

An Exploration of Trauma in Children and Youth with Intellectual Disabilities

by

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Dedication

A sense of responsibility towards all others also means that both as individuals and as a society of individuals, we have a duty to care for each member of our society. This is true irrespective of their physical capacity or of their capacity for mental reflection. Just like ourselves, such people have a right to happiness and to avoid suffering. We must therefore avoid, at all cost, the urge to shut away those who are grievously afflicted as if they were a burden. The same goes for those who are diseased or marginalized. To push them away would be to heap suffering on suffering. If we ourselves were in the same condition, we would look to others for help. We need, therefore, to ensure that the sick and afflicted person never feels helpless, rejected or unprotected. Indeed, the affection we show to such people is, in my opinion, the measure of our spiritual health, but at the level of the individual and at that of society.

His Holiness the Dalai Lama,

Ancient Wisdom, Modern World: Ethics for the New Millennium, at p. 176

As cited in McCallum, 2001

Abstract

Children and youth with intellectual disabilities (ID) and their families are not currently receiving appropriate therapeutic support to meet their mental health needs. This study looks at the concept of intellectual disability and the impact it has on the family system, siblings and the child with the intellectual disability as whole. The current research demonstrates that children and youth with support needs are at increased vulnerability to experience victimization, social exclusion and abuse in comparison to their typically developing peers. This can lead to early-life exposures to adversities putting them at greater risk for mental illness, post-traumatic stress disorder and physical health concerns later in life. The review of the literature determined this population is underrepresented in the research on adverse childhood experiences (ACEs), which was transformative in raising awareness of the importance trauma-informed practice in the field of mental health. Better data on ACEs among youth with disabilities are needed to clarify the significance of ACEs among this vulnerable group and to identify opportunities for prevention, protection and trauma-informed clinical therapeutic counselling for this population. The results of this study indicate that more research is needed to identify how adverse childhood experiences affect children and youth with support needs, how they communicate these experiences (i.e. internalizing/externalizing) and evidence-based therapeutic treatment options for post-traumatic stress disorder among the disability population. This study concludes with an overview and discussion of the World Health Organizations (WHO) recommendations of cognitive-behavioural therapy (CBT) and eye movement desensitization and reprocessing (EMDR) for treatment of post-traumatic stress disorder in adolescents, noting that future research is required on methods of adapting these treatments for children and youth with support needs.

Chapter 1

An Exploration of Trauma in Children and Youth with Intellectual Disabilities

Children and youth with intellectual disabilities experience the world differently than their peers. From birth, they face challenges and obstacles that the rest of us may take for granted, including difficulties at school, social and emotional challenges and increased vulnerability. Young children may go through their early years wondering why they are different and have problems keeping up in class, which can potentially lead to low self-esteem, self-worth and behavioural challenges prior to receiving a diagnosis. All of these experiences can be detrimental to a young persons' mental health, especially as they grow into their teenage years.

It would be presumptuous to assume that all children and youth with support needs grow up in homes without the stressors that many families in western society face such as financial burdens, parental and relationship distress, physical and emotions abuse and substance misuse concerns. These additional factors within a family system can lead to adverse childhood experiences (ACEs) in children and youth leading to the experience of trauma and increased health concerns later on in life. There has been significant research conducted on ACEs which has led to systemic changes and a focus on trauma-informed care within the field of social services. Children and youth with support needs have not been included in past research and may have increased vulnerability and additional risk-factors due to deficits in intellectual and adaptive functioning.

In order to understand the current needs of children and youth with diverse abilities, it is important to look to the past as it can be helpful in setting the stage for the future by providing insight, awareness and learning opportunities. The history and treatment of individuals with intellectual disabilities in British Columbia is important as it demonstrates learning and growth

that has happened within society but it also highlights the stigma, challenges and barriers that young people with support need and their families face on a daily basis.

The Beginning

Individuals with developmental disabilities have existed throughout human history and they make up a small part of every culture in the world (Parmenter, 2011). They are a minority and therefore have been stigmatized, abused, exploited and treated as less than human. In the early 19th century, disabled people were considered mentally ill or insane and the terms idiocy, imbecility and epilepsy were a few of the many terms that contributed to the definition of insanity in the early 1900s (Adolph, 1996).

In addition to being labelled, individuals with noticeable physical “defects” were paraded around in front of crowds under the labels of “wild people” and “pinheads” (Clarke, 2004). Children with Down syndrome were photographed and labelled as defective. Parents were shamed for having “defective” children and were not provided with any support while at the same time were labelled as ill-equipped to provide the supervision that their “mentally deficient” children needed. Authorities demonized these children further by claiming that the children were at fault for the declining physical and mental health of their parents (Clarke, 2004). According to Clarke, the commissioners stated in their report that, “the care of idiots and imbeciles in the average home is too great a burden and too often results in break-downs of other members of the family” (p. 6). It was this type of thinking that led to parents relenting to the pressure put on them by the government of BC to institutionalize their children.

The Woodlands Institute

The Woodlands Institute or Provincial Hospital for the Insane (PHI) first opened its doors on May 17, 1878 in New Westminster, BC. It was the first of its kind in British Columbia. The

creation of this institution was the result of the jails in Victoria being overwhelmed with both criminals and “lunatics” in the late 1800s (Adolf, 1996).

By 1880, the Grand Jury reported that the building was not suitable for the 48 residents and they were understaffed. Interestingly, a letter was written to the newspaper at this time calling for an investigation of the institution:

...it is true that chains and shackles are not habitually used, but the unfortunate inmates are confined in cells without being able to see anything but bare walls around them...All day long without occupation...these poor creatures are condemned to a life of inaction. Their exercise is taken by being driven into a yard...there they are condemned to remain doing nothing (Adolf, 1996).

For the next 116 years, the patients at the Woodlands Institution were victims of a tumultuous systemic failure, which resulted in the abuse of the province’s most vulnerable people. Admittance to Woodlands required a diagnosis of mental retardation for all of its residents, children were admitted by their parents, child welfare legislation, or by provincial mental health and adults were admitted by their caregivers or in accordance with mental-health legislation (Kodar, 2012). For years, children, young adults and adults did not have any control over their lives, and they were not able to make the small decisions we take for granted such as picking a tv show to watch or choosing when or what they wanted to eat. Every decision was made for them and every aspect of the residents’ life was controlled and provided by the individuals who were responsible for running the institution (McCallum, 2001). An institution that promoted education, medical support and treatment turned out to be more of a prison for individuals whose only crime was being born differently than conventional society.

The Woodlands Institution closed its doors in 1996 due to the persistence of community living advocates who continued to lobby for institutions such as Woodlands to be permanently closed (Boei, 2002). Residents were integrated into society and placed into small group homes within the community or they went to live with paid caregivers. The Ministry of Children and Family Development (MCFD) was given the task of resettlement and the responsibility to provide support for children and adults with intellectual disabilities (Friedlander, 2006). While this transition would have been difficult for some, for others it was a sign of freedom and an opportunity to become part of mainstream society. An article by Paul Horn describes the transition for an individual named Janice that that he was caring for at the time:

“I remember her in the car with her hands pressed over her face, squirming and writhing as if in terrible pain. I remember asking her if she was okay, peeling her hands back and seeing a smile as wide as Heaven. I remember thinking to myself that I had seen how pure joy could look” (Horn, 1998).

Systemic Changes

As time progressed and new systemic structures took over the responsibility for children and adults with intellectual disabilities, new programs were formed and new organizations were tasked with supporting these individuals. When Woodlands closed, the B.C. government created two community-based health programs across the province including Health Services for Community Living (HSCL) and a Mental Health Support team. One provided health care services including dental, medical support and at-home nursing, and this program is still active today (Friedlander, 2006).

The Specialized Mental Health Teams had a specific mandate to assess, treat and provide consultation for individuals with intellectual disabilities for a population of 14 years

and older. This program is now known as Developmental Disabilities Mental Health Services (DDMHS), which is run by the Fraser Health Authority. In 2006, this program was serving approximately 12,000 children and adults with dual diagnosis (Intellectual Disability) and mental health concerns (Friedlander, 2006).

In order to receive services from DDMHS an individual under the age of 18 must be referred by a Social Worker (CYSN) and must meet a specific criterion in order to be eligible for services. While this is a step forward, this writer questions whether this service is adequate for the population of individuals with intellectual disabilities who may not have access to services within the Ministry of Children and Family Development (MCFD), or may not meet the criteria of dual diagnosis, which is a requirement of DDMHS. While it is important to have a service like DDMHS that will provide a medicalized method of treatment and behavioural support and consultation, it is equally important to have services in place that can meet the needs of those who may be experiencing social exclusion, emotional troubles or anxiety that accompany having an intellectual disability.

Intellectual Disability

The medical model defines intellectual disability in *The Diagnostic and Statistical Manual of Mental Disorders* as a neurodevelopmental disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits. This can be measured according to severity which may include mild, moderate, severe or profound (American Psychiatric Association, 2013).

Both intellectual and adaptive functioning are measured via standardized testing that is completed by medical professionals including doctors and psychologists. These assessments provide recommendations to other government bodies with the intention of supporting

individuals and families by providing them with specialized services such as access to a CYSN social worker, services from Community Living British Columbia (CLBC) and modified programming within the education system. In my experience, there are not many recommendations provided to support the individual to understand what this diagnosis means for them or their family, or the social stigma or trauma that may be associated with a label of intellectual disability.

It is important to note some concerns around labelling that a diagnosis of intellectual disability may generate. On one hand the label itself provides funding and opportunities for respite, life skills support and access to specialized social groups. The label of an intellectual disability can mark an individual with a stigma that could adversely affect the way they live their life or how they perceive themselves (Scior, Connolly & Williams, 2013). This could potentially lead to the individual feeling isolated, stigmatized and powerless, which could affect their quality of life and an experience of trauma. The Golem effect is also important to consider when discussing diagnosis and labelling a child or youth. In opposition with the Pygmalion effect, which has been known to heighten student learning, the Golem effect can impede learning and produce maladaptive outcomes due to the lowered expectations that are placed on the individual by people of authority (Woods, Floyd & Singh et al., 2019).

Who is Affected by this Problem?

The purpose of this research project is to review the literature to identify if children and youth with intellectual experience increased adverse life experiences in comparison their typically developing peers. It is important to note that the experience of adverse life events does not necessarily mean an individual will experience a trauma response. Additionally, it is necessary to recognize that what may be perceived as traumatic to one individual may not be

traumatic to another (Keelser, 2014). This research project will explore how/if adverse life experiences in individuals with intellectual disabilities contribute to their experience of trauma. It will also look at how individuals with intellectual disabilities are considered in the Adverse Childhood Experiences (ACEs) screening tools as an effective way to assess trauma in individuals with diverse abilities or if this population is underrepresented in this type of measurement tool.

Considering the historical treatment of individuals with intellectual disabilities and the epic systemic failure that ensued, this writer will discuss the results of this research and identify ideas that indicate best practices for supporting individuals with diverse abilities and their families. This may include different methods for individuals and families to learn about the diagnosis, how it may affect their child or young adult and the potential impact it could have on their family as a whole. This will begin by looking at the different paradigms of intellectual disability and the effect on individuals and families. The focus will then shift towards looking at parents raising children with intellectual disabilities and the impact this may have on their mental health. The latter part of the literature review will look at the impact having an intellectual disability has on the individual using a trauma-informed lens.

Chapter three will explore different ideas to better support individuals and families by looking at appropriate counselling support, psychoeducation and group therapy for the individuals and their families to help support them through the early stages of this journey. It will also include recommendations for opportunities for professionals to learn how to build community via workshops, groups and learning opportunities that will provide education and ideas about the importance of using a trauma-informed lens when working with children and youth with support needs.

Where do I Stand on this Problem?

I have spent most of my professional career as an advocate working with vulnerable or at-risk youth. I have worked in both nonprofit and government sectors, learning about the support and services available to young people with intellectual disabilities, youth who have experienced violence, abuse, addiction and social isolation. For the past 4 years my role has been to provide person-centered planning for young people with intellectual and developmental disabilities, autism and Fetal Alcohol Spectrum Disorder (FASD). It is my responsibility to build a relationship with young people and provide them with appropriate connections to services based on their hopes and dreams for the future.

In my role, I have noticed gaps in the system and a lack of services for these vulnerable individuals. I have also observed the social and systemic challenges that these individuals and their families face on a daily basis and the discrimination that occurs in present day society. While there has been a vast improvement since the days the Woodlands Institution closed its doors, there is still such a stigma within society that affects these young people on a daily basis. I have been a witness to the isolation, social exclusion, feelings of anxiety, experiences of depression and despair that they have shared with me about having a disability. These experiences have led me to wonder if all of these combined adversities contribute to an experience of trauma for these young people.

I have also had experiences with family and friends who are struggling to support their child and provide them with a meaningful life. These conversations highlighted that the families of these individuals are also struggling and at times breaking apart due to the amount of stress they are facing in their daily life.

My inspiration for this project came from the observed daily struggles of individuals with diverse abilities and their families. I am curious whether these young people are more vulnerable to adverse life experiences and how this contributes to their everyday life. I am also curious if these young people are underrepresented in the ACE measuring tools and if this is something that may require further study.

My hope is to learn more about the literature on this topic and hopefully provide some recommendations for future study and also to identify gaps in services that may require modification or further funding to adequately support this population of individuals.

Theoretical Framework

This project will utilize a systems theoretical framework with the goal of remaining objective while looking at how the different systems in place may affect the well-being of young people with intellectual disabilities and their families. This writer will then utilize a trauma informed/person-centered approach to gain an understanding of the experiences of youth and families.

My Hopes for this Study

It is my hope that this research project will provide some awareness on the importance of establishing a trauma-informed way of being when working with children and youth with diverse abilities and their families. By looking at the past, we have an opportunity to learn how to create positive, meaningful change for the future and ensure that the abuse that individuals with disabilities have suffered in the past never occurs again. Although a lot of progress has been made, I feel that there continue to be gaps in the current systems, specifically for mental health concerns related to adverse life experiences and trauma that children and youth with disabilities continue to experience. The current systems leave a gap for children and youth with support

needs and their families to obtain adequate mental health support, limiting the quality of their lives.

In my experience, the current supports in place for children and youth with diverse abilities focus on providing medication and behavioural interventions as an initial course of treatment. This type of response may be appropriate for some however, in my current role supporting individuals with diverse abilities I have noticed that there is a need for other types of support that create space for a young person to talk about their life experience, debrief about their frustrations and have a safe outlet to talk about their mental health concerns with a professional.

It is true that regular talk therapy may not be as effective with every individual who has been diagnosed with an intellectual disability due to not being able to cognitively process this type of intervention. However, with appropriate training I feel that it would be possible to modify therapeutic interventions that would be beneficial for individuals with intellectual disabilities. Therapeutic intervention is built on rapport and a therapeutic alliance with the client, and this can be done with most individuals by using a trauma-informed, person-centered approach and creative modalities.

Chapter 2 Literature Review

Systemic Maltreatment of Vulnerable Individuals

Individuals with Intellectual Disabilities

The abuse and maltreatment of individuals with intellectual disabilities has a long and horrific history in British Columbia. This abuse has manifested itself in different ways, including physical, emotional and sexual abuse, but it also includes neglect, exploitation, abandonment and sterilization (Rowlands & Amy, 2019). It is difficult to imagine that individuals did not have any rights in Canada until 1970 due to a disability. Prior to this time, they were vulnerable, and unprotected in both childhood and adulthood.

There were no laws in Canada to protect and serve individuals with disabilities before 1970 (Canadian Human Rights Act, RSC 1985, c H-6). Between the years 1870-1930, the BC government dehumanized disabled individuals and children. They were seen as a drain on the system, and as economically “worthless” and a burden on their families (Clarke, 2004). They were not recognized as people. They were classified as “defectives” by medical professionals and as “low- or high-grade defectives” by the City of Vancouver between 1911 and 1917 (Clarke, 2004). These systematic influences had a massive impact on how society viewed people with disabilities and families with disabled children.

The families caring for their children were doing it without support and were also living with the shame that society inflicted on them for having a child with a disability (Clarke, 2004). Children and adults with intellectual and behavioural challenges were labelled as mentally deficient and seen by many as menaces to society, incapable of contributing to society and oftentimes these individuals were labelled as deviants (Thornberry & Olson, 2005). These

stigmas, together with government and social pressure pushed families to institutionalize their children, siblings and relatives (Thornberry & Olson, 2005).

The creation of institutions in BC provided a place for individuals with disabilities to be housed and hidden from society. Families were pressured to institutionalize their children under the guise that it would be the best place for them to become educated, provided with appropriate medical care and to have the social opportunities that they were lacking in mainstream society. The messaging at the time indicated that by institutionalizing their children, families would have the opportunity to have more children, it would give parents a break from the challenges of raising a disabled child and the opportunity to return to the workforce. The segregation would “clean up” society and focus on those who could contribute to the economic and social well-being of the province.

The abuse and maltreatment that occurred within the walls of the Woodlands Institution demonstrated the injustice and horror suffered by a marginalized and vulnerable population (McCallum, 2001). This sparked the beginning of the advocacy that led to the systemic changes and the closure of the institution. The process of integrating the individuals into mainstream society may have created a shift in the general understanding of individuals with disabilities, the reconciliation process and the services that came out of deinstitutionalization. By looking at the past, this writer hopes to understand if the views of conventional society have changed and the impact these changes may have on individuals with disabilities and their families.

Woodlands Institution

The Woodlands Institution was the beginning of the 118 years of institutionalizing individuals with disabilities. However, these individuals were not recognized as having a disability at the time. Instead, they were classified as insane and in 1862 there were 16 different

types of insanity, including idiocy, imbecility and epilepsy. There were also a number of different causes of insanity, including alcohol, drug addiction, heredity, old age, childbirth and domestic worry (Adolph, 1996).

The abuse that occurred within Woodlands and other institutions during the first half of the 20th century included non-consensual sterilization, and physical and sexual abuse. The so-called feeble-minded were a prime target of the eugenics movement as these individuals were thought of as a danger to the community and it was believed that sterilization would lead to the betterment of society (Rowlands & Amy, 2019). Sterilization also prevented pregnancies of those who were sexually abused by their caregivers at institutions (Rowlands & Amy, 2019, McCallum, 2001).

In the *Administrative review of Woodlands School*, it was found that there was extensive physical abuse at the institution. The details found in this report documented hitting, kicking, restraining, isolating, very cold showers and hot baths resulting in burns to the skin, wearing shackles and belt-leash with documented evidence of injury as just a few examples of the physical abuse occurred within the institution (McCallum, 2001). This review also found no evidence that parents and families were notified when an incident involving a resident occurred. There was also evidence of a code of silence among many of the employees working within Woodlands, including those who were not engaged in the abuse. The residents were isolated from society, trapped in a facility that abused them and violated their rights as human beings (McCallum, 2001).

The closure of the Woodlands Institution is a significant milestone in the history of British Columbia. The facility that once housed 1400 individuals closed its doors permanently in

1996 creating space for new perspectives on social inclusion for individuals with disabilities and their participation within conventional society (Friedlander, 2006).

How is Disability Conceptualized?

Defining Disability

The term ‘intellectual disability’ has transformed over time creating barriers, opening doors and impacting those who fall under its classification. Although the term intellectual disability has held a lot of power since its inception, it is a relatively new term that is now being used internationally to describe individuals who meet the DSM-5 criteria for Intellectual Developmental Disorder. According to Schalock (2011), the “increased usage reflects the changed construct of disability, aligns better with current professional practices that focus on functional behaviours and contextual factors” (p. 224). Admittedly, this term is not perfect, however, it is a vast improvement from the terms used historically such as mental retardation and mental deficiency.

The concept of intellectual disability (ID) is a socially constructed term that identifies limitations of individual functioning within a social context (Schalock, 2011). The label itself segregates, disempowers and creates dependency on social institutions for support. This label also provides much needed government funding, support and services to individuals and families making it difficult to reject completely. It is difficult to distinguish whether this label hinders or helps individuals, and perhaps it does both and it is the system that needs to be restructured in order to provide equal opportunities and social inclusion. There are many schools of thought that have considered these questions and have provided context to both sides.

Two of the main models identified have greatly influenced policy and practices at a societal level, which have had significant impacts on individuals with ID and their families. The

medical model and the social model of disability have opposing viewpoints with regard to how the term is defined, how it is understood by society and the impacts this understanding has on the individual.

The Medical Model

The medical model is a classification system that looks at the limitations that disability has on an individual in both intellectual and adaptive functioning in order to provide a diagnosis of intellectual developmental disorder, which is seen as an impairment (Mackenzie, Cologne & Fenech, 2016). This perspective focuses on social stratification by looking at the functional, physiological and cognitive elements of an individual within the Diagnostic and Statistical Manual of Mental Disorders (DSM) and grouping them according to socioeconomic factors. This model operates from a top-down perspective and assumes that a person with identified challenges or differences that cannot be 'cured' or rehabilitated by professionals has a limited ability to participate or contribute to society in a meaningful way (Bunbury, 2019). This perspective can lead to feelings of exclusion, loss of autonomy and a dependence on social institutions at an individual level (Thornberry & Olson, 2005).

In order to meet the diagnostic criteria for intellectual developmental disorder, the onset must occur during the developmental periods (0-18 years) and the individual must have deficits in both intellectual and adaptive functioning (American Psychiatric Association, 2013). These deficits are measured by an individual's inability to meet the socio-cultural standards for personal independence and social responsibility within western culture and are measured via standardized testing through the education and medical systems (Schalock, 2011).

The Social Model of Disability

The social model of disability is a response to the inadequacies of the medical model of disability. It was initiated and influenced by individuals in the 1960s and 1970s by individuals with disabilities as a response to remove the social barriers and promote social inclusion (Bunbury, 2019). The social model advocates for the inclusion of individuals with disabilities by focusing on the idea that society is the cause of exclusion from the means of production such as social norms, roles and not the impairment itself. This perspective disregards the functional, physiological and cognitive elements that the medical model utilizes and instead focuses on the external environmental factors such as social structures and social institutions asserting that disability is socially constructed (Bunbury, 2019).

Disability cannot be seen in a silo as it is a multifaceted socially constructed term. By breaking it down and utilizing an integrated way of explaining intellectual disability, it is possible to encapsulate a greater understanding of intellectual disability and its relationship with society, family and the individual.

The Justice Perspective

The justice perspective of disability promotes and emphasizes that all individuals regardless of a diagnosis of intellectual disability have the same human and legal rights as the rest of the population (Schalock et al., 2018). This perspective protects individuals with disabilities from discrimination and social inequality, which is something that has deeply impacted this population in the past.

The Psychoeducational Perspective

The psychoeducational perspective provides an understanding of intellectual functioning, and psychological and behavioural limitations associated with having an intellectual disability

(Schalock et al., 2018). By addressing the limitations, it provides an opportunity to learn how to adapt to the needs of the individual to ensure that they are successful in their endeavors.

The justice and psychoeducational perspectives used in conjunction with the biomedical and sociocultural perspective can provide a holistic theoretical framework to help understand intellectual disability by organizing and integrating information thereby creating a roadmap to support a greater understanding of individual identity, challenges and experiences (Schalock et al., 2018).

The Impact of Intellectual Disability

The concept of ID has taken many forms and different paradigms have been used to conceptualize what it means to have an intellectual disability. As discussed, these approaches have historically focused on the limitations having an intellectual disability can have on an individual, their family and their experience in the world. The medical model is an example of a dated perspective that focuses solely on disability as an individual health problem with a biological cause (Hogan, 2019). More recently, these models have shifted and are focusing more on human potential, self-determination and social inclusion. Although a paradigm shift towards inclusivity has started to provide more opportunities for adolescents and their families within their communities, there is much more work that needs to be done to empower, support and provide opportunities to include youth with diverse abilities and their families within British Columbia.

Raising Children with Intellectual Disability

Raising a child with an intellectual disability is associated with higher levels of stress, anxiety, depression and marital challenges (Hayes & Watson, 2013). Additional emotional distress has been associated with receiving the initial diagnosis of a disability, to searching for

specialized resources and supports (Diare, Munyon, Carlson, Kimenmia & Mitcham, 2011), to the perceived stigma and isolation that may come with having a child with a disability (Robinson, Hastings, Weiss, Pagavathsing & Lunskey, 2017). There may also be increased financial burdens associated with a disability diagnosis, including the cost of the assessment itself, behavioural supports and the costs of additional supports, which may contribute to increased stress and anxiety.

There are many factors that contribute to additional stressors within the family system beginning with the initial diagnosis and type of disability, social & community support, levels of familial support and the impact on siblings of children with disabilities. This section will explore and identify both internal and external support needs of families with children who have a disability to provide some insight on how to increase the systems of support for families with the hope to decrease the level of distress within the family system.

Family System

Parental emotional distress that leads to feelings of anxiety and depression can have an impact on the entire family unit, which may contribute to instability within the family system. Increased distress within the family unit may prevent a return to homeostasis following the introduction of a stressor (e.g. child's behaviour) by engaging in their regular coping strategies (Hayes & Watson, 2013). Additionally, research suggests that parental distress also impacts parenting behaviour, which consequently contributes to child behaviour problems (Sanner & Neece, 2018) thereby continuing the cycle of distress. It has been suggested that parents with high levels of stress may perceive their child as more difficult and as a result may lack warmth and responsiveness towards their child (Sanner & Neece, 2018). These types of reactions could

lead to a child feeling unloved and disconnected from their parent and may contribute to a state of dysregulation.

From this perspective, it is important that parents of special needs children have access to support that will provide them with strategies to cope with the additional stressors, build community to combat feelings of isolation, and learn self-compassion & acceptance to support their ability to maintain a healthy family unit. Early intervention would ideally begin at the time of diagnosis or earlier to allow parents the space and time to process new information in a safe environment.

Parental Distress

Parents who are raising children with intellectual disabilities have higher levels of parental stress in comparison to parents of typically developing children (Sanner & Neece, 2018). Stress can be defined as a person's emotional or behavioural response to an unpleasant event in which the level of stress negatively affects the individual's behaviour and functioning (Woodman, Mawdsley & Hauser-Cram, 2015). As the parental role is not considered an event, it can be assumed that parents of children with special needs may be living in a constant state of distress. This may be particularly true for mothers of children with disabilities as nearly two-thirds experience significantly elevated stress levels (Lindo, Kliemann, Combes & Frank, 2016). Elevated stress levels can be attributed to the greater responsibilities that are associated with having a child with a diverse ability including; greater financial responsibilities, maladaptive behaviours, feelings of social isolation, concern about lifelong care and in some cases physical burdens.

The diagnosis of a disability has an impact on the entire family system. Parents of the child may experience a sense of relief in knowing that their suspicions were confirmed. They

may also experience feelings of grief, sadness and disappointment as they adapt to this new information and explore acceptance and next steps. As they process this new information, parents may experience high levels of emotional distress related to the diagnosis of a disability for their child and their concerns for the future. This distress can often take shape in the form of anxiety, depression or marital discord (Hayes & Watson, 2013).

The type of disability can play a role in the amount of stress a family experiences as the needs of children with disabilities and their families are dependent on the particular features of the disability (Vanegas & Abdelrahim, 2016). This may be due to the associated behavioural phenotypes, which are considered to be the expressions of behaviours associated with a diagnostic label such as intelligence, social skills and agreeableness (Hayes & Watson, 2013). Children with disabilities have increased difficulty with self-regulation of their emotions and behaviours, which can contribute to the escalation of distress within the family system. According to Woodman, Mawdsley & Hauser-Cram (2014), “the prevalence of emotional and behavioural problems is estimated to be 3-7 times higher in children with intellectual disabilities than typically developing youth” (p.265).

Currently, in order for a child or youth to qualify for financial, social and educational support in British Columbia they must have a DSM diagnosis of an intellectual disability or impairment, which means according to the DSM they must have deficits in both intellectual and adaptive functioning. A formal diagnosis can be experienced by adolescents as exclusionary and segregating. According to Merrells, Buchanan & Waters (2019), children and youth with intellectual disabilities have experiences of being seen as different. The lack of understanding within the community can lead to social humiliation, bullying and employment rejection:

...She doesn't understand how, where we're coming from because she hasn't got a disability, it's hard to say what we feel like...And we always feel left out and...it was really really hard to handle and I just completely shut down and felt like killing myself and I said, 'Nuh, can't handle any more (Merrells et al., 2019).

The experiences of individuals with intellectual disabilities feeling left out is concerning and may result in mental health concerns. The awareness of segregation from individuals without an ID diagnosis can be seen as a result of the impact of the stigma that continues to exist within society (Scior, Connolly & Williams, 2013).

Family Support

The challenges of parenting children with disabilities can affect the relationship between the parents causing distress and feelings of isolation. Parents who are raising a child with a disability experience caregiving demands that far exceed those who are parenting typical developing children. These additional needs can include time, money, employment limitations and an inability to participate in recreational activities (Goudie, Hall, Narcisse & Kuo, 2014), and can contribute to a strain on the marital relationship.

For families who are struggling financially, caring for a child with a disability may cause an even greater financial burden thereby increasing marital stress (Daire, Munyon, Carlson, Kimemia & Mitcham, 2011). The need for specialized programs and additional therapies that a child may require or benefit from may not be covered by medical or extended benefits (e.g. speech, occupational, physical therapies, etc.) and may require additional private funding that the parents would be responsible to finance. As the programs may be expensive, it is probable that the financial challenges would contribute to added marital distress.

The inability for both partners to work full-time due to increased care needs or behavioural challenges may require one parent to terminate their employment to take care of their child on a full-time basis. The correlation between parents of children with disabilities and poor financial status indicated that 25% to 30% of families have to cut back work hours or stop working entirely to take care of their child (Goodie et al., 2014). The decision to decrease from a double income to a single income so that one parent can stay home to care for their child would be a tough decision for both parents. A parent may also choose to work evening shifts if the opportunity is available. This would allow them to continue to contribute an income but may cause additional stress due to a lack of sleep, missed opportunities to connect with their partner or friends and lack of time for self-care. The lack of social connections and financial stress are associated with high psychological stress in caregivers, which may contribute to less responsive, warm, and affectionate parenting, increasing child behavioral problems (Sanner & Neece, 2018).

Siblings

Living with a disabled individual in the family home can lead to substantial changes and may require additional support and resources. A family systems perspective considers how the family functions as a system and as an emotional unit (Caliendo, Lanzara, Vetri, Roccella, Marotta, Russo, Cerroni & Precenzano, 2020). As such, the relationships and problems of any member affects the other members including siblings. One of the elements that can affect the personal and social lives of the family members is the disability of one family member (Shojaee & Alizadeh, 2019). Looking at sibling relationships from a systems framework implies that the sibling of an individual with a disability is affected by the nature of being a member of the family and could be more affected by their position of having the longest relationship with their sibling (Luijkx et al., 2016).

Siblings are often the longest standing relationship within a family, outlasting relationships with both parents and peers. The sibling relationship can take on more of a hierarchical form within a family as the sibling with the disability may be more reliant on their sibling for emotional support (Avieli, Band-Winterstein & Bergman, 2019). The sibling without the disability may experience increased pressure to take on a caregiving role early in the relationship to provide relief for their parents or caregivers, which may continue throughout their lives.

It is common for siblings to take on a caregiving role for their siblings and some adopt the role of primary caregiver once their parents are unable to continue to care for their child (Avieli et al. 2019). This may include providing personal care, ensuring adequate living arrangements and taking on the financial responsibility for their siblings. The added responsibility may be due to the pressures of family obligation or the positive relationship they have with their sibling. Nevertheless, the quality of life of the sibling caregiver may be affected as a result of their increased responsibility including the impact it has on their personal and professional goals as well as their relationship status over the course of their life.

Along with being positioned as their parents' successors with regards to providing care for their sibling, the sibling without the disability may also experience conflicting emotions and increased stressors related to their disabled sibling. The type of stressors and sibling relationship may differ depending on the type of disability (Roper, Allred, Mandelco, Freeborn & Dyches, 2014) and can originate from family problems as well as behavioural and social issues experienced within the family system.

Siblings may experience increased stressors by witnessing the physical, emotional and social challenges of their sibling. This may include witnessing their sibling being bullied by

peers, embarrassing behaviours in public and learning challenges that may contribute to low self-worth. These observations can lead to heightened emotions and may also result in less attention for the typically developing child (Luijkx, Van der Putten & Vlaskamp, 2016), which may lead to the sibling experiencing conflicting emotions such as fear of death of their sibling, jealousy, anger, loneliness and feelings of isolation (Shojaee & Alizadeh, 2019). The myriad of conflicting emotions may be difficult for a typically-developing sibling to identify and process without support.

Children and youth with a disabled sibling are at increased risk for experiencing psychological disorders such as anxiety and depression than siblings of typically-developing children (Shojaee & Alizadeh, 2019). They may also experience positive impacts such as improved sibling relationship and improved social functioning (Walton, 2016) as they are more likely to show less unkind behaviour, increased empathy, positive sibling interaction (Luijkx, et al, 2016) and increased emotional intelligence. While positive outcomes such as higher empathy, patience and greater social competence (Diener, Anderson, Wright & Dunn, 2015) may provide the typically-developing sibling with some advantages, it is imperative to recognize that they may also contribute to negative impacts such as depression and anxiety (Walton, 2016).

It is important that the sibling has the opportunity to access counselling services and social groups where they feel supported in their experience of growing up with a disabled sibling. It is equally important to find activities that the siblings can participate in together to increase their bond and to access professional supports such as respite care and day activities in order to create moments of private time for the typically developing child (Luijkx, et. al, 2016).

Therapeutic Tools

As previously discussed, caring for a child or being a sibling of someone with a disability is associated with increased stressors and psychological distress. In the past, parents were directed and encouraged to institutionalize their child if they were unable to cope, dividing the family unit, which also led to the experience of significant distress and trauma for both the individual with the disability and their family. The societal stigma of having a child with a disability can be overwhelming, isolating and exhausting, which can lead to dysregulation within the family unit. Some of the challenges associated with parenting a child with a disability may include difficulties in responding to their child's behaviour problems, social barriers and challenges associated with transitional periods including the transition to school or adulthood (Rayan & Ahmad, 2016). According to Maté (2003), "if the parent is stressed, harbors unresolved anxiety or is agitated by unmet emotional needs, the child is likely to find herself in situations of proximate abandonment regardless of the parent's intentions" (p. 212). This can be understood as the parent being physically present but emotionally unavailable for their child, which may lead to increased emotional and behavioural dysregulation in the child. In order to support their child, parents must be emotionally and physically available, which demonstrates the importance of providing psychoeducation, counselling services and having support groups for parents of children with support needs.

There are several tools that can be taught in groups or individually to help support parents. Research indicates that self-compassion is a possible internal coping tool for parents that is linked to effective mental health outcomes (Robinson, Hastings, Weiss, Pagavathsing & Lunskey, 2017). Self-compassion involves non-judgmental understanding of our own pain, inadequacies and failures and connects our experiences to part of the greater human experience

through self-kindness, self-love and forgiveness (Robinson, 2017). Encouraging self-compassion may help families cope better with daily challenges and frustrating experiences. One of the components of self-compassion is mindfulness, which can be defined as non-judgmental, awareness and attention to the present moment while responding with acceptance and nonreactive responses to present thoughts and emotions (Rayan & Ahmad, 2016).

Mindfulness activities can be facilitated in groups, in individual psychotherapy sessions and at home. According to Ryan & Ahmad (2016), there are several formally structured mindfulness-based programs that support pain relief and multiple psychological symptoms that may be helpful for parents experiencing increased stress including: Mindfulness-Based Stress Reduction (MBSR), Acceptance and Commitment Therapy (ACT), Dialectical Behavioural Therapy (DBT) and Mindfulness-Based Cognitive Therapy (MBCT). Mindfulness-based treatments are able to reduce distress by developing self-acceptance towards an individuals' internal and external experiences through their observation of these experiences in a non-judgmental way (Osborn, Girgis, Morse et al., 2018). The focus on acceptance through mindfulness-based treatments as opposed to change may be helpful for parents of children with support needs. It would be beneficial to families if these types of programs were offered as they have the potential to decrease feelings of isolation and distress by increasing coping skills and increasing self-acceptance while providing the opportunity for connection and support. This type of therapy could reduce a child's exposure to adverse childhood experiences and therefore may contribute to the reduction of trauma in a child's life.

Adverse Childhood Experiences and Intellectual Disability

What are Aces?

Adverse childhood experiences or ACEs are the results of a longitudinal study that was conducted in the United States among an adult cohort from 1900-1978 who assessed their childhood adversities retrospectively (Dube, 2020). The results of the study concluded that within that cohort, the generations with one or more early-life adversities were found to be at greater risk for substance misuse, mental health concerns and violence compared to those without ACEs (Dube, 2020). These findings have provided empirical support with regards to intergenerational trauma and the importance of recognizing ACEs among adults to facilitate healing but also to raise awareness about trauma-informed practice in the field of mental health and social services.

As individuals with disabilities were institutionalized and dehumanized at the time this study was conducted, adults with intellectual disabilities were not included and therefore both children and youth are underrepresented in international ACEs research (Vervoort-Schel, Mercera & Wissink, 2018). The result of this underrepresentation is that there is not a lot of research to support children and youth with intellectual disabilities who have adverse childhood experiences, fewer ways to measure these outcomes and inadequate mental health services. Current research indicates that children who are at-risk for or diagnosed with a developmental delay are disproportionately exposed to ACEs (Zeng & Hu, 2018). They are more likely to be exposed to violence, victims of crime and are more likely to be neglected and abused both physically and sexually (Zeng & Hu, 2018).

There have been several reviews since the initial ACEs study that have found that children with disabilities are 3.5 times more likely to experience any physical violence and 2.8

times more likely to experience sexual violence than typically developing children (Masseti, Hughes & Bellis et al., 2020). The exposure to adverse childhood experiences at a young age including institutionalization can lead to many long-term health risks including chronic depression, obesity, heart and liver disease (Van der Kolk, 2014). These statistics do not address the additional systemic barriers individuals with diverse abilities face such as challenges with education, obtaining employment and living independently, which are large milestones for a typically developing young adult.

Behaviour regulation is an important aspect of development for all children and youth and is particularly challenging for individuals with disabilities. In past studies, researchers have concluded that children and adolescents with intellectual disabilities have an increased rate of behavioural problems 3 to 7 times higher than those who are typically developing (Hauser-Cram & Woodman, 2016). The challenges with behavioural regulation can present both internally and externally and can act as a communication tool if seen with a trauma-informed lens.

The consistent occurrence of ACE's in children may have substantial negative effects on internalizing and externalizing problem behaviours and on IQ than limited occurrences (Vervoot-Schel et al., 2018). Internalizing behaviours as a result of ACEs could include feeling afraid, sad, unloved or unwanted. They may also present themselves in the form of headaches, stomachaches or other physical symptoms that are not related to any other physical illness. These internalizing behaviours would be difficult to diagnose as the result of adverse childhood experiences without additional knowledge, a trauma-informed perspective and a person-centered approach. These types of behaviours are often invisible and can be easily overlooked as they are not disruptive to others and therefore have not been studied as consistently as externalizing problems (Houser-Cram & Woodman, 2016).

Externalizing behaviours in children have been linked to include the framework of Disruptive Behaviour Disorders (DBD) in the DSM-5 which includes hyperactivity, conduct problems and aggressive behaviours (Cooper, Hobson & van Goozen, 2020). According to the DSM-5 (American Psychiatric Association, 2013), “disruptive, impulse-control, and conduct disorders include conditions involving problems in self-control of emotions and behaviours” (p. 461). This category includes the diagnosis of Oppositional Defiant Disorder, Intermittent Explosive Disorder, Conduct Disorder, Antisocial Personality Disorder, Kleptomania (American Psychiatric Association, 2013). Although Attention-Deficit/Hyperactivity Disorder falls into the category of Neurodevelopmental disorders, it also has a diagnostic criterion of externalizing behaviours. With so many diagnostic options, these young people may be easily over-diagnosed either due to their disability, which could lead to them being underdiagnosed and receiving inadequate interventions based on their externalizing behaviours being diagnosed as a disorder and not considering that it may be a reaction to a traumatic experience (Vervoort-Schel et al., 2018). Children with an intellectual disorder that demonstrate externalizing behaviours have been found to be overrepresented in the child welfare and justice systems (Schuiringa, Nieuwenhuijzen, Orobio de Castro et al., 2017).

Trauma in Individuals with Intellectual Disabilities

Children and youth with intellectual disabilities are more likely to experience traumatic events and negative life events than those without a disability (Mevisen, 2011). This may be due to an increased level of vulnerability, social isolation and victimization that occurs within this population. It could also be related to difficulties with communication, peer and family relationships or community stressors. There are many factors that may contribute to the experience of trauma in children and youth with intellectual disabilities. The concern is that the

increased risk-factors and traumatic experiences of this population are not being identified, acknowledged or appropriately supported within the field of mental health. Children and youth with diverse abilities may not be receiving the support they need and consequently developing post-traumatic stress disorder (Truesdale, Brown, Taggart et al., 2019). In order to create change within a system, it is essential to understand the problem at the micro level and the potential impact it could have at a macro level if changes are not implemented.

Adverse childhood experiences can be loosely defined as experiences causing mental or emotional stress early in life. These experiences can include all forms of physical and emotional mistreatment, neglect, sexual abuse, exploitation, witnessing domestic violence, incarceration parental divorce, alcohol or substance use, or growing up with family members who have substance use disorders (Zeng & Hu, 2018). They can also include stressors such as negative school experiences, feeling disconnected from peers or community, and victimization such as bullying and discrimination.

On a micro level, adverse childhood experiences could also include being unable to communicate, understand or express emotions. Children with extra support needs have an increased likelihood to be exposed to a wider range of adverse life events or traumatic events than their peers and are less likely to be able to communicate or express their emotional state (Vervoort-Schel et al. 2018). Challenges with identifying and communicating emotions can create additional barriers to accessing therapeutic support. This could indicate why individuals with an intellectual disorder are 2-4 times more likely to develop mental health challenges than those without an intellectual delay (Byrne, 2020), potentially contributing to the presence of co-occurring mental health conditions and higher ACE scores among this population.

Increased Vulnerability

Children and youth with diverse abilities are more likely to be victimized, bullied and exploited than those without a disability (Griffin, Fisher, Lane et al., 2019). Having an intellectual disability can impair the level of functioning in several domains. The conceptual domain involves executive functioning, abstract thinking and short-term memory. The social domain includes the perception of social cues in peers and strangers, difficulties with emotional regulation and understanding level of risk in social situations (i.e. manipulation). The practical domain pertains to personal care, money management and daily living tasks (American Psychiatric Association, 2013). Having an intellectual disability increases vulnerability to victimization, bullying and exploitation due to the lack of understanding of what may be happening in the moment or the risk level in certain situations.

In order to provide a clearer understanding of the risk-factors for trauma and the increased susceptibility to develop post-traumatic stress disorder within this population, it is important to understand how children and youth with support needs are at a higher risk for adverse childhood experiences by looking at social inclusion, victimization and diagnostic overshadowing.

Social Exclusion

The desire for friendship and connection is a part of human nature, to feel included creates safety, increases social and emotional support and helps establish community. A lack of social inclusion can have a significant impact on the health and wellbeing of individuals with intellectual disabilities (Wilson, Jaques & Johnson et al., 2017). Feeling socially excluded and devalued within society can result in people becoming segregated, contributing to a negative

sense of self and placing them at risk of negative life experiences (Merrells, Buchanan & Waters, 2019).

The term social inclusion has generally been viewed at a systemic level by ensuring children and youth with support needs are connected to formal supports through agencies, employment programs and the school system. These supports are often time limited and are paid for by families and government funding. They are an important part of skill development, learning how to build positive relationships and increasing recreational opportunities for children and youth but do not provide the natural connections that typically developing children have the opportunities to establish and as a result may not reduce the level of vulnerability or desire meaningful connection.

Victimization

Individuals with intellectual and developmental disabilities are more likely to experience bullying and other types of victimization than individuals without disabilities (Griffin, Fisher, Lane & Morin, 2018). Current research on victimization and exploitation indicates that the risk of sexual abuse or sexual assault or trafficking is estimated to be 4-8 times higher for children and youth with intellectual disabilities when compared to typically developing individuals within the same age range (Reid, 2018). The physical and psychological consequences of being sexually abused or assaulted for individuals with an intellectual disability are similar to the consequences experienced by victims without a disability. The physical effects may include pregnancy, sexually transmitted diseases or other physical injuries. The psychological consequences of sexual assault may result in depression, anxiety, loss of trust, guilt and shame (Reid, 2018). The results of poorer mental health and ability to process traumatic experiences leaves victims with intellectual disabilities at a higher rate of fragility and an increased likelihood of experiencing

mental and physical health challenges later on in life when compared to victims without an intellectual disability (Vervoort-Schel et al., 2018).

There can be a power imbalance between individuals with extra support needs and those without. As a result of increased vulnerability directly related to deficits in intellectual functioning, these individuals may experience victimization in the form of bullying, verbal abuse or violence by their peers, professional caregivers, strangers or family members. Children and youth with diverse abilities are three times more likely to experience violence in their lives than their peers (Vervoort-Schel et al., 2018). It is important to recognize that children and youth with diverse abilities are at increased risk to experience physical abuse or neglect within their own homes and in the community. Additionally, highlighting some of the existing risk factors within a family may create awareness and ideally set the groundwork for prevention programs for families and additional support in the future.

A child or youth with a disability may place additional financial, social, physical or emotional demands on their caregivers (Nazer, 2019). This increased strain along with the need for closer supervision and assistance with daily routines may overwhelm a parent who has limited support. Some of the identified risk-factors for abuse and neglect that are caregiver-related include: socioeconomic status, mental health (substance misuse & interpersonal violence), level of isolation and lower levels of education (Nazer, 2019). This is not an inclusive list and it does not encapsulate all risk factors however, it does demonstrate the increased vulnerability of children and youth with extra support needs within the family home. It is essential to ensure that families have adequate support and the opportunities to engage in mental health services to increase their wellbeing and to reduce risk factors for abuse and neglect.

Diagnostic overshadowing

The lack of mental health support for children and youth with intellectual disabilities is concerning considering their increased vulnerability to adverse childhood experiences as discussed in this paper. This may be a result of diagnostic overshadowing, which attributes the problem behaviours to a comorbid disorder instead of a trauma-related disorder related to adverse childhood experiences and intellectual disability (Vervoort-Schel et al., 2018). The underdiagnoses of trauma could also be due to communication difficulties related to intellectual disability (Byrne, 2020). The population of individuals with intellectual disabilities who have unmet mental health needs is estimated between 1.2 and 27% (Halol, Jobson & Langdon, 2014) and has likely increased in number since 2014. Current research indicates that the prevalence of a psychiatric disorder in individuals with intellectual disabilities is around 2-4 times higher than typically developing counterparts, with the most prevalent conditions being ADHD, mood & anxiety disorders, conduct disorder, schizophrenia, autism spectrum disorder and PTSD (Mevissen, Didden & de Jongh, 2016). It is imperative that professionals working with children and youth with support needs have an increased awareness of the potential for adverse childhood experiences and psychiatric disorders within this population to meet the need for mental health assessment and support. This may require utilizing additional assessment tools to ensure that clients are offered the appropriate treatment to ensure they have similar opportunities for good health and quality of life as those without intellectual disabilities.

Current assessment tools for this population include the Anxiety Disorders Interview Schedule-Children Intellectual Disabilities, PTSD Section (ADIS-C-IDs; Mevissen et al. 2016). This tool assesses PTSD in children and adolescents (aged 6-18 years) with mild to borderline intellectual disabilities by using simplified language and visual cues. The events that the child

has been exposed to are conceptualized on a timeline to support the child with keeping in mind the events that occurred when symptoms are asked for by the clinician (Mevisen et al. 2016). The lack of well-developed questionnaires to assess for symptoms of post-traumatic stress disorder (PTSD) in people with intellectual disabilities has led to the development of the Impact of Event Scale-Intellectual Disabilities (IES-IDs) and the Lancaster and Northgate Trauma Scale (LANTS).

Although these questionnaires have been proven to have had some success with assessing for PTSD symptoms within the population of intellectual disability (Hall, Jobson & Langdon, 2014), further research is required to fully understand the impact of post-traumatic stress disorder on individuals with support needs as well as the implementation of preventative measures and programs.

As previously mentioned, services for children and youth with support needs do exist through Developmental Disabilities Mental Health Services (DDMHS) which is a specialized service that came into existence as a result of the deinstitutionalization of the Woodlands Institute (Friedlander, 2006). Although this program is considered a specialized service, it is also segregating as it limits the services available for children and youth who may not meet the mandate and is limited as it requires a referral from a Child and Youth with Special Needs (CYSN) social worker via the Ministry of Children and Family Development (MCFD). Not all children with support needs are connected to a social worker.

The other government supported option for children and youth is Child and Youth Mental Health (CYMH) services which is also available via MCFD. This program does not consist of therapists who specialize in working with individuals with extra support needs and focuses on a more “at-risk” population. This appears to be a systemic issue that affects children, youth and

families as there seems to be a gap in the system. This writer would support the amalgamation of both services and appropriate training to ensure that all children and youth receive appropriate mental health support regardless of extra support needs as it would make services more accessible. There are difficulties that persist for individuals with support needs in accessing appropriate therapeutic supports. This could be due to communication difficulties that are associated with intellectual disabilities or a lack of appropriately skilled therapists working with this population (Byrne, 2020). As previously mentioned, diagnostic overshadowing may also be a barrier to accessing appropriate therapeutic support. There may also be some confusion around what therapeutic modalities can best support children and youth with support needs due to communication challenges, the intellectual disability and adaptive functioning.

Therapeutic Modalities for Children & Youth with Support Needs

This paper has focused on highlighting how children and youth with support needs are at an increased susceptibility to adverse life experiences and trauma sequelae. Despite their increased risk of exposure to traumatic life events there is a lack of evidence that demonstrates effective treatment options for post-traumatic stress disorder (PTSD) among this population (Truesdale, Brown & Taggart et al., 2018). This may contribute to the lack of understanding, feelings of powerlessness and effective treatment options for therapists working with this population. This next section will look at different treatment options that may be useful for treating young people with support needs who have experienced trauma or those who have been diagnosed with PTSD.

Along with psychotherapy, Mevissen and De Jongh (2010) identified that treatment approaches should also include pharmacological interventions and changes in environment. The two evidence-based modalities for the treatment of PTSD that are recommended by the World

Health Organization (World Health Organization, 2013) for children and adolescents include eye movement desensitization and reprocessing (EMDR) and both individual and group cognitive-behavioural therapy (CBT). The recommendations do not differentiate between typically developing individuals and those with support needs, which may indicate that these modalities may be effective for both populations.

Cognitive Behavioural Therapy (CBT)

Cognitive Behavioural Therapy is a common type of psychotherapy that helps the client become aware of inaccurate or negative thinking patterns by making connections between thoughts and feelings. Some of the key elements of CBT treatment can include psychoeducation, reassessment of problematic meanings, retrieving and changing memories and discerning between trauma and the present (Byrne, 2020). Children and youth who are diagnosed with a mild to borderline intellectual disability (MBID) may be effectively treated with trauma-informed CBT with the provision that the intervention is adapted to the cognitive abilities of the individuals (Schuiringa et al., 2016). The individual should be able to engage in CBT if they are able to accurately distinguish between the triggering event, thoughts and emotions and recognize the connection between events and emotional experiences (Byrne, 2020). The approach taken by the clinician should be person-centered and tailored to the client and at a pace that the person can cope with (Truesdale, 2018). The CBT approach is largely goal oriented and problem-focused which is why it is imperative to maintain a person-centered approach with this type of therapy to ensure that the modality stays true to the individual's goals, especially when working with a population with increased vulnerability. A clinician would need to be aware of the individual's internal dialogue and ensure that the client does not feel that they are unable to comprehend the

material. The CBT techniques would need to be adapted to ensure accessibility, and this may mean that a support person needs to be included in the therapeutic process.

The process of adapted CBT may begin with building a therapeutic alliance with the client and ensuring they feel safe in the environment in which the therapy is taking place. The next step may focus on psychoeducation to help normalize the trauma response for the individual. It may also help to use a metaphor to explain a simplified model of PTSD. During an intervention by (Carrigan & Allez, 2017), the clinician used the metaphor of a kitchen cupboard to explain the brain to the client and identified the pots and pans that have not been stacked properly and keep falling out as the trauma memories. This metaphor was used to help the client with support needs make sense of his symptoms and is a good example of being creative and person-centered with a client. The next step would be to use cognitive restructuring to modify the client's belief that they are to blame for what happened to them and carefully use Socratic questioning to help the client realize that they are not responsible for what happened to them (Carrigan & Allez, 2017). The clinician may use imaginal reliving of the event if they deem it would be helpful and support the client to disclose the trauma to loved ones if appropriate. According to Byrne (2020), "dismantling studies regarding prolonged exposure therapy have found that both imaginal and in vivo exposure are key in successful treatments" (p. 2).

There are very few studies that have explored trauma-informed cognitive behavioural therapy and have found success with this method. It may be more effective in a group environment as this would provide the opportunity for participants to have peer interactions and support and it would also be more cost-effective in the long run. Results of a pilot study using trauma-focused cognitive-behaviour therapy for people with intellectual disabilities in groups

found that participants felt listened to and enjoyed knowing they were not alone (Kroese, Willott & Taylor et al., 2016).

The studies conducted were varied in their results and it was noted that little research to date has looked at what changes should be made for CBT approaches with regards to PTSD in individuals with intellectual disabilities (Byrne, 2018). The trauma-focused group intervention found some success in achieving the objective of decreasing PTSD symptoms and alleviating distress (Kroese et al., 2016). There were also favorable results by using exposure therapy where imaginal and in vivo exposure were combined and the client reported no further distress after 25 sessions combined with homework. The anger outbursts and hypervigilance decreased (Mevisen, Didden & de Jongh, 2016). Further research is needed to provide suitable adaptations to this modality and to measure its effectiveness with children and youth with support needs.

Eye Movement Desensitization and Reprocessing (EMDR)

Individuals with trauma may benefit from a therapy that does not involve talking in detail about the trauma. EMDR may be a helpful therapy for children and youth with support needs as it takes a bottom-up approach as opposed to a top-down processing approach and does not involve talk therapy, which uses a cognitive approach to treatment. Using this modality involves processing the trauma on a physiological level which may allow for new associations, insights or emotions to emerge (Shapiro & Forrest, 2016). This model is guided by the Adaptive Information Processing Model which asserts that reprocessing connects unprocessed traumatic memories to adaptively processed memories of experience (Byrne, 2018). EMDR treatment involves an 8-phase psychotherapeutic approach to treatment.

The 1st phase of EMDR consists of taking the clients' history, and this can be done with the client, family and support team. This phase results in case conceptualization and the

treatment plan. Phase 2 consists of describing and preparing the client for memory processing. The 3rd phase asks the client to prepare the memory, and the client is asked to focus on the worst part of the memory by thinking about the image, thought, emotion and the somatic sensation (Mevisen, Lievegoed & de Jongh, 2010). The 4th phase involves active reprocessing of the memory; the clinician asks the client to hold the select image in mind while concentrating on bilateral stimulation for around 30 seconds. The client then reports what comes up for them during this time and is guided by the therapist to refocus while paying attention to the stimulus. The 5th phase calls for the client to hold on to a positive belief regarding the event. The 7th phase allows for a positive closure to the session with the client and the 8th phase involves a re-evaluation during future sessions in which the client discusses former targets as a baseline for future interventions (Mevisen et al., 2010).

The process of EMDR is regulated and structured, which allows the client to know what to expect at every session. It is an evidence-based therapeutic method that has been successful at reducing symptoms of PTSD for individuals with intellectual disabilities as it is effective in a nonverbal manner and can be catered to specific populations by using different bilateral stimulation such as visual, auditory or tactile. This could involve the client watching the therapist's hand or a moving light from left to right and back, depending on preference. EMDR has also been proven to be effective using a lower number of sessions in comparison to other therapeutic approaches (Byrne, 2020).

Currently, there are no empirically-based treatment methods for PTSD for people with support needs and not a lot of research on this topic (Mevisen-Renckens & de Jongh, 2010). More research is needed to provide more empirically-based treatments for PTSD in children and youth with support needs. Further research may include somatic methods of healing trauma

(Levine, 2010), therapeutic play and polyvagal theory (Porges & Dana, 2018) and Experiential Unity Theory and Model (Quinn, 2012).

Chapter 3 Analysis and Conclusion

The review of the literature provides some context as to why children and youth with support needs are at an increased risk for adverse childhood experiences than their typically developing peers, and as a result may develop post-traumatic stress disorder. It is evident from the literature that children and youth with diverse abilities have increased vulnerability and face additional challenges in their lives. This study has served to demonstrate the historical impact and dehumanization that individuals with ID faced in British Columbia by taking a closer look at the Woodlands Institution, and the power it held over its residents and families. It is important to look to the past to provide insight and awareness so that the same mistakes are not repeated in the future.

The shift towards integration and deinstitutionalization over the past twenty-five years has increased self-determination for the disability population but has also created a need for external support for individuals and families as a result of these changes. The impact of having a child with disability affects the family system as a whole and as a result may require outside support. Types of support may include increasing services aimed at reducing parental and sibling distress by developing support groups and expanding options for individual and group counselling. It may also include supporting social inclusion through advocacy, psychoeducation and peer support opportunities. Additionally, decreasing the financial burden of raising a child extra support needs by increasing government funding options for families such as the disability tax credit, child tax credit or Persons with Disabilities Benefit (PWD) may have a positive impact on the individual and their family.

Children and youth with ID are increasingly vulnerable to victimization, social exclusion and abuse due to deficits in intellectual and adaptive functioning. This has led to increases risk-factors for mental health concerns such as anxiety and depression among this population. The research indicates that individuals with disabilities are more at-risk for diagnostic overshadowing, which attributes the problem behaviours to the disability and not unmet mental health needs (Vervoort-Shel et al., 2018), resulting in the underdiagnoses of trauma and a lack of therapeutic support. There are various assessment tools available such as the ADIS-C-IDs and the LANTS that can support the assessment of PTSD symptoms of children and youth with support needs. Increased assessment tools and the implementation of mental health awareness programs would provide an opportunity for more research increasing awareness on these concerns.

Adverse Childhood Experiences (ACEs)

The research has demonstrated that children and youth with disabilities are at significant greater risk for experiencing adverse experiences. However, the data on this subject is limited and requires more research to identify the long-term consequences of ACEs for children and youth with disabilities in comparison to those without. It may be helpful to assess the household challenges including substance abuse, mental illness, domestic violence, divorce and incarceration within the broader ACEs categories of abuse and neglect to obtain more accurate and current information (Masseti, Hughes & Bellis, 2020). A study of this magnitude could impact systems-level care and services for the disability population and may support the shift in paradigms leading to increased awareness of the significance of impact of trauma as it has done for the non-disability population (Piotrowski, 2020). This new information may support new

models of trauma-informed practice for children and youth with support needs, which may lead the way towards the creation of additional programming.

Increased Training for Mental Health Professionals

As a result of the minimal amount of research on the impact of trauma on children and youth with support needs, there is a lack of understanding around how best to support this population therapeutically. Current therapeutic modalities do not account for intellectual disability and trauma within their framework and as a result current services for this population are limited to Developmental Disabilities Mental Health (DDMHS) and behavioural consultation and intervention, which may not address the direct needs of the client if these concerns are mental health related.

Future research in this area would provide an increased understanding of the mental health needs of children and youth with diverse abilities, which may lead to further development or adaptations of current modalities that are used to treat trauma, anxiety and depression. Increased training and educational opportunities for therapists may alleviate some concerns around therapeutic techniques and increase comfort levels for therapists when working with children and youth with diverse abilities in a therapeutic setting. This could potentially expand access from specialized supports such as DDMHS to a more inclusive model within a child and youth mental health framework (CYMH), increasing access to clinical counselling services and therapeutic support.

Proposed Programs for Families with Children with Support Needs

The literature review highlighted the importance of social inclusion, connection and emotional support for both youth and families. According to family systems theories, resilient family systems can promote individual resilience. The development of resilience in the

individual and therefore the family, is highly dependent on social systems that provide positive support (Sippel, Pietrzak, & Charney, 2015). This can be established by providing opportunities for social connections through support groups for children and youth with support needs, their parents and siblings.

Parent Support Groups

A parent support group could be established on a quarterly basis upon diagnosis. This would provide parents with an opportunity to connect upon the initial diagnosis and maintain contact throughout their child's life if desired. A referral to this type of support group could be obtained by the child's doctor, psychologist or school and may occur online or in person. A facilitator could provide psychoeducation, therapeutic support and coping strategies within the program to reduce distress and increase resilience through mindfulness techniques, acceptance and commitment therapy (ACT) and cognitive-behavioural therapy.

Proposed Programs for Children & Youth with Support Needs and their Siblings

In order to reduce the potential for adverse childhood experience and increase resilience in children and youth with support needs, it is important to provide them with an opportunity to connect with other children their age in a supported setting. This would increase social inclusion and give them the space to identify and communicate their emotions in a healthy environment. In accordance with the theme of increasing resilience in the family system, it is necessary that siblings have an opportunity to be supported. A sibling's support group would provide the space for siblings to connect, learn coping skills and have an opportunity to discuss challenges or concerns in a safe, healthy and supportive setting.

Child Feelings Group (5-9)

A children's group could be established on a biweekly or monthly basis in order to provide the opportunity to build relationships and create friendships. This could be established via a parent referral, a referral from the child's doctor, psychologist, social worker or teacher and facilitated by a clinician. This group could operate from a play-therapy and trauma-informed perspective with the intention of teaching children how to identify and feel emotions, develop positive coping skills, build resilience and increase social inclusion.

Youth Groups (10-19)

A youth group could be established on a biweekly or monthly basis with the intention of providing a safe space for individuals to build relationships, develop life skills, create opportunities for advocacy and learn coping strategies. This group would operate from a trauma-informed perspective and utilize adapted cognitive-behavioural therapy, led by an experienced clinician, with the intention of teaching emotional regulation techniques, identifying and processing emotions, recognizing internalizing and externalizing behaviours. It could also provide the opportunity for peer leadership and mentoring, which would increase resilience and leadership skills.

Siblings Group

A sibling's group could be established on a monthly or bimonthly basis with the goal of providing a positive space for siblings to connect, debrief and learn positive coping skills. This group would not be separated by age and would be run by an experienced clinician. This group may break into smaller cohorts based on primary concerns and roles they have in their family system. There may be an opportunity for a smaller group of caregivers to support each other or younger siblings to connect and build positive relationships. This type of group would operate

from trauma-informed perspective and utilize cognitive-behavioural therapeutic techniques to address anxiety, depression and compassion fatigue within the group with the intention of increasing resiliency, connection and social support.

Conclusion

In summary, this study has concluded that children and youth with support needs are at increased risk of adverse childhood experiences and therefore are more likely to experience post-traumatic stress disorder than those without a disability. Following an extensive review of the existing literature, the increased level of vulnerability, social isolation and victimization affects the entire family system leading to distress, which may perpetuate a cycle of adverse childhood experiences within the disability population. Current services do not address the support needs of the family system, which may contribute to increased financial and emotional stress, resulting in high psychological distress that may contribute to less responsive, warm and affectionate parenting increasing the susceptibility of ACEs and trauma sequelae.

Further studies are encouraged to identify evidence-based assessment and treatment options for post-traumatic stress disorder in children and youth with support needs. Currently, the World Health Organization (WHO) has identified eye movement desensitization and reprocessing (EMDR) and cognitive-behavioural therapy (CBT) for PTSD among the non-disability population. Current studies have provided several positive outcomes for adapted treatments of EMDR and CBT for individuals with diverse abilities but further studies are needed to obtain conclusive results.

Glossary of Terms

Child and Youth Mental Health (CYMH): The Ministry of Children and Family

Development's Child and Youth Mental Health teams located across B.C. provide a range of mental health assessment and treatment options for children and youth (0-18 years of age) and their families.

Child and Youth with Support Needs (CYSN) Social Worker: Is an employee of the Ministry of Children and Family Development. A CYNS Social Worker works with children/youth that have been identified with support needs and their families to determine their eligibility for appropriate and available programs and services.

Community Living BC (CLBC): Is the provincial crown corporation that funds support and services to adults with developmental disabilities, as well as individuals who have a diagnosis of Autism Spectrum Disorder (ASD) or Fetal Alcohol Spectrum Disorder and who also have significant difficulty doing things on their own.

Developmental Disabilities Mental Health Services (DDMHS): Provides specialized mental health community services for ages 12 and over who live with co-existing developmental disabilities and a mental illness. Individuals may also struggle with behavioural challenges that are often influenced by the mental illness and developmental disability.

Intellectual disability: This refers to a disorder where onset takes place during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social and practical domains.

Ministry of Children and Family Development (MCFD) British Columbia: The primary focus is to support all children and youth in British Columbia to live in safe, healthy and nurturing families and be strongly connected to their communities and culture.

Appendix A

Parent Support Group: 5 Session Outline

Session	Theme	Goals
1	Getting to know everyone	<ul style="list-style-type: none"> • Create a safe environment (confidentiality, informed consent, group contract) • break through silence /talk about each other's home situations/struggles/frustrations • Mindfulness Activity – Becoming aware of our breathing • Homework: Thought journaling / breathing practice
2	Becoming aware of your feelings (developing awareness)	<ul style="list-style-type: none"> • Share challenging home/community situations and related feelings or reactions • Mindfulness Activity – Body Scan • Homework: Self-Compassion letter / body scan practice
3	Showing your emotions	<ul style="list-style-type: none"> • Understand the relationship between behaviour/event and feelings. • Share feelings of guilt, shame, anger • Mindfulness Activity: name the emotion, locate emotion in your body, apply soothing touch, change your channel of thought to improve mood. • Homework: Emotion journaling/ practice name the emotion activity.
4	Developing Awareness of the consequences	<ul style="list-style-type: none"> • Wide overview of Adverse Childhood Experiences (ACEs). • Psychological & Physiological effects of stress. • Mindfulness Activity: 5, 4, 3, 2, 1, Grounding Technique. • Create a calm down kit • Homework: Use calm down kit / practice 5, 4, 3, 2, 1 Grounding Technique
5	Developing a Social Network	<ul style="list-style-type: none"> • Gain insight into personal social network. • Increase awareness around the importance of leisure activities. • Overview of current resources in place and discussion of potential resources that can be accessed. • Mindfulness Activity: Guided Meditation

Appendix B

Child Feelings Group: 4 Session Outline

Session	Theme	Goals
1	My Emotions	<ul style="list-style-type: none"> • Learning to identify feelings / feelings chart/acting out feelings game. • Colouring Feeling chart • Zones of Regulation game
2	Regulation	<ul style="list-style-type: none"> • Freeze Tag • Simon Says • Feelings Check in • Finger painting using zones of regulation colours.
3	The way I feel	<ul style="list-style-type: none"> • Create a face activity: use pie plates to create a face with movable parts and facial expressions. • Exploring Feeling Centers • Play “I feel” game
4	Emotion / Body Regulation	<ul style="list-style-type: none"> • Create an Emotions Discovery Bottle • How am I feeling game • All tangled up activity – Everyone has worries and sometimes we have so many worries that they get tangled up inside. We are going to untangle those worries by pulling one thread at a time and naming the worry (youth can make worry as long or as short as they would like). The youth can take a piece of yarn home and give a piece to their parent whenever they are feeling anxious.

Appendix C

Young Adults Group: 4 Session Outline

Session	Theme	Goals
1	Getting to know our peers	<ul style="list-style-type: none"> • Introductions, confidentiality, limits of confidentiality, group contact. • Human Bingo • Introduction to Cognitive Behavioural Therapy. • Recognizing our emotions • Introduction to thought journaling • Mindfulness activity: 5, 4, 3, 2, 1 Grounding Exercise • Homework: Thought journaling using words or art
2	Understanding our Emotions	<ul style="list-style-type: none"> • Understand the relationship between behaviour/event and feelings. • Share feelings of guilt, shame, anger • Mindfulness Activity: name the emotion, locate emotion in your body, apply soothing touch, change your channel of thought to improve mood. • Homework: Emotion journaling/ practice name the emotion activity.
3	Health & Wellness	<ul style="list-style-type: none"> • Understanding our sleep patterns, exercise, nutrition. • Let's talk about anxiety (Internalizing/Externalizing) • Zones of Regulation • Regulation exercises • Homework: Self Compassion Letter/mindful breathing exercises
4	Identifying Coping Strategies	<ul style="list-style-type: none"> • All tangled up activity – Everyone has worries and sometimes we have so many worries that they get tangled up inside. • Discussion about worries and other coping strategies. • Homework: Give yarn to parent when feeling worried or anxious. Mindful breathing.

Appendix D

Siblings Group Outline: 4 Session Outline

Session	Theme	Goals
1	Getting to know each other	<ul style="list-style-type: none"> • Introductions, confidentiality, limits of confidentiality, creating safety within the group. • Human Bingo Activity • Share challenging home situations and related feelings. • Name 1 think you appreciate about your sibling. • Introduction to journaling • 5, 4, 3, 2, 1 Grounding Exercise • Homework: Thought Journaling / practice grounding
2	Learning about our emotions	<ul style="list-style-type: none"> • Introduction to relationship between our behaviours/event/feelings • Share feelings of worry, anger, shame, guilt. • Mindfulness activity: Body scan • Homework: Self-Compassion Letter/practice body scan.
3	Acceptance and Compassion	<ul style="list-style-type: none"> • Reducing the Stigma – Art Project • Empty chair activity • Mindfulness activity: Guided meditation on self-compassion • Homework: Thought journaling/ practice guided meditations
4	Managing Expectations & Self-Care	<ul style="list-style-type: none"> • Coping skills wheel • Self-care activity • Communication practice and boundary setting. • Setting Goals activity • Self-care Kit • Homework: Journaling/use self-care kit

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