additional training?
- Will it be specific to their area?

PART VI – CONCLUSION AND KEY RECOMMENDATIONS

This section of the report provides some concluding comments as well as recommendations for moving the work forward for establishing a continuum of care for persons who are developmentally disabled and traumatized.

1. A trauma informed framework for conceptualizing the range of abuse-related trauma therapeutic needs of developmentally disabled individuals that is understood and broadly accepted in both the developmental disabilities sector and the family violence and trauma services.

2. Development of an integrated network of services that offer the continuum of treatment (See section II of this report). 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 the 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 at trauma services and trauma service workers can work at developmental disabilities sector.

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 conference sessions that would have an educational component and a case presentation component.

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Appendices

Area **Waterloo**
6 groups

Assessment

1. Access to Psychiatrist for dual diagnosis
   2 yes
   4 no (or you have to travel outside the region)

2. Access to a Dual Diagnosis team of professionals
   2 yes
   3 no or limited

3. Access to Trauma informed Therapist who works with people with a DD
   1 yes
   4 no or limited

4. Recognition of symptoms of trauma such a flashbacks and disassociative behaviour by therapist or team members
   4 yes
   1 no

5. Barriers to assessment of trauma for people with a DD in your community.

Lack of knowledge
Waitling lists
Transporation
Services and supports
Funding
Trained professionals
stigma
Medication is focus of psychiatrist
Focus on behaviour

6. Strengths in your community related to trauma assessment and people with a DD

None
DSAC
Home support
Transportation

Psycho-Education

1. Have you had an opportunity to seek trauma services with a client
   5 yes
   1 no

2. If yes, how easy was it to find and access trauma services for a person with a DD.
   - ❑ Easy
   - ❑ Easy to find but hard to access 2
   - ❑ Challenging to find and access 1
   - ❑ Very Challenging 1
   - ❑ Gave up 2

3. The clients you have worked with have been taught about trauma and its effect on their emotional state?
   1 yes
   4 no
   1 unknown

4. Who has provided the psycho-education?

5. The clients you have worked with have had access to meaningful social-sexuality education

6. Who has provided the social sexuality education

1 yes
2 limited
2 no

Working with Families and Communities

1. List training opportunities in your community related to trauma and affects on people with a DD

Today and no others

2. With the consent of the client have you been able to work collaboratively with family members for trauma work?

Benefits:

Support
Trust
comfort

Challenges:

Triggers
Not supportive
Own DD

3. With the consent of the client have you had opportunities to work collaboratively with other support persons?

Benefits:

Challenges:

First Stage Trauma

1. Self-Awareness and positive Identity

Do you feel the person with a DD was treated using a Strength based approach to therapy?

 Yes 4 No 2 mixed

Do you feel the person with a DD had their experiences redefined to view behaviour as an adaptation to trauma rather than seen as inadequacies.

 1Yes 4No 1 mixed

2. Developing a respectful therapeutic alliance.

On a scale of 1-10 how much respect has been afforded the client with a DD during trauma treatment. For example

- Addressing people directly
- Using their name
- Involving them in decisions
- Respecting consent
- Respecting Privacy

And overall scale of 1-10
4 10

3. Affect regulation and tolerance

Circle those that have been used with clients:

a. Providing a safe environment 2
b. Calming techniques 2
c. Breathing Exercise
d. Self-soothing techniques
e. Distraction 2
f. Grounding during flashbacks and disassociation

4 said all

Trauma Processing

Have any of your client's with a DD and Trauma had access to any of the following Processing Therapies?

1. Cognitive Behaviour Processing
   □ 3Yes □ No

Where or with whom?

2. EMDR- Eye Movement Desensitization and Reprocessing Therapy
   □ Yes □ 6No

Where or with whom?

3. Neurofeedback
   □ Yes □ 6No

Where and with whom?

4. Body Therapies
   □ 1Yes □ 5No

Where and with whom?

Environmental Scan Summary

Area **Wellington**
10 groups

Assessment

7. Access to Psychiatrist for dual diagnosis
   10 yes and 1 No (some at table could and some at table could not)
   1 mixed depending on location

8. Access to a Dual Diagnosis team of professionals
   7 yes
   3 no
   1 mixed

9. Access to Trauma informed Therapist who works with people with a DD
   7 no
   3 yes
   1 mixed
10. Recognition of symptoms of trauma such a flashbacks and disassociative behaviour by therapist or team members
   6 yes
   5 no
   1 mixed pockets of service only

11. Barriers to assessment of trauma for people with a DD in your community.

Waitlist
Few services
Lacking in knowledge
Trauma recognization
Lack of expertise
Lack of assessments
Communication when language barrier exists
Social stigma and judgement
Blame disability
Lack of alternatives
Rural areas face greater challenges
Unable to identify triggers
No consistency of care providers
Interpreters required
Transportation
Funding

12. Strengths in your community related to trauma assessment and people with a DD

Police and hospital
Drop ins
Open groups
Trellis
Gateway
Oaklands CWSNC

Family Health team
Staff wiliness to learn
Caring community

Psycho-Education

7. Have you had an opportunity to seek trauma services with a client

8 yes, 1 no and 1 mixed

8. If yes, how easy was it to find and access trauma services for a person with a DD.
   - ❑ Easy
   - ❑ Easy to find but hard to access-2
   - ❑ Challenging to find and access- 6
   - ❑ Very Challenging-2
   - ❑ Gave up

9. The clients you have worked with have been taught about trauma and its effect on their emotional state?
   5 yes
   2 no
   3 mixed

10. Who has provided the psycho-education?

Front line and wide variety of services

11. The clients you have worked with have had access to meaningful social-sexuality education
    Yes 3
    No 4
    2 mixed

12. Who has provided the social sexuality education

New team and curriculum that is being rolled out in Wellington is improving access to sexuality education

Bib

Working with Families and Communities

4. List training opportunities in your community related to trauma and affects on people with a DD

10 respondents said today was there first but hoping for more

5. With the consent of the client have you been able to work collaboratively with family members for trauma work?

mixed
Benefits:
Better understanding of hx
Different view points
trust

Challenges:

Consent
Offenders
Family as offenders
Families want to forget past trauma
Limited consistency
Families already overwhelmed

6. With the consent of the client have you had opportunities to work collaboratively with other support persons?

Mixed
Benefits:
Knowledge of resources
Hx
Increasing access to services but reluctance to get involved past referrals
Team work
Better support

Challenges:
Confusion of tasks and roles
Different mandates
Timing
budgets

First Stage Trauma

4. Self-Awareness and positive Identity

Do you feel the person with a DD was treated using a Strength based approach to therapy?

 6Yes 2No mixed 2 1 unknown

Do you feel the person with a DD had their experiences redefined to view behaviour as an adaptation to trauma rather than seen as inadequacies.

 5Yes 3 No and 2 unknown

5. Developing a respectful therapeutic alliance.

On a scale of 1-10 how much respect has been afforded the client with a DD during trauma treatment. For example

- Addressing people directly
- Using their name
- Involving them in decisions
- Respecting consent
- Respecting Privacy

And overall scale of 1-10
ranged from 1-10 with 7 on average and privacy being the least respected

6. Affect regulation and tolerance

Circle those that have been used with clients:

a. Providing a safe environment
b. Calming techniques
c. Breathing Exercise
d. Self-soothing techniques
e. Distraction
f. Grounding during flashbacks and disassociation

Trauma Processing

Have any of your client's with a DD and Trauma had access to any of the following Processing Therapies?
5 no to all or did not know

5. Cognitive Behaviour Processing
   □ 3Yes □ No 1 mixed

Where or with whom?

6. EMDR- Eye Movement Desensitization and Reprocessing Therapy
   □ 1Yes □ No4

Where or with whom?

7. Neurofeedback
   □ 2Yes □ 4No

Where and with whom?

8. Body Therapies
   □ Yes □ all No

Where and with whom?

Environmental Scan Summary

Area **Dufferin**
2

Assessment

13. Access to Psychiatrist for dual diagnosis
    1 yes
    yes to adults and no for children

14. Access to a Dual Diagnosis team of professionals
    1 yes
    yes to adults and no for children

15. Access to Trauma informed Therapist who works with people with a DD
    1 yes and no
    limited for adults and No for children

16. Recognition of symptoms of trauma such a flashbacks and disassociative behaviour by therapist or team members
    1 yes
    limited
17. Barriers to assessment of trauma for people with a DD in your community.

Waitlist
Client focused barriers
No barriers b/c no services

18. Strengths in your community related to trauma assessment and people with a DD

None in our area
Have to go to Peel

Psycho-Education

13. Have you had an opportunity to seek trauma services with a client
    2 yes

14. If yes, how easy was it to find and access trauma services for a person with a DD.
    - ❑ Easy
    - ❑ Easy to find but hard to access-1
    - ❑ Challenging to find and access
    - ❑ Very Challenging-1
    - ❑ Gave up

15. The clients you have worked with have been taught about trauma and its effect on their emotional state?
    No but its been tried

16. Who has provided the psycho-education?

17. The clients you have worked with have had access to meaningful social-sexuality education
    Yes and no
    In house training at KP

18. Who has provided the social sexuality education

Working with Families and Communities

7. List training opportunities in your community related to trauma and affects on people with a DD

Today for both

8. With the consent of the client have you been able to work collaboratively with family members for trauma work?

Yes for 1

Benefits:
Recognize the benefits of trauma work

Challenges:
Cultural belief and barriers
Ability to give consent is difficult

9. With the consent of the client have you had opportunities to work collaboratively with other support persons?

Benefits:

Challenges:

First Stage Trauma

7. Self-Awareness and positive Identity

Do you feel the person with a DD was treated using a Strength based approach to therapy?

□ 1Yes □ No

1 na

Do you feel the person with a DD had their experiences redefined to view behaviour as an adaptation to trauma rather than seen as inadequacies.

□ 1Yes □ 1No

8. Developing a respectful therapeutic alliance.

On a scale of 1-10 how much respect has been afforded the client with a DD during trauma treatment. For example

- ❑ Addressing people directly 10
- ❑ Using their name 10
- ❑ Involving them in decisions 7
- ❑ Respecting consent 10
- ❑ Respecting Privacy 10

And overall scale of 1-10

8

9. Affect regulation and tolerance

Circle those that have been used with clients:

a. Providing a safe environment 1
b. Calming techniques 2
c. Breathing Exercise 2
d. Self-soothing techniques 0
e. Distraction 1
f. Grounding during flashbacks and disassociation 1

Trauma Processing

Have any of your client's with a DD and Trauma had access to any of the following Processing Therapies?

9. Cognitive Behaviour Processing
   □ Yes □ 2 No

Where or with whom?

10. EMDR- Eye Movement Desensitization and Reprocessing Therapy
    □ 1 Yes □ 1 No

Where or with whom?

11. Neurofeedback
    □ Yes □ 2 No

Where and with whom?

12. Body Therapies
    □ 1Yes □ No

Where and with whom?
An OT

Environmental Scan Summary

Area **Halton**
6 groups responded

Assessment

19. Access to Psychiatrist for dual diagnosis
    4 yes
    2 no
    1 na

20. Access to a Dual Diagnosis team of professionals
    4 yes
    2 no

21. Access to Trauma informed Therapist who works with people with a DD
    2 yes
    3 no
    2 limited
22. Recognition of symptoms of trauma such a flashbacks and disassociative behaviour by therapist or team members
    3 yes
    2 no

23. Barriers to assessment of trauma for people with a DD in your community.

Communication
Waiting lists
Lack of awareness
Diagnostic overshadowing
Lack of hx
Communication between agencies
funding

24. Strengths in your community related to trauma assessment and people with a DD
Supports but no connections
More info for front line vs EDs

Psycho-Education

19. Have you had an opportunity to seek trauma services with a client
    3 yes
    3 no
    1 mixed

20. If yes, how easy was it to find and access trauma services for a person with a DD.
    - ❑ Easy
    - ❑ Easy to find but hard to access-2
    - ❑ Challenging to find and access-1
    - ❑ Very Challenging
    - ❑ Gave up-1

21. The clients you have worked with have been taught about trauma and its effect on their emotional state?
    6 no

22. Who has provided the psycho-education?

23. The clients you have worked with have had access to meaningful social-sexuality education

24. Who has provided the social sexuality education

1 yes
3 no
1 mixed

Working with Families and Communities

10. List training opportunities in your community related to trauma and affects on people with a DD

All 6 were none or today oly

11. With the consent of the client have you been able to work collaboratively with family members for trauma work?

Benefits:
Natural support

Challenges:
Part of the trauma
Family unable to reframe their thinking
Cultural influences

12. With the consent of the client have you had opportunities to work collaboratively with other support persons?

No responses

Benefits:

Challenges:

First Stage Trauma

10. Self-Awareness and positive Identity

Do you feel the person with a DD was treated using a Strength based approach to therapy?

 1Yes 1No 4unknown

Do you feel the person with a DD had their experiences redefined to view behaviour as an adaptation to trauma rather than seen as inadequacies.

 3Yes 1No

11. Developing a respectful therapeutic alliance.

On a scale of 1-10 how much respect has been afforded the client with a DD during trauma treatment. For example

- Addressing people directly
- Using their name
- Involving them in decisions
- Respecting consent
- Respecting Privacy

And overall scale of 1-10
Varied
One group rated it 1 while the rest between 5-9

12. Affect regulation and tolerance

Circle those that have been used with clients:

a. Providing a safe environment 3
b. Calming techniques 2
c. Breathing Exercise 3
d. Self-soothing techniques 1
e. Distraction 1
f. Grounding during flashbacks and disassociation 1

Trauma Processing

Have any of your client's with a DD and Trauma had access to any of the following Processing Therapies?
1 no to all
1 unanswered

13. Cognitive Behaviour Processing
    □ 3Yes □ 1No

Where or with whom?

14. EMDR- Eye Movement Desensitization and Reprocessing Therapy
    □ 1Yes □ 2No

Where or with whom?

15. Neurofeedback
    □ Yes □ 3No

Where and with whom?

16. Body Therapies
    □ 3Yes □ 1No

Where and with whom? Massage pet and arometherarapy

Environmental Scan Summary

Area **Peel and one TO respondent**
6 groups

Assessment

25. Access to Psychiatrist for dual diagnosis
    5 yes
    not readily
    but its easier for kids
26. Access to a Dual Diagnosis team of professionals
    6yes

27. Access to Trauma informed Therapist who works with people with a DD

    Yes3
    No3
    (trauma informed but not DD informed)
28. Recognition of symptoms of trauma such a flashbacks and disassociative behaviour by therapist or team members
    No2
    Yes3
29. Barriers to assessment of trauma for people with a DD in your community.

Access to trained clinicians
Consultants were limited in time
Wanting to help but feeling a lack of skill set
Clear indications of a trauma
Lack of hx
Priority of tx is masking trauma
Discipline is missing
Behavioural challenges
No LT services
Funding
Education
Awareness
General Access
Waitlist
Nonverbal have no access

30. Strengths in your community related to trauma assessment and people with a DD

collaboration
links
a willingness to learn
Specific services- CAMH/ DD halton peel, Family Services, Trillium, Rape crisis

Psycho-Education

25. Have you had an opportunity to seek trauma services with a client
    Yes3
    No4 (some have and some haven't within a group questionnaire)
26. If yes, how easy was it to find and access trauma services for a person with a DD.
    - ❑ Easy
    - ❑ Easy to find but hard to access 2
    - ❑ Challenging to find and access 1
    - ❑ Very Challenging
    - ❑ Gave up

none

27. The clients you have worked with have been taught about trauma and its effect on their emotional state?
    No 5
    Tried 1

28. Who has provided the psycho-education?

Psychiatrist
Psychologist
OT
Social Work

29. The clients you have worked with have had access to meaningful social-sexuality education
    Yes3
    No3 (or not enough)
    Group split with some having had experience and others no education
30. Who has provided the social sexuality education

KPAs sexuality
CAM-h
Not always meaningful
Kerry's place
Family Services

Working with Families and Communities

13. List training opportunities in your community related to trauma and affects on people with a DD

Today4
none
Video conference with CW
Vicarious trauma
Some agencies provide training for clients and families but none for staff

14. With the consent of the client have you been able to work collaboratively with family members for trauma work?

None3
Yes 1
Benefits:
Continuity
Understanding of behaviour

Challenges:
Would not get anything out of it

15. With the consent of the client have you had opportunities to work collaboratively with other support persons?

None
Yes2
Benefits:

Allows for longer-term support
Builds capacity
Community Partners

Challenges:
Dynamics of relationship
Losing therapeutic rapport
Continuity/ overlap of care
Lack of resources
Generalization
Shared responsibilities

First Stage Trauma

13. Self-Awareness and positive Identity

Do you feel the person with a DD was treated using a Strength based approach to therapy?

□3 Yes □ 2No

na

Do you feel the person with a DD had their experiences redefined to view behaviour as an adaptation to trauma rather than seen as inadequacies.

□ 1Yes □2 No

na2

14. Developing a respectful therapeutic alliance.

On a scale of 1-10 how much respect has been afforded the client with a DD during trauma treatment. For example

- ❑ Addressing people directly
- ❑ Using their name
- ❑ Involving them in decisions
- ❑ Respecting consent
- ❑ Respecting Privacy

And overall scale of 1-10

8

8 or 9

na4

15. Affect regulation and tolerance

Circle those that have been used with clients:

a. Providing a safe environment
b. Calming techniques
c. Breathing Exercise
d. Self-soothing techniques
e. Distraction
f. Grounding during flashbacks and disassociation

Na3

Trauma Processing

Have any of your client's with a DD and Trauma had access to any of the following Processing Therapies? None for all3

17. Cognitive Behaviour Processing
    □ 3Yes □ No

Where or with whom?

18. EMDR- Eye Movement Desensitization and Reprocessing Therapy
    □ Yes □ 6No

Where or with whom?

19. Neurofeedback
    □ Yes □ 6No

Where and with whom?

20. Body Therapies
    □ Yes □ 6No

Where and with whom?