A Parent's Perspective: The Experience of Accessing Autism Services

An Autoethnographic Study

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Acknowledgements

> No [hu]man is an island, entire of itself; every [hu]man is a piece of the continent.
>
> (John Donne,1959)

The success I have found is not due to my skill alone; it is due to the support of many. Thank you to my community, which has invited me to serve and be accompanied throughout, continuing to allow me to be an amplifier of community narrative, and to contribute to change. Welcoming me to walk alongside you has been greatly healing as I discover myself and the differences I possess.

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Thank you to all who have supported me along the way, for the love and guidance through dark times in my life, and to my children for being an inspiration always. Gratitude to my sister, who through her own journey, invited me to experience my own in a new way. Love to my friend Lisa, who has stood by me like no other friend has and has offered kindness and compassion in the darkest of times. Gratitude to Lindsay for the patience to walk alongside me during the challenge. Thanks as well to Alexandra and Manoj for editing and supporting me through the completion of this project.

Abstract

This study uses the autoethnographic method of research to examine the experience of accessing services for a child within autism services from a parental perspective. It is the reflection of the impact of personal experience, the journey of discovering differences within ourselves, and embracing the disabilities we may have while seeking support for a child in our care. There has been little research that examines the lens of growing up as a child with disabilities, raising children with disabilities, working in the field of social services, and supporting families that include children with disabilities. This autoethnography aims to provide a voice to the complex experience of accessing autism services, and the attitudes and challenges we experience as service navigators and as children within the social services systems.

Prologue

I am blessed in most aspects of my life, including the privileges I was born into and continue to enjoy. I was in a long-term partnership for 16 years, which offered me the stability and safety to create a family, including raising my biological sister. I also live with many invisible impairments, including Attention Deficit Hyperactivity Disorder (ADHD) combined type, Anxiety Disorder, the long-lasting effects of Post-Traumatic Stress Disorder (PTSD), and learning disabilities.

This manuscript is a summary of the various parts of who I am, including many highlights and lowlights I have experienced so far in my life. The first section uncovers what it was for me to discover the strength in my neurological differences, the second section shares the experiences raising my son and accessing autism services, and the third focuses on how to adapt family-centred practices for families that include children with disabilities. Although there was an attempt to define each as their own section, as with life, there is overlap. As I wrote this over the past years, I have made new meaning of my history and the lessons learned, and thus the sections intersect, creating new layers of knowledge.

I have had many opportunities to share my truth through writing, within media, teaching educators and community members, in public speaking engagements, and now this project, where I am exploring my life lessons to benefit my community, but mainly to flourish into my happiest and most authentic self. My unique perspective of growing up as a child with disabilities and complex needs and then as a parent of children with disabilities has driven me to learn to provide meaningful support to caregivers and children with disabilities for over 20 years. Being raised with a label like “complex needs” has contributed to my sense of identity, as I was considered disabled and challenging in numerous areas (Burnside, 2012), and this affected how my self-image began to form. Despite all this, I consider myself fortunate as I continue to learn alongside community, and feel it is the right time to share my experience more fully, to offer opportunity for discussion about details that often remain private.

Being a parent has also shaped my experience, as there are intense joys to raising my beloved children, particularly my son Liam. Yet what you will read here won’t highlight that, because it is not the focus of this part of the journey. What you will read is an expression of discovering the differences within my son, within myself, and the changes I long to see in my community.

I will share my experience in acquiring autism services within Manitoba, Canada, seeking to understand the barriers and challenges. I will discuss the impact, both in the short term and longer term, as it affects mental health and overall well-being of the many families like mine.

My family members have had many professionals in our lives, and we continue to benefit from their support to this day. I am truly grateful for the encouragement, guidance, and especially the compassion that has been shown to my family over the years. I could not write about every experience, and many were affirming and encouraged our growth. However, not all experiences have been positive, and so the names of individuals and organizations have been changed to protect their privacy. I have also changed the name of my ex (to simply “T”) to protect his privacy.

Within this document, the term “service provider” is the label to describe specialized clinicians (e.g., psychologists, speech and language pathologists, etc.) who actively provided therapies for my son and families like ours.

January 18, 2018

How did I get here? I am here again, deep in sadness, reaching for a future for my son. Each decision I make, each distraction I allow myself has an impact on life. Waiting for crisis services feels like eternity, and the weight increases on my shoulders each day. Night goes on and on, and I dare not rest, or I’ll miss something, as the danger is lurking. And tomorrow there will be work, and other demands that will not be turned away. I am here, my son, and I will not give up. One more step ahead, and I will get there.

Parent's Perspective: An Introduction

Caregivers of children with disabilities express that accessing services is different than their expected experience (Bossard, Braxton, & Conway, 2014; Bourke-Taylor, Howie, Law, & Pallant, 2011; Chilvers, Gratton, & Bernard, 2013; Collins & Collins, 1990; Cuzzocrea, Larcan, & Westh, 2013; Duchnowski & Kutash, 2007; Huang, Chang, Chi, & Lai, 2013; King, King, & Rosenbaum, 2004; Kogan et al., 2008; Lindsay, King, Klassen, Esses, & Stachel, 2012; Shannon & Tappan, 2011; Truesdale-Kennedy, Mcconkey, Ferguson, & Roberts, 2006). Given the high rates of disability within the world (Woodman, Smith, Greenberg, & Mailick, 2014), I plan for this window into my reality to support the growth of service providers as the gateway into accessing services for our children. My story will be unique in some ways and cannot reflect each individual who has a disability, nor every person who has gone through accessing services for their child, yet I will share some of what are common experiences within these social services. This document can be used as a tool to build competencies and compassion as we strive to do great things as service providers.

My lived experience allows me to share multiple angles of accessing disability services, both as a child who was labeled as having complex needs, as a parent of two children with neurodevelopmental disabilities, and a clinical service provider offering support to families like mine. The term "complex needs" encompasses all those with multiple health and developmental needs who require several services over multiple sectors, often in multiple locations (CanChild Centre for Childhood Disability Research in Ontario, 2004; Child Welfare League of America, 2007).

I have learned a great deal, both within the joys and the pains of my life. The exploration of the layers of who I am becoming, including the effects of others, the history of my family, and the depth of trauma I am only beginning to uncover intersect with the experiences I have navigating services for my son. The interplay of being a service provider for my full adult life, accessing services during the years prior or going without, and now using my skill and graduate years learning about supporting families more effectively is how I have chosen to share this research. This has become how I see the world and who I am. Therefore, I wish to explore this through autoethnography. Autoethnography will express my own personal journey, of all angles of the experience of having a disability. I write as someone who identifies as having disabilities, or as I prefer to call it differences, and I often use those terms interchangeably, as differences are part of every person and embodies the idea that it is normal to be different.

Mental health is an important aspect of our overall health, and with most of us belonging to a family, the mental well-being of families affects most of our community. Families that include children with more complex needs, like autism or mental health disorders, experience life with more stress (Bourke-Taylor et al., 2011). I work alongside caregivers of children with disabilities, such as autism spectrum disorder (ASD), who are often in distress. As I share time with families, I enjoy giving them space to say what's on their mind. With this approach, I hear a repeated narrative that the day-to-day feels difficult, that service providers “don’t get how hard it is," and that additional supports would make things feel more manageable. To bring these messages to the larger public body, increasing awareness of the intricate realities of raising children with disabilities, will help families like mine.

Research Problem

Caregivers of children with disabilities indicate there is a disconnect between service provider ideals and support reality (Bossard et al., 2014; Bourke-Taylor et al., 2011; Chilvers et al., 2013; Collins & Collins, 1990; Cuzzocrea et al., 2013; Duchnowski & Kutash, 2007; Huang et al., 2013; King et al., 2004; Kogan et al., 2008; Lindsay et al., 2012; Shannon & Tappan, 2011; Truesdale-Kennedy et al., 2006). I will examine the current support within the service provider framework (specifically ASD) and the impact it has on families from the perspective of a caregiver of a child with ASD, who grew up as a child with disabilities, and currently supports families that include children with ASD as a service provider. Consequently, the following questions will guide this research:

- What is the procedure for acquiring autism services? I will seek to understand the barriers, challenges and therefore the opportunity to improve this.
- What is the experience from the inside, both as a parent and a service provider? I will look at balancing resources and investigate ways to streamline communication and priorities.
- What is the impact on families? This information will come from my own personal experiences as a parent with children with disabilities as well as my professional experiences in the social services system.

Purpose Statement

The purpose of this study is to explore the experience of navigating autism services as a parent of a child on the autism spectrum. The intended outcome is to create an effective understanding of the journey, allowing service providers who interact with families that include a child with ASD, and to increase effectiveness in providing services. Knowing the deepness of the despair or joy has the potential to illuminate the discrepancies between service expectations and reality.

Design and Method

I will use autoethnography as a means to self-reflect within my own narrative and history, exploring the connection between my autobiographical story to a wider meaning of life and the evidence**.** With “auto” meaning self, “ethno” meaning culture, and “graphy” meaning writing which reflects the research component, it combines research and personal narrative with the goal of understanding the human cultural experience (Creswell, 2015).

This methodology will allow for a full exploration of my personal experience of being a child who lived with disabilities, raising children who experience disabilities, and being a clinician who supports families that include children with these same disabilities, and now including my personal experience and life with my son by gaining access to services through and with providers.

This topic will benefit from this unique and multi-layered perspective due to the complexity of human interaction and the systems we are working within. It has the potential to bring about additional understanding and potentially lead to changes within those services available to families. Increasing understanding and offering insight into reasons why options work for one family may assist service providers in recreating a framework of service to families like mine.

My personal narrative is built on previous conversations and journal entries, within a complex reciprocal relationship and connected to research. My life history has shaped who I am and how I experience my life. Each interaction cascades to another and affects how I see and feel the next sequence of events, which in turn affects my son and family. The unraveling of the complexities can lead to clarity for readers and the chance for the change I seek. Thus, the method of autoethnography explains this appropriately.

Autoethnographic inquiry benefits those who read it, as they have an opportunity to examine a full understanding of one life, or as in this case, one part of a life. Those in a place of power and those who may be service providers can use this study as knowledge to inform their practice in supporting others. Autoethnography allows us to understand how culture and theory can affect our ideas, feelings and actions (Creswell, 2015).

Theory

Theory informs research, and in this case autoethnography, by creating the lens onto the environment and the interactions within it. The theoretical model for this journey is **social** in nature, meaning that disability of all types, including visible, invisible, within our mental, physical or developmental health, views human impairments as a contract of social limitations in society. The social model refers to the social environment requiring adaptation to fit different bodies and needs (Berger, 2015; Siebers, 2008). This environment is inclusive of attitudes, culture, system barriers and oppression. Similarly, stereotypes directed at those living with disabilities include that we require help or are unable to help ourselves, live in poverty, and need society to alleviate our inabilities (Bowe, 1978). The social model of disability is formed at the basis that disability is not something that can be remedied by intervention, as they are due to society’s inaccessibility.

The medical and social models are dichotomized in that the notions they are based on are opposing. Social theory allows a lens beyond the limitations of the medical model, which seeks to change the impairment and the person with impairments. The medical model “defines disability as a property of the individual body” (Siebers, 2008, p. 25), the labeling or diagnosis, prevention and treatment of said disability.

Social theory within Disability Studies encompasses the unique experiences, gifts, skills and value in being different, encouraging advocacy for social change to increase the well-being of those living with impairments, embracing difference as valuable (Berger, 2015; Siebers, 2008). Living with a different perspective can support others who also experience difference and creating inclusive environments benefits all within that environment. Within this theory, disability cannot be remedied by medicalization, as it is not a medical condition. It is instead a socially constructed idea, leading those who align with the theory to seek to change the environmental factors that allow us to feel “disabled.”

I was born with impairments, and through my life, additional impairments developed due to my environment. Within the social framework, my impairments are unique differences about me, and with them, the environment should be adapted to allow me the same choice as others who may live without impairments. As I live within a social theorized lens, I can see how my impairments no longer hinder my success, as with adaptations and inclusion at school and at work, I am able to live as any other. Throughout my career I have experienced the expectation to meet a typical status quo and failed. This does not negate my abilities and gifts, nor does it mean I cannot thrive. I live with accommodations, understanding and compassion, and with this, I have felt safe to explore and expand my wings. Within a social theory it is my environment that needs to change to allow my growth and development, and when it does, success follows. There is both personal and wider relevance and potential of this approach to explore alternative experiences.

Limitations

There are limits to autoethnography as a research form as one uses our own lens, within our own evidence as the subject for the study. Due to this, there will be limited objectivity as I provide my own analysis of the information I have experienced in my life. This bias means my autoethnographic story will not represent every person who experiences disability, nor every parent who raises a child or children with disabilities. Saying this, my varied background has also allowed me a deep sense of compassion for all parts of the equation, propelling me into advocacy and bridging service providers to families and back again. I feel my unique personal experience will add to the integrity of the story with a balance of compassion and need for transparency of the challenges met by community members. The additional stress families hold raising children with additional challenges (Bourke-Taylor et al., 2011) encourages us to take a deeper look at the realities faced by this population.

Literature Review

Family-centred care is considered a framework for effective support to families experiencing disability (Bossard et al., 2014; Centre for Addiction and Mental Health (CAMH), 2012; Chovil, 2009; Dostaler & Cannon, 2011; Duchnowski & Kutash, 2007; Emerson 2003; Foster, Whitehead, Maybee, & Cullens, 2013; Kuhlthau et al., 2011; Lindsay et al., 2012; McKay & Bannon, 2004; Ontario Centre of Excellence for Child and Youth Mental Health, 2016; Sloper, 1999; Truesdale-Kennedy et al., 2006). However, families can experience it differently than intended. There is evidence indicating the disconnection between how clinical service providers support families and what families that include children with a disability experience, including communication, understanding and validation (Bossard et al., 2014; Bourke-Taylor et al., 2011; Chilvers et al., 2013; Collins & Collins, 1990; Cuzzocrea et al., 2013; Duchnowski & Kutash, 2007; Huang et al., 2013; King et al., 2004; Kogan et al., 2008; Lindsay et al., 2012; Shannon & Tappan, 2011; Truesdale-Kennedy et al., 2006).

Family engagement practices include an active partnership between families and service providers, listening and engaging in reciprocal communication, and involving them in all decision making (Ontario Centre of Excellence for Child and Youth Mental Health, 2016). Further, it is meant to be based in collaboration, where the family's needs and priorities create the service plan, increasing capacity for the family to meet their own needs (Bossard et al., 2014; CAMH, 2012; Chovil, 2009).

In a national study in the United States, Kogan et al. (2008) expressed,

> …an estimated 535,000 children have special health care needs and autism spectrum disorder, a prevalence of 86 per 10,000 children aged 3 to 17 years...Compared with other children with special health care needs without emotional, developmental, or behavioural

> problems, children with special health care needs with autism spectrum disorder were more likely to have unmet needs for specific care services, family support services, delayed or forgone care, difficulty receiving referrals, and care that is not family centered.” (p.1)

These findings indicate that those children living with disabilities often have unmet health needs, leading to care that is not meeting the needs of families or the children within them. Caregivers, and particularly mothers, often carry the weight of social expectations and the child’s needs. Hedov, Anneren, and Wikblad (2000) found that mothers spent significantly more time caring for their child compared to mothers who had a non-disabled child, spending 80% more time with their child than the fathers within the same family. These mothers, compared with those in the control group (with children without disabilities), also had lower self-esteem than their spouses, noting poorer overall health (Hedov et al., 2000).

In Australia, Bourke-Taylor et al. (2011) explored how raising a child or children with impairments can lead to increased stress and have a significantly negative impact on the mental health and well-being of a family. Through this mixed method study in Victoria, BC, mothers self-reported their medical history and shared the challenges and gifts of caregiving for a child with differences. A high correlation of heightened depression and anxiety for these caregivers was discovered, outlining that mothers identified with having higher levels of stress, anxiety and depression, as compared with other mothers and other Australians in general. Approximately 50% stated it affected their parenting ability to meet their child’s needs, with an additional 50% reported having frequent interrupted sleep. Mental health concerns were statistically significant for mothers with children under five, those with additional children with disabilities, a child with

ASD, and those who knew their health affected their ability to parent (Bourke-Taylor et al., 2011).

When comparing diaries of mothers with children who have autism and those who did not, Seltzer et al. (2009) noted that mothers parenting children with autism noted both acute and chronic stress, matching the heightened cortisol levels to their child’s behavioural concerns. Long-term heightened cortisol levels have a high impact on overall health and well-being, and lead to poorer cognitive performance and appear similar to combat soldiers, Holocaust survivors, and those diagnosed with PTSD (Seltzer et al., 2009). Seeking ways to address these issues, such as the negative health effects of chronic stress, including the care of children with behaviour concerns and autism may be an important part of a solution.

There are significant negative correlations documented for maternal mental health and raising a child with an intellectual disability. For example, Emerson (2003) explored statistics of 10,438 random children’s files (aged 5-15) within England, Scotland and Wales, with the additional sample of 245 mothers of children with differences (opposed to 9,481 mothers who had children without differences), and had poor social, economic and stress outcomes reported. The outcomes show that mothers of children with differences were “significantly economically disadvantaged” and a greater social and psychological impact was found for these mothers. Males were reported to have additional risk factors which is correlated to poorer mental health outcomes, including having one or more stressful life events, living in poverty and experiencing “unhealthy” family functioning (Emerson, 2003).

Similarly**,** Cuzzocrea et al. (2013), investigated how each family functioned within their current stress level and the correlation of their parenting style in the hopes of identifying information that could improve the family's quality of life. In monitoring strengths and the ability to adjust to challenges, interactions between parent and child, analyzing energy levels, attention levels, and experiential modality and regulation, great disparities were noted. Higher parental stress correlated with lower parenting efficacy, maternal well-being and family resources. Further, mothers tended to contribute more care to children with higher needs, in comparison to other parents in general. Furthermore, having higher needs and lower resources lead to higher overall stress (Creswell, 2015).

The challenges do not stop within the home or in the general community. Higher needs affect the child within their education as well. When children have special educational needs, barriers that the caregivers have impact their experience, including their engagement with service providers.

> Parents feel blamed and disrespected by school personnel. Parents reported feeling frustrated by the lack of understanding of ED (educational disability) that they have encountered from teachers and school administrators. They feel that because their children’s disabilities are invisible, the children are simply labeled as ‘bad kids’...Possibly because of this sense of being blamed, parents are very sensitive to being talked down to and resent teachers who...They feel that school personnel do not understand the level of parental stress, lack of emotional energy, and practical concerns (e.g., transportation) that keep them from more actively participating in school-related activities.” (Duchnowski & Kutash, 2007, p. 26-27)

These findings indicate that communication difficulties can transpire from the perception of being blamed, which in turn could contribute to a breakdown in the relationship between the caregiver and service provider. The numerous supports in place do not appear to be fitting the need.

Despite there being numerous support systems in place in most regions, there are few supports that create purely positive experiences. Gundersen (2012) examined families using additional supports for their family, while accessing welfare or employment and income assistance. The in-depth discussion about the challenges of the application processes alone is surprising. Results indicated that caregiver fear of their emotional triggers, such as having to retell the challenges and deficits of their child (within the medical model), the inequality of their child versus “typical” children, as well as the rejection of still not being accepted within their circumstances and therefore being denied service, were overwhelming and a significant challenge for many caregivers. The authors suggest there is a gap between ideal service provision and the reality of the way many of us experience it (Gundersen, 2012).

The World Health Organization (2011) reported increasing numbers of both the number of children being diagnosed with disabilities and mental health concerns of parents providing care for these diverse children. Likewise, Yamaoka et al. (2015) examined 549 pairs of children (aged 6-17) and their caregivers and reported that nearly half (44.4%) reported psychological distress. Levels of distress increased with factors that included having younger children, having their own health concerns, living with activity restriction, lower levels of social support, three-generation family homes and low socioeconomic status. Alleviating income discrepancies for families, especially for those that include a child with autism, can increase positive outcomes, as disabilities like ASD tend to reduce a family’s financial security (Yamaoka et al., 2015).

Parental stress and family functioning impacts children’s cognitive, behavioural and social emotional development (Sloper, 1999). Consequently, effectively supporting parents may decrease stress and set the stage for better family and child outcomes. Effective support includes a parent-professional relationship. As many factors can lead to higher or lower rates of parental distress, it is important to support parents in ways that parents themselves say are effective. For example, Sloper (1999) recommends having one primary contact for parents to refer to instead of numerous; parent partnership models, where the professional seeks to align with parents, essentially treating them as though they have expertise; a coping skills model where there is a focus on building on parents' coping strategies, and others. The common theme for these approaches suggests a holistic view is warranted, and includes relationship building, a consistent and single point of contact, they are flexible and individualized, they value the parents' own perceptions and expertise, and therefore they empower families (Sloper, 1999).

Levels of parental stress are mitigated by interactions and the environment. Huang et al. (2013) found that fathers of children 3-17 years old who live with a developmental disability have higher stress levels and a lower mental and physical quality of life. Service providers should watch for this, including the father’s increased negative interactions around support, which are linked with depressive symptoms (Smith, Greenberg, & Seltzer, 2011). Given this information, it is clear that service providers' attitudes for supporting fathers is an important role in the success of the family.

Through a comparison of the economic status of mothers of both children who have an intellectual disability and children who do not, there is a notable disparity associated with those negative outcomes found in the statistics of 10,438 random children’s files (aged 5-15) in England, Scotland and Wales. Within the research, the social, economic and stress reported by mothers of children with disabilities showed they were “significantly economically disadvantaged," showing a need for greater and more complex models of understanding and intervention (Emerson, 2003).

Service deficits are plentiful; waiting, not feeling or being understood, the confusion, team professionals with different opinions and experiences can be both a gift and a challenge (Davis, 2013). Shilling, Bailey, Logan, and Morris (2015) suggest that ongoing service provider training and ongoing supervision can provide effective support to caregivers. Showing service providers compassion and respect for their own personal and professional barriers has the potential to make a positive impact, as to feel understood and accepted can allow for a more connected and positive relationship (Shilling, Bailey, Logan, & Morris, 2014).

Support and service can affect more than just the caregiver. Like ripples in a pond, society not welcoming and being prepared for differences can lead to effects elsewhere. The entire family, including non-disabled siblings, are documented to be negatively affected by poor family well-being as well as having a sibling in their family with differences and challenges (Wolfe, Song, Greenberg, & Mailick, 2014).

Many things affect the trajectory of the well-being of youth with neurological differences like autism. While parental dysregulation patterns negatively impact all children, those children with ASD and developmental disabilities are particularly implicated and may demonstrate increased behaviour problems (Granic & Patterson, 2006). Similarly, increased maternal warmth is linked with higher levels of adaptive behaviour and lower levels of what is referred to as “autism symptoms," and fewer behaviour problems, while maternal depressive symptoms and criticism were linked to higher levels of child psychological symptoms (Smith, Hong, Greenberg, & Mailick, 2016).

While acknowledging service challenges, there are also impacts of positive service to the centrality of family well-being. Over seven years, Taylor and Seltzer (2010) invited 170 mothers to share about their relationship with their child who had been diagnosed with ASD. Mothers who had children with ASD had a greater number of unmet service needs showing the least relationship improvement, even if their child did not have additional barriers like an intellectual disability. This impact can last over years, after high school and possibly beyond (Tirch, Silberstein, & Schoendorff, 2014).

The health implications of being under-resourced and in distress over a period of years can also have lasting health impacts. Smith, Seltzer, and Greenberg (2011) compared the health of mothers of children with fragile X syndrome (FXS) to a sample of mothers of children with autism and children without disabilities. Those mothers with children with FXS or autism had a higher proportion of days with physical health symptoms such as headaches and fatigue. Mothers of children with disabilities appear to be at a higher risk of both physical and mental distress symptoms, showing the need for effective service for these families throughout their life (Smith, Seltzer & Greenberg, 2011).

Section 1: Discovering the Strength in Being Neurodiverse

Growing up Strange

> I used to think I was the strangest person in the world but then I thought there are so many people in the world, there must be someone just like me who feels bizarre and flawed in the same ways I do. I would imagine her and imagine that she must be out there thinking of me, too. Well, I hope that if you are out there and read this and know that, yes, it’s true I’m here, and I’m just as strange as you. (Frida Kahlo, n.d.)

I was born March 2, 1983, in a low-income area of a medium-sized Canadian city in the heart of the prairies on Treaty 1 territory, the home of the Metis Nation. I was brought home to be the newest addition to a complex union of childhood sweethearts. My mother worked as a nurse and was very proud of achieving what she did despite her mental illness. She had been diagnosed and misdiagnosed through her life since adolescence, and from early on, I knew there was “something” that stood between us. “Bipolar disorder” was common language used in our home from an early age, as well as conversations about the trauma she had experienced as a child. My father was a self-proclaimed addict who moved out of his family home at the age of 14, and with schooling incomplete began working as a labourer.

In 1985 at two years of age, I heard, “Don’t go on the stairs!” as I was grabbed from behind and placed firmly on the floor below. A finger pointed at my face, waving, with an escalated tone, “It’s not safe!” I recall this feeling of danger as early as two years of age, both within my home and within my wider environment. I learned quickly I was not allowed to go up the stairs at home, as the stairs were without a railing and there was a large hole cut into the floor of the attic-like second floor.

My needs as a child were modest in comparison to the needs of my parents. At age two I would sit in my crib, which was more of a playpen, and sing to myself quietly and feel my fingers repeatedly until I fell asleep. If I spoke, there would be shouting and upset in my direction and between my parents, so I attempted to self-soothe as much as possible. This had a long-term impact, as falling asleep has always been a challenge for me. It allows the opportunity for my mind to race about each detail of the day and of my life. This isolation and feeling of being alone continues still, with the time to fall asleep being moments when pain and fear come to life.

My parents fought regularly, with physical and verbal violence being a typical part of our days. One cold and dark evening in 1986, at age three I witnessed a physical altercation between my mother and father. My mother had been dressing and preparing for her shift work at the hospital and my father shouted, “I’m going out!” strung along with profanity and fear-inducing comments about not returning. My mother crouched down to my face and calmly told me I was to hide behind our sofa. She explained I would sit alone in the dark for a time, and even though I was afraid of the dark, “everything will be okay." I was instructed not to move “an inch" until my paternal grandmother knocked on the door. Mom continued that Grandmother would pick me up and take me to her home to watch me, as she had to work, and Dad was going out. I moved my body along with my Lightbrite and wedged myself in a small space between the couch and the wall. It seemed like I had hidden there for hours and I felt intense fear as I heard a knock at the door. I froze in terror as I imagined it was a stranger who had come to take me away from my mother. This was a common and frightening threat that was talked about in my home and had become a part of my thought patterns. I saw my grandmother's eyes peer through the small window in the door, searching for me. I was safe this time, and my grandmother had come for me just in time to save me from my fear.

Mine was not a happy childhood. Throughout my first years I was shouted at, called names, and ridiculed for having typical childhood difficulties, and thus the essence of feeling strange began. I felt as though if my parents treated me as if I was strange, and since my parents were my main guide, then I must certainly be strange. I began attending daycare at age three and saw this repeated in my new environment, with both adults and peers. I would do and say things my peers did not understand. Moreover, I recall trying to make sense of other children’s behaviours, enacting what I knew to be typical. This included directing other children the way I was directed at home, raising my voice, and telling children how to play or how to use the toys available to us. I would often become agitated with directions from adults such as the daycare staff, responding in tears and running away to hide from them. My sensitivity to others' facial expressions and body movements began at this time. I could sense if another person was low on patience with me or was having a difficult day. I could use this to achieve attention by responding in ways to irritate them and get them to respond, allowing me to feel a sense of control I felt nowhere else in my life.

Research confirms the structure of the human brain is impacted by the experiences we have growing up which affects emotional regulation and the ability to detect threats (Teicher, Samson, Anderson, & Ohashi, 2016). Trauma causes changes in the dorsolateral prefrontal cortex, amygdala and hippocampus (Teicher et al., 2016), which can affect people long-term, and certainly for me this is the case.

Attachment as a Foundation

The ability and way we connect throughout our life is linked to the experiences we had as children and the ways we were connected. At its best, attachment is the strong emotional bond that infants form with their caregiver(s) and is viewed as a basis for normal emotional and social development (Bowlby, 1973). Healthy attachment is based on attuned parenting, which equips us for attunement with others, increases resilience, and contributes to our emotional, psychological and physiological well-being (Attachment, n.d.). No other variable has as far-reaching effects on our development than the experiences we have as children within our family (Bowlby, 1973).

For me, the trauma experiences I lived increased my detection of threats, which increase my fear response, thus affecting my attachment to my main attachment figures. This is linked to my mother’s own childhood and attachment experience, and her mother’s as well. Growing up my mother experienced her own pain and trauma. Her parents had a long history of instability which was caused by many factors, including my maternal grandmother’s mental illness and depression, and frequent uprooting and moving, a part of being a military family. The life circumstances of my grandmother and those like her were very difficult.

While I lived with my grandmother, she would occasionally explain some of the challenges she faced throughout her life. In the home she welcomed me into in East Kildonan, she would say, “We all have problems” and explain she had to raise her children on her own and now she was in charge of me. “I thought my years of parenting were done, and here I am.” This scenario of grandparents taking on the role of parents is not uncommon and presents challenges for the adults and children. It was certainly true in my family. My mother’s way of creating and maintaining relationships is connected to her life as a young child, along with the high stress and limited ability of her parents to connect to her and meet her needs. I saw in her that the additional stresses and challenges in raising children combined with old wounds resurfaced in future relationships, including survival strategies that erupted when she was distressed. This looked like avoidance in communication, explosive or reactive expressions of herself when faced with disagreement, and emotional distance within even close familial relationships.

In mother-child dyads, attributes such as maternal sensitivity, remaining positive, not feeling resentful, and having meaningful engagement and responsiveness to a child’s needs lead to increased positive attachment (Lopez, 2013). This suggests the disability of a child has a limited impact on the mother’s ability to create a secure attachment with their child. That is, as long as the mother is healthy. My mother was alone in her parenting journey with multiple additional challenges, including significant mental health illness, financial insecurity and unhealthy coping strategies, like shopping. Connection to a child who exhibits challenges is at the best of times complex, and with internal limitations, this becomes increasingly difficult.

My challenging behaviours were a form of communication, telling the world around me the high levels of distress I felt and how unstable my home was. These behaviours also exacerbated my mother’s illness and threatened the precarious nature of her mental health. The contagion of my distress would trigger my mother’s vulnerabilities and impact her responses to me. This affected the closeness we felt to one another. This also affected my short- and long-term ability to get my needs met by my caregivers, increasing my challenging behaviours as I repeatedly sought connection, attention and care. Mothers who report higher levels of stress related to their child’s difficult behaviour are associated with lower levels of closeness with their children, meaning that the more stressful a mother finds their child’s behaviour, the less closeness they feel, leading to insecure attachment (Lopez, 2013). The less my needs were met, the more my body and mind told me to increase my behaviours to get them met. This in turn increased my mother's stress response, creating a cycle that pushed us apart instead of getting closer together. This also affected my mother's sensitivity to my needs as she became increasingly fatigued by the cycle. Maternal sensitivity mediates the link between maternal insightfulness/resolution and child-mother attachment (Oppenheim, Koren-Karie, Dolev, & Yirmiya, 2012). The experiences my mother had impacted her parenting, and so too did my experiences as a child impact how I perceive the world, connect to my son and navigate the social services required to maintain his wellness.

Developing a Sense of Self

I have always thought of myself as being different. It was more than a feeling, it was the reflection I saw of myself from my parents, extended family, peers, and those around me. I never knew quite what to say in social situations and had interests outside the realm of others' experiences or at an intensity other didn't understand.

This feeling of myself seems to intensify as I continue to unravel who I am from the cocoon created by my traumatic past and affects how I experience my world today. Considering myself as strange, or as the odd one out, has remained, yet I don't hold it to the negative light I once did. Raising my children and seeing their unique gifts has brought about great change for me. Just as I see them, I see in myself a unique set of strengths, rooted in my strangeness, but fueled by intelligence, empathy and curiosity. This lens has allowed and encouraged innovation, unrelenting tenacity for supporting community and my family, and created the resilient person I see now.

I have many strengths and I am resilient, but I am also tired. My tiredness is unlikely the definition of tired you know, as my state of fatigue comes from using my strength to hold myself up, decade after decade. It has taken a toll on me that is hard to explain after years of neglect, abuse, emotional and psychological trauma, and the pressure to be “perfect,” all in an environment created to force imperfection, and the requirement of self-reliance without connection to others has impacted every part of who I am.

However, my true identity lies in the celebration of my differences and the joys of seeing myself in strength and weakness and realness. The cells of my body are puttering yet driven to find comfort, even in the midst of a tornado. The strength of forging on, surviving through the pains of life, seeking the joys I know are hiding, because I have tasted the fruit of love, connection and happiness, and I want more. I am here, as one human, sharing a story to benefit others perhaps, but mainly to find myself.

I invite others to know me as I have grown to know myself, through the journey of learning about and finding services for my beloved son. So many times, I have felt torn between decisions, and ultimately, I realize there is no perfect solution or answer. There are only informed decisions.

Figure 1: Torn

Multimedia on canvas, 18x24”

The colours of blue bring to mind the openness of the sky and the effortlessness of floating in water. As a child my recurring dreams were of flying above my life and far away from the reality I knew. As a bird, I could do as I wished and did not have to be concerned with others. Swimming in and being close to water I have experienced as healing, with a feeling of weightlessness taking away my worry. My fondest memories as a child were of swimming throughout the summer.

When I paint, I use the colour blue to ground me in my pain, and often by simply visualizing it, I feel the soothing sensation within the colour. I sense its coolness, in a depth as deep as the ocean, which mimics the depth of the pain felt in my life. When I have a difficult experience, such as the loss of my mother or a misunderstanding, I feel torn to where it feels my being has been ripped in two. This intensity of feeling I understand now is part of the way I am and comes with both problems and gifts. The gift of understanding others, of offering an authentic and boundless compassion to others’ pain, is a strength I have developed by embracing the intensity of my own feelings. The downside is that during moments of distress, words cannot express the level of my emotions nor can they remedy my existence in that moment.

August 10, 2018 (A. Taylor, 2018)

Spinning

Motionless.

Beyond now is stillness.

“Enough,” echoes

Step into step,

On and on.

"I got this," leaves emptiness.

My Family; My Heart. "The best and most beautiful things in the world cannot be seen or even touched- They must be felt with the heart." (Helen Keller, 2012)

Families all have a history and mine is no different. The generations before me continue to shape who I am and how I experience my life. Mental illness exists in my family, as 20% of Canadians every year experience mental illness or addiction problems, and by 40 years of age there is a 50% chance of having or have had a mental illness (Smetanin et al., 2011).

Many that I admire in my family have had experiences that overlap with disability, in either living with impairments themselves or being connected to those who did. My grandmothers and grandfather hold a special place in my heart and are important players in my life. I see myself as a mother with impairments/neurological diversities myself, which impacts my day-to-day living. Some may see my impairments as disabilities, although as I have developed my sense of self, I now see these differences within the social model of being part of the human condition.

My grandmother. My maternal grandmother Pat was a trailblazer, and as I understand it, one of the first nurse practitioners in Canada. From a young age, she was both edgy in her communication style and innovative in health services. She was always there, doing her best, not only for the community, but for her children and me. On bad nights and weeks, my mentally ill mother would drive me late at night to my grandmother's home, to have me stay there until she was well.

One evening, late in 1989, as the sky approached dusk, my mother grabbed me roughly from where I had been crying in my room and ordered me to get in the car. She drove me across the city, yelling, unwell, stating repeatedly, "Shut up" and "I can't deal with you anymore!" When we arrived outside my grandmother's home, she screamed, "Stay in the car!" and I watched her stomp to my grandmother's door and begin a lengthy verbal altercation. My grandmother walked quickly over to the car as my mother cried beside the front steps and told me everything would be okay, and that I should come inside. She had a room made up for me, with rainbow sheets and a comforter and my favourite fluffy soft white blanket in-between. The painting of a sleeping infant hung on the wall, and I sat on the bed and cried. Later my grandmother came into my room, wiping the tears from her eyes, and helped prepare me for bedtime which had been delayed by over an hour. This is but one small memory to illustrate the role my grandmother played in my troubled childhood. She provided protection from a great deal of pain, and I saw how she internalized it as she grew older.

My granddad. My maternal grandfather Ian is one of the most brilliant and caring people I have ever known. For most of my life, he was kept away from me, as my grandmother's pain clouded her judgment and prevented the family from reaching out. As I grew, he welcomed me as I was, always offering encouragement and support to see myself in a positive light. When my son Liam was diagnosed with autism, I called him and shared the news. He responded with a calm and kind voice, assuring me we had many family members with autism, and when he was growing up, his brother "didn't talk until he was five" and always had certain "quirks." The normalization of difference is something I treasure, and within my extended and married family, where disability and difference are not necessarily celebrated, these conversations have made a lasting impression on me. These messages were new and exciting to me as they entered my life and have become a part of how I long to see the world. As I move forward in my life, raising my children and supporting community, I hear these messages echoing to me.

Omi. My paternal grandmother, or Omi, which is grandmother in Dutch, is a quiet warrior, blessing every life she touches with kindness and love. Immigrating to Canada while carrying my father, she made brave steps into a new life. She grew up in rural Holland during the war, and as she explained to me, her motto was “always make the best and most of everything, no matter how hard things are.” She has developed neurological and physical health concerns as she’s aged, and I admire her speaking up for herself when she needed time to rest, and always sharing gratitude as others gave her compassion and care. Throughout my life, she has always allowed me to be myself, helping me to see myself as worthy through her eyes.

My mother often dropped me off at Omi’s home during a crisis and on the way to work, to play and enjoy my many cousins. We all loved to visit my grandmother’s home. As soon as you entered, you felt comforted and smelled the aroma of nutmeg. Each time I entered, Omi would sit beside me, encouraging me to care for my infant cousins, and once we were done, to go off and play. She encouraged my independence and positive view of myself by calling me “Angel-a,” consistent in reassuring me I was a kind and beautiful child. This positive view of who I was affected the foundation of who I am today. To see myself reflected in the eyes of my grandmother as precious and capable despite the chaos of my home life allowed me hope. This hope is something I still carry with me.

She lost her long-time love, my grandfather, to suicide after years of mental and physical illness and would develop severe neurological symptoms that would continue to affect her daily living. The pain of a lifetime can catch up with the strongest of people, and it certainly did for her.

These caregivers were available to me at different parts of my life, and combined with teachers and daycare teachers, made significant positive impacts to who I am today. I feel I benefited greatly from the positive view of being different and being who I am, despite the other louder messages of not being enough, and even being made to feel ashamed of who and how I am.

The Past Should Stay in the Past

> “Developing my sense of self in the face of criticism and projected suffering has been the truest test of surrender and strength.” (Taylor, 2019)

“What happens in the past, should stay there” was a message I felt from a young age. The urging to leave behind all hurts immediately as a testament to my ability to love and care for my caregivers was a necessity in the life I lived. The occurrences were commonplace and affected my ability to see emotions for what they are - natural.

I am three years old. I felt cold to the core of my body, and my ears heard a loud noise. I see that the front door is open, and my parents stood in the doorway, shouting. They hit each other, and watching them, I somehow felt I could get them to stop by yelling. But instead of stopping the violence, they looked down towards me sitting at their feet and shouted for me to leave. My father moved towards me threateningly and my mother moved in between us. I hid to shelter myself from the noise, and a short time later I heard the door slam shut. My mother came to find me and started to pack my toys and clothing into a bag. As I protested, she explained there was no time to take everything and we could buy more toys later. She grabbed me and my bag and placed us in her car.

My mother left our family home, escaping from the chaos to a women’s shelter. My mother and I arrived late in the evening and she banged on the door repeatedly until an older woman answered. The building smelled musty and it was dark inside, with only a few dim lights on. The staff walked us up several flights of stairs and brought us to a small attic-like space which was filled with other mothers and children in similar circumstances. I was told I had to go to sleep and sat on the cot offered without blankets. I cried for the kitten we left, the toys I had not had the chance to take, and for the awful night I had. My mother assured me she would be there for me and that we were safe, holding my hand as she lay on the floor next to me. I wept, covered with my mother's sweater to keep me warm, and drifted off to sleep. When we woke, we understood we were to meet in a cafeteria-like room to share our meal. There we were amongst children running wildly, with staff offering strict controls on the levels of noise. I acted out my fears and insecurity as I played with old broken toys with other scared children beneath the long tables.

The years afterward, with my mother and I alone, were difficult. I was left without supervision to play at the park, often until late, frequently got milk at the corner store on my own, and went without many necessities others took for granted. School was always difficult for me, and I remember by this time I noticed often how things seemed easier for others than they were for me. Reading and writing took longer, I was sent into a panic when the class worked on learning to tell time, and friendships seemed complex and like a different language.

From the ages of three to six, I rotated myself and my belongings from my mother's apartment when she was well enough, to a family friend's home, and my maternal grandmother's residence. I rarely spoke about the hurt and fear I felt, and when I tried, I would receive "everything is going to be okay" and "your mom is just sick right now." I internalized the pain of growing up without a regular residence and without having consistent caregivers who were able to be there for my emotions and offer the guidance I needed. I began to communicate through verbal and physical aggression, which in addition to my biological family's inability to care for me, eventually contributed to being placed into public foster care. I now see the effects of not having a place to call my own or a regular primary caregiver for all those years. I see it in my ability to trust in relationships and connecting with others. I also see it in the way I relate to others going through difficulty, in that I can be attuned and share deep compassion for those in pain or who are suffering. Being disjointed from normalcy all those years has invited me to be adaptable in the face of challenges that would send others into distress.

While playing in my bedroom at age four, I heard my mother begin to yell and I became curious. I went into the next room to see my mother crying and looking physically unbalanced, appearing to have difficulty walking. She shouted, “Go play!” and I hesitantly yet hurriedly went back into my room. Moments later paramedics entered our home, moving quickly towards my mother. One strange man lowered his body to look into my face at eye-level and said they were going to help my mom and “please stay over there,” pointing away from where they worked to assess my mother for suicide risk. When my grandmother arrived, she told me my mother had taken too much medicine and needed to go to the hospital to get better. I walked through our home to show her the brightly coloured pills in prescription bottles in various parts of our kitchen, on the table and counter, which I said had always been there. “Are these what made her sick?” I asked and was told my mother needed the medication to be healthy, but she took too much. My grandmother assured me I could stay with her until she got better, and everything would be okay and I would be with my mother again soon. This was very hard for me to believe, given that while living with my mother, I would often wake up and dress myself, prepare breakfast, lunch and sometimes dinner, and play alone for hours within our sparse home. I had friends in the neighbourhood who would attend the local park, and I was encouraged to mind myself and attend the park alone to let my mother sleep. Although my belief at the time was that things would be okay, I look back now and see the familiarity with families I have met through the years and the power of telling children what they might need to hear to make it through the day.

One morning, at seven years old, I played in the basement daycare centre which I had grown to know as my one safe place. A stranger came down the stairs, dressed in formal business clothes, past the wall of glass, and began to speak to the director. The children in the centre and I wondered about this new person, but after a few moments went back to our toys. The stranger was a Child and Family Service Worker, and she walked over to me and asked me my name and introduced herself. As she spoke, I heard a scream at the stop of the stairs and saw my mother hitting the glass, watching our conversation. The CFS worker leaned down further, coming close to my face and told me I could no longer be with my mom because she was “sick.”

This stranger drove me to a building where another stranger met me. This woman instructed me to put plastic bags on my boots, as they were full of mud and would make her clean car dirty. We drove for 25 minutes to an area of the city I did not recognize, and she told me I would “meet a nice lady who is going to take care of you for a while.” When I inquired as to why, this stranger confirmed my mother was “sick” and was unable to care for me. As we walked up to the row of joined homes, I was instructed that the “lady” had a daughter my age, and she stated while looking at me expectedly, “Isn’t that great?” I did not feel anything was great, and longed to run away from the world and not look back. I walked into the house, and the smiles on their faces and the smell of potpourri overwhelmed my senses. I was invited into their home and asked if I wanted to see my new room. This would be the beginning of several years of supervised visits with my own family, awkward answers about what “sick” meant, and an intense feeling of loneliness.

While in the foster care system, I had numerous Child and Family Service providers sit with me. On one occasion, a new guardian took me to McDonalds and said honestly, “I won't be your worker for much longer and probably won't see you again...you can tell me things if you want to.” I sat in silence for the rest of the mandatory visit, unsure of her and why I was there. This ridiculous visit is sadly symbolic of the superficial “care” I received. As a foster child, I felt perpetually silenced, unable to share my worries or pain, and I could not see one person who would be there to truly listen. What would be the point of telling her anything? I felt like I would never see her again, and anything I had shared in the past changed nothing about my current situation and would likely not change anything about my future. I felt alone and without a lifeline for any of the daily struggles I lived with.

After years of court battles, my mother succeeded in her fight to get me returned to her care. I was returned despite the numerous sexual allegations made of her new partner, who would become my adopted father. During that time my mother, her partner and I would share a new level of abuse by the man I would call “Dad”. I realized as an adult that much of the behaviours that made me feel uncomfortable occurred prior to being placed into formal foster care, during the supervised visits where a hired staff from CFS would attend our home, and then during unsupervised and overnight visits. There were many times I shared the details of the abuse to the adults in my life, and I am still unsure if I was not believed due to my history of trauma, or if it was simply due to my age and inability to articulate the depth of what I experienced. The effort and courage it took to whisper to my grandmother, my eyes closed, gripping onto her arm, telling her I had been harmed and felt scared with my mother’s new partner took everything I had. I understood years later that she followed up with CFS and nothing was done. It was one child against a system. I see now the complexities of a fragmented system not meant to believe children, especially if they present as “challenging.” This is the reality of my situation, of who I was and the history I live with. This inability to believe that others will protect me when necessary has enveloped my childhood experience, yet it has also projected me into an adulthood that allows me to protect myself, my children, and my community.

When I moved home with my mother, I lived in near-constant fear. The service agency that had removed me did not check in or come to see if I was okay. Once I returned home, I understood there were no safety net for me. The relationship between my maternal grandmother and mother had ended due to my mother blaming her for my removal. There were bitter and constant expressions of pain and shame about what had taken place years prior. I understood I was not to mention my grandmother or ask for her, nor anyone else in our extended family as they “had allowed it [my being removed into foster care]” to happen.

After returning home, my mother told me about her consistent “sickness:” about how she first started to consider and act on her suicidal thoughts at age 12, about the ineffective and harmful electric shock treatments and the psychotic episodes that had become part of living. When she was lucid, she would share that she believed parts of her memories were false, but she could never be sure how much or how little. I understood I was not to ask questions or bring it up, and understood that if she was sharing, it was on her own terms. I grew to know from these discussions that mental illness lies, and that even an adult sufferer cannot be sure where the truth begins and ends.

My mother shared how both as a nurse and receiver of mental health care, those with mental illness were not treated well, especially if they expressed their suicidal ideation. She told me one afternoon, “When people try to kill themselves, the nurses aren’t gentle like they are with most people. They feel like if they didn’t think their life was worth living, why should they.” She shared that she saw this often, and despite this, sometimes people still tried to kill themselves. I wondered as an adult if this foreshadowing was something I could have seen or done something about. Perhaps there were many clues to her death I have missed throughout my childhood and youth, and perhaps there was still nothing I could have done to stop it. These thoughts are hard to shake free of, as I live my life without a mother.

I had longed for safety throughout my life, and although my mother promised to create this for me, her illness wouldn't allow it. I remember one afternoon while my mother was at work, running from my room from my adopted father who had stood over me. I ran through the house to discover the doors were locked, and the key that was kept in the double deadbolt was missing. I head sounds of him following me and I hid in the basement of our home, under a coffee table, certain my life would end that day. I heard his footsteps lightly on our basement floor, telling me I could not hide forever, and when I was sure he was upstairs again, I called my adopted paternal grandmother for help. There was not one moment in that home where I did not have to pretend to be unafraid or pretend to be something I wasn't. There were 16 years of abuse, and of all the trauma I experienced, the psychological abuse has had the longest effects. Having a history of either sexual, psychological and physical forms of abuse leaves individuals, such as myself, with increased rates of psychopathology, in addition to difficulties in sexuality, self-esteem and interpersonal relationships (Mullen, Martin, Anderson, Romans, & Herbison, 1996).

The experiences we have as children can affect us for the entire length of our lives. Maltreatment is linked to many brain structure changes, which affect function and stress-responsiveness and reactions (Felitti et al., 1998; Anda et al., 2006). Adverse childhood experiences (ACEs) can create challenges for children in their focus, self-regulation, trust, and impacts cognition. This includes emotional, physical and sexual abuse, emotional and physical neglect, intimate partner violence, household substance abuse, mental illness, divorce, and criminal behaviour and incarceration (Felitti et al., 1998; Anda et al., 2006). Children with four or more ACEs were found to be 32 times more likely to have behavioural or cognitive problems than a child without (Plumb, Bush, & Kersevich, 2016). Because I experienced all ten adverse childhood experiences on the scoring assessment tool, I have been profoundly affected by my childhood. These experiences include physical, sexual and emotional abuse, physical and emotional neglect, my mother being treated violently, substance misuse in our home, household parental mental illness, parental separation and criminal behaviour and incarceration.

My mother remained with the man who had abused me throughout my childhood. My prayers, whispers and longings had not been answered, and he remained as he had been and without a set of eyes to watch out for me. He had segregated us from any maternal family who would serve as protection, and his family was in denial about his extensive history of violence and predatory behaviour. I was alone and vulnerable.

When I was 17, my mother had another child with my then-adopted father. This child awoke a love inside me I hadn't known possible and allowed me to feel a joy and pride that breathed life into me. As I began my first year of university, I chose to take earlier classes so as to rush home and care for my sister, who was only one year old.

It was the second week of university and I had planned my buses to align and make it home for 11:45 a.m. I took two classes that began at 8:30 a.m. which led to early mornings, but that allowed me to meet some of my family’s needs. I walked quickly as I knew my infant sister was waiting for me to arrive. I used my key to open to the door and kicked off my shoes toward to the closet, shouting, “Hey! I’m home!” I walked towards her, and saw she was still in her pajamas in her crib. She held a bottle in her left hand, full of thick and sour milk, waving with her other hand, smiling and babbling to me with her soother in her mouth. “Hi baby. What are you doing with that yucky diaper?” I lifted her out to begin caring for her. Our mother was at work to enable us to pay for our home, and her father was asleep upstairs. There was no option to reach out to CFS at that time. The narrative in our home about community services was fear based, and with the experience our family had been through with me in care, accessing any services was prohibited.

I had hoped this choice would be a new and more positive chapter in the history of our family and bring a different future. Yet life continued to be difficult at home, with long periods of silence from my adopted father, switching to violent outbursts towards my mother, our dogs and me. There would be weeks and months where he would not say one word to me or look in my direction, as if I did not exist at all. Threats of violence were articulated with intensity, inches from my face, where I could feel the heat and moisture from his breath. “Discussions” would occur where his arm would be wound straight in the air, and I knew that any time his mood would change from ordering me to action, to rejection and, “Get out of here. What a waste of skin.” The profound internal reaction of hearing these words had to be stuffed deep within, because I had to survive for my sister. I knew at that time and always that I had to push on from the pain and leave the suffering for another time when and if I could ever become safe.

As the years went on and my step-father intensified the abuse, this solidified my stance in not raising children of my own. My concern was how I would protect children in a world without protection. If I could grow up in a house with so many caregivers who were in charge of my safety and still not receive care, what chance did I have in having children and keeping them safe?

My mother’s health and wellness were also unpredictable, and at times as her behaviour could be both unstable and frightening. No matter how high the level of effort I exhibited, the type of response I received from both my caregivers was erratic, often with unpleasant and derogatory statements about my worth and abilities. No matter the lengths I went to do the laundry, make dinner and care for the home and my mother's health, there was no recognition nor feeling of success. Yet I carried on in survival mode, moving one foot in front of the other, moving through the big feelings of rejection and keeping a focus on the minimal joy I could find at school and through other means.

"I heard that the cactus needs to be moved," my mother said aloud to herself about our plastic plant, while I sat motionless on the couch. She'd occasionally share about the voices she heard, and I'd respond with silence or curiosity. The visions were more difficult for me as I would look around and not see the person or being she spoke of, and sometimes spoke with. The evidence shows that the effects of mental illness in families and the children within them are profound (Felitti et al., 1998; Anda et al., 2006), and to this day I think of those conversations and see the connection to my current experiences with illness, disability and services. The conversations my mother had with people who did not exist to me create understanding and compassion for those living with differences or difficulties. A child may feel a sensitivity to sound or light that others do not have, and that does not mean it is not real to them. Their reality is their own, and as a helper, it is my job to understand that and see there is a good reason for everything. This is how we can offer meaningful support. Treating someone as though their reality is not real will only separate us from them, when really, they need an ally.

On September 19, 2001, after planning it for months, my mother died of suicide. The fights with her husband I had heard included comments like, "No one cares. Just go kill yourself," which certainly added to her already desperate pain. Despite my gratitude that my mother was now without the illness she had so long struggled with, the pain had shifted from her to those she left behind. My sister and I were without a mother and we lived with a monster. I scheduled my life to protect her however I could from home, struggling to find balance between being a child, needing my own freedom, and the fear of what would happen if I didn't stay close.

Although I have focused on her illness and negative behaviours, I must say my mother was a beacon for many, and perhaps especially to me. Following in her mother's footsteps, she graduated as a nurse and began to support community as soon as she could. I wish I knew more about these positive aspects. In fact, I know relatively little about my mother: truly I know most about her mental illness as it consumed every part of my life. From as early as I can remember, I recall psych wards, staying with friends and family, and playing alone. When I think back, I can remember traumatic and concerning events where I hid, with emergency personnel in our apartment, crying, yelling, and my mother near death.

My mother had an idealization of perfection as she walked through life, with high expectations of both herself and my sister and me. She expressed concern with failing at life, parenting and her career, and rarely felt as though she was good enough, no matter her success or accomplishments. Her suicide attempts and eventual death stem from these impossible expectations and this failure identity.

I understand my mother in a new way every year that I live. Her illness was not who she was and is not the entire story. Those who live with any type of illness, including a mental health illness, need an environment that lends itself to success. As an example, her partner choices did not allow her to find the balance she could have found even by being alone. I see now the desire she had for connection and belonging overshadowed her sense of self, and this was the beginning of the end.

August 15, 2018 (A. Taylor, 2018)

Hand on heart,
Find patience.
Consistency, the virtue.
“Best Practice” parenting,
Evolving humanity.
From wilted
To
Mother, friend, perfection.
A blossoming rose.
Highest expectations
More than of self,
To all.

September 22, 2001

I still can’t believe you’re gone. I dream I see you walking outside and no matter how I call to you, you don’t come. It’s not fair that you left me here. Things were already so hard, even with having you on my side and now I have no one. Things are worse than ever at home, and I just don’t know how much longer I can live like this. Constant lies, and drama, and again who has to be the grown up? I am only 18! How can I focus on university when I feel lost and alone? I want to run away from all of this, but who will watch out for Julia? She is only a baby, and no one is protecting her.

January 11, 2002

I continue to have dreams you’re still here, Mom. When will they end? I dreamt that as I left my home, you were waiting in your car, but you were so far down the street, that I couldn’t reach you no matter how far I went. I wish you were here with me.

When my mother took her life, it was not what you may think. She was a strong woman with a deep love and admiration for life, and especially her children. Her pain and illness lied to her, telling her the world would be better off without her, just as mental illness does. Can you imagine the pain she must have felt to think this way? As I grow older, I understand more and more how desperate she must have felt, and I grow more compassion for her every year. Also, I miss her so much and wish she could just be here with me.

June 9, 2018

I understand suicide.

In a world not made for disabilities, and where invisible disabilities do not receive the support they deserve. I understand.

When things feel hard, then harder, our minds can lie and say no one cares.

Because new skills and ways of being are difficult, and resources are not as meaningful as necessary. Because pain hurts no matter how strong you are and self-medication is. Right. There.

Losing my grandfather and mother to suicide was a mystery to me for most of my life. As I've grown, I've been maliciously hurt, loved beyond any love children who are suffering, and seen the ultimate pains in my community.

So, yeah, I feel like I get it. I struggle like many.

I've learnt that suicide may end pain, only to pass it on, and that every life has innate value. I've learnt that the waves of pain don't last forever and that there is support for everyone.

So, don't give up. I'm rooting for you. Many are trying to change the system as fast as we can. For you, for me, for our children. Because we're all worth it.

I have carried my mother’s illness for a lifetime and continue still today. Dreams I have had since age five have included a recurring theme of my mother in a sea of flames and me being in charge of rescuing her despite the onlooking adults. The danger was always lurking. There was a palpable fear that mental illness would find me and affect my life, which intensified through my 20s. Youth aged 15 to 24 are more likely to develop mental illness and/or substance misuse strategies than other age group (Pearson, Janz & Ali, 2013). Thus, perhaps it’s unsurprising that I began to have panic attacks at age 17, unable to breathe, feeling swallowed within my life, frozen and unable to move forward, and despite aging, this fear continues, although in different forms.

Figure 2: Lurking

Multimedia on canvas, 18x24"

The theme of danger lurking is consistent in my narrative, as growing up, danger was around each corner. Even during times of beauty, I wait for the danger to find me. I have continued to have a fear of spiders for decades; they symbolize unpredictable behaviour and a small infiltrator that can affect my sense of safety in many ways. I use spiders as a symbol for the perpetrators in my life, those who harmed me psychologically and physically throughout my childhood. The beauty of this image, of the blues and greens that calm me, is overshadowed by the red violence that has damaged my growth. The infiltration of pain, suffering and fear invades each joyful moment, as the perpetrators continue to influence my choices. With the death of the spider comes relief, and without that, the fear continues. But I cannot kill every spider.

Finding My Way

There was an intense feeling of being alone, beginning as a young child playing quietly in our apartment careful not to disturb my mother. This continued as I pursued my university degree full time, managing the heavy weight of complex emotions and swirled with internal chaos. During this time, I worked four jobs: supporting community by offering respite to families that included children with disabilities, a cashier at the University of Manitoba bookstore, in sales at Eaton’s, and creating and selling artwork for custom requests.

In the two long-term partnerships I experienced during this time, I recognized my unhealthy connectivity to individuals who were unwell but felt there was little I could do to avoid it. The men in my life exhibited dangerous behaviours, including verbal abuse and physical violence directed at objects and at times, me. Within one partnership, there were also repeated suicide attempts.

It was 10 p.m., and as my phone rang I wondered, “Who would be calling this late?” I had school the next day and there was little time to waste with my tightly-packed schedule. As soon as I answered, I realized my boyfriend was unwell. He yelled into the phone that he was going to kill himself while driving his car on the highway. I spoke to him calmly, saying things must be really hard for him to feel like he needed to do that. But inside, I felt tired of how difficult things were, how my needing to respond appropriately was going to make a difference of life or death. I called his family and the RCMP, and that was one of the last times I spoke to him. He had brought up marriage on several occasions throughout our relationship and the fear of losing him to suicide outweighed my love for him.

I was afraid for his life, to leave him alone, or what he might do if I told him it was over. He survived that night and the many similar nights that followed over our six months together.

He ended up seeking treatment and I assured him we would always be friends as confirmation for him to continue to stabilize. Months later, I pulled away from the chaos and fell into new patterns, away from the unpredictable danger that he shared. I sought safety. The impacts of these relationships were heavy, as my vulnerability seemed to draw individuals who were vulnerable in their own way. I realized at the time I was at risk and did what I could to protect myself and keep myself safe. I stayed on schedule, filled my time productively, and worked to keep connected to family as a barrier to the mental illness I felt may be following me.

During a break from university and work, I took a short break from studying to eat, and watched Oprah speak to a pedophile about how he groomed children over the years. He stated that sexual abuse is not only intercourse but can include many acts of sexual exploitation and child sexual abuse. I began to breathe shallowly and quickly, feeling faint, and had the realization that from the ages of three to 18 I had been sexually abused, including assault. The definition of sexual abuse that I had grown up with did not include the specific experiences I lived, and to find a reason why things were continuously difficult was both a relief and a burden.

Months later I sat alone in my apartment, the one I had shared with my former boyfriend, and understood I did not have anyone to protect me. I was without my mother or father and had to make a choice. I reached out to the extended family who lived out of the province and asked for help. There were occasional times in the past when I had called on them for money for food, as I had been without or to pay for my books for school, and to help me move apartments or deal with court and other crisis situations. They had always come through. I am grateful I had that option, as although there was no consistent support for me in the province, it would have been far more difficult without my distant relatives’ help.

I met my ex-husband at the age of 20, first at the bookstore where I worked where he purchased items I later discovered he did not need and met again later through mutual friends. When I began to spend time with him, I noticed how being with a partner who did not emotionally or physically abuse me felt very strange. I considered it at the time an opportunity to daydream about what a healthy relationship could look like. I took strategic steps towards what I imagined it could be, one step after another, returning calls, planning dates, and speaking in ways I thought someone healthy would do it. It was a constant internal battle, and against the grain I spoke up when I was upset, told him what I needed and found the joy I had been seeking.

Partners for Life?

“Love is being truly seen and accepted for how and who you are.”

(A. Taylor, 2018)

My ex-husband "T" is the first safe person I encountered who stood by my side in the long term. Our journey has not been an easy one, and looking back, I can see that the safety I received was exactly what I needed throughout the time we shared. Our marriage recently ended, and I have reflected on the high rates of stress we encountered. Divorce rates are higher for those who raise a child or children with disabilities (Freedman, Kalb, Zablotsky, & Stuart, 2011). Children’s disabilities affect a marriage and relationships. In fact, 85.6% of parents say their child's condition has caused disagreements/arguments, and 76% of divorced parents share that their child's disability led to their separation or divorce (Statistics Canada, n.d.).

T has blessed my life in many ways and has been my partner in creating and raising children, building a life, and allowing me a feeling some sense of safety to try new things over the first years of being together. He was the platform for my emerging into what I could become, and without him I am certain I would not have had the chance.

I stood at the end of the driveway at the home my partner and I shared in Prince Rupert, British Columbia. We were late for an engagement; my anxiety was high, and I struggled to control it as I saw T moving more slowly as if he felt rushed. I felt the words come out of my mouth, hot and screaming, “I’m anxious!” I stood there, ten metres away from him, on the dirt road, wet from the rain, and he walked down to me and simply said, “I see that,” and walked calmly past me. I have struggled to regulate myself throughout my life, and until several years ago, in attempting to contain my emotions, I would have become dysregulated and resort to a fight, flight or freeze response for what felt like every moment of my life. Dysregulation is an impairment of our physiological regulatory mechanism, including our metabolism, immune response and organ function (Dysregulation Medical Definition, n.d.). This is a well-documented response to emotional trauma, but that does not make it easy to understand nor deal with.

Emerging

“Be tired. Be still. Be as you are. Welcome yourself, here, as you need to be.”

(A. Taylor, 2018)

I am still figuring out who I am, emerging into what I will become. Despite my many privileges, of being cisgender, heteronormative, Caucasian, highly educated and middle-class, I have barriers that are invisible to the naked eye which lie just beneath the surface. I am also aware of my resilience, in that the learned process of “bouncing back” protects me in adverse situations and enhances the outcome when I am up against risk factors like depression (Tusaie & Dyer, 2004). Some of the protective factors known are life satisfaction, optimism, positive effect, self-efficacy, self-esteem and social support (Lee et al., 2013) and although I don't possess all of these, I do benefit from many. I also use humour as a coping strategy to deal with the challenge life brings. Although the relationship between laughter and health is complex, laughter is known to alleviate pain and reduce feelings of stress (Strean, 2009). Having the opportunity to experience humour, laughter and happiness is strongly associated with favourable bereavement adjustments, including lower grief and depression symptoms (Lund, Utz, Caserta, & De Vries, 2008). My strength in problem-solving challenges protects me from the risk factors I have lived through, and in addition, my adaptive nature promotes my physiological and psychological growth (Tusaie & Dyer, 2004). I am told I am "charming" and "bubbly" and this increased my likeability factor, allowing me to have more positive social outcomes. I have longed for acceptance throughout my life, and I am now discovering I can create this for myself.

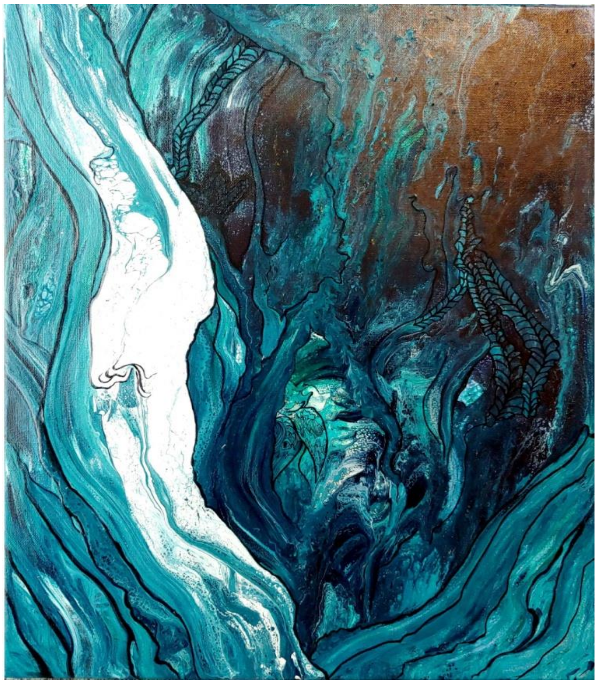

Figure 3: Emerging

Multimedia on canvas, 12x18"

The “Emerging” image represents the tornado effect of growing up in trauma and seeking emergence from a violent cocoon. Despite the barriers to finding joy and success, I have continued to fight for survival, and now see myself in a journey of metamorphosis and change. In the centre of this piece is a feeling of calm, and within it, an angel. I see the angel as a symbol of my mother guiding me throughout my life and the peace I have found. I am no longer the problem child and am engaged in a process of emergence toward fulfillment. The path is not clear, and the details and frantic nature of the surrounding image depicts this. Life will not be without difficulty, and we can find a refuge of calm and beauty to pull ourselves through the waves of challenge when they find us.

> All men and women [people] are born, live suffer and die; what distinguishes us one from another is our dreams, whether they be dreams about worldly or unworldly things, and what we do to make them come about... We do not choose to be born. We do not choose our parents. We do not choose our historical epoch, the country of our birth, or the immediate circumstances of our upbringing. We do not, most of us, choose to die; nor do we choose the time and conditions of our death. But within this realm of choicelessness, we do choose how we live. (Toussaint, 2004, p. 30)

“I’m going to go back to school,” I said to T at the kitchen table. He hesitated, showing his distress on his face that reminded me of the hectic nature of our life. I had wanted to get my master’s degree since I was 24 and had a sinking feeling there would be no perfect time. I felt my history had held me back, the relationships I once had with family had disintegrated, and education was a way I could find myself. In a life full of uncertainty, going to school was a choice I could control. Throughout the nine years I waited to complete my master’s degree, T had told me I could go back to finish once he had completed school, and he was still not done. I felt as though it would never be done. I created our family, and the burning desire I had to change the world would not quiet. The passion was growing by the day and I could not do what was needed without finishing my degree.

<u>August 18, 2018</u> (A. Taylor, 2018)

Being raised to silence,
Is cracking glass
Stretching in motion.
Wordless,
I wandered,
No fitting response.
Gasping.
Dismissed.
“Problemed,”
Blame me.
Pleasant from pain isn’t easy.
“No,” found its way,
Alarmed, hidden, escaping,
To safety.
You shouldn’t throw stones.
They’re beneath you.

Using Art

“Art speaks where words are unable to explain.” (Unknown, n.d.)

I use art in my life for many things, as it brings me peace, purpose, the opportunity to express, and to find mindfulness. Artistic expression is a tool that has allowed me to become who I was meant to be and to explore what always was. It has allowed me a window into my emotions, a way to be separate enough from their intensity without inviting the pain to implode the strengths I possess.

Figure 4: Seeing is Believing

Multi-image painting, multimedia on canvas.

Total size 18 x 48”

“Seeing is Believing” is a representation of the eye being a window to our soul, showing the truth that can be seen, beyond words. Looking into someone’s eyes can tell you a great deal about them and who they are. The branches are the creeping challenges that inevitably meet us on our journey, and the barriers that scar. The spider coming down from one of the branches, like a tear from the eye, represents the sorrow internalized. The sadness must be expressed, and in my case, the expression for many years bubbled out as if it had a mind of its own, through art, through anxiety and panic attacks, and now through articulation.

I use art for many reasons, as art does not know I’m different, it does not lie to me, and cannot create the sensation of danger. Art has always been my friend, a companion when others have left me, something that allowed me to communicate my biggest hurts. Art has allowed me to feel. For me, being still requires maximum effort: with a history of stillness leading to harm and death, I avoid them at all costs.

Figure 5: Still

Multimedia on canvas, 18x24”

The idea of stillness remains foreign to me. Even in what appears to be an exterior of calm, the undercurrent is like a swiftly moving river. My ability to be still and enjoy stillness has been impeded by all those experiences that tell me if I stop moving, something bad will happen. Bad things did happen. The day I remained motionless as my mother reached out to me, she lost her life to mental illness. The times where I have sat still in the face of danger, harm has come to me. I was still when I was a child and unspeakable things occurred. Even while I am motionless my mind remains busy, looking at how I can impact my surroundings, how I can ensure safety for not only myself and my family, but for virtually everyone. Thinking about others' needs has become integrated into every part of my life, to the point where the intensity of my caring can become overwhelming.

Despite knowing the danger was not about me and being still did not invite the harm to come, neurologically the pathways are difficult to recreate. My brain understands that stillness is danger due to thousands of links saying this is true. The reality is that danger still comes, although the forms are different. So I have sought control in other areas of my life, because in my personal life it seemed impossible to find balance and wellness. I found work, or rather work found me.

When Work Found Me

"Great things are done by a series of small things brought together."

(Vincent Van Gogh)

Stillness and safety came for the first time as I dove into research and innovation within the social services as a service provider. My work has become another form of art, as I use the building of supports for diverse populations and caring for community members as an expression of my creativity. To be honest, I have continued to catch myself frantically busy, filling my time with work, art and motion that takes any form, as a distraction from my own emotions.

I spent eight years working on the front line in homes, providing care to families that included children with disabilities, including autism. I would sit with children, attending to their strengths and skills, and noticing how I could adapt to their needs to increase their joy and success. I was later hired to work in the provincial government, and three years later, hired as a clinical case manager in a specialized foster care program working with at-risk youth. I valued the opportunity to have a supportive boss who valued what I brought to the table and looked beyond the differences I possessed. I thrived there, as I related well to children with complex mental health and neurological differences, seeing for the first time that my own differences could be an asset in the right environment. I would pick up youth at their home or school and listen to the stories about their lives, reflect back what I heard, and offer kindness and compassion. Much of the time this offering invited revelations they had not offered others. I felt I could really make a difference in community, and felt my experiences created the bridge to youth who had also lived through trauma and harm.

Confessions of a Do-Gooder (A. Taylor, 2019)
Emerging despite mirrored perfection,
I'm here.
The glorified perception
Feels severe.

Under layers,
Disabled label hidden.
Keeping quiet as
Amplifying truth forbidden.

A joy in embracing the difference,
To a life worth living.
Contradiction lies in
Endless giving.

Being a new me;
Be bold, be kind, be real,
Yet, the truth lies
And I’m unable to feel.

I’m tired,
True to the bone.
I’m fraying,
Trying to be known.

Never enough,
Burning the candle at both ends.
Is it worth it?
I guess that depends.

The smile of a child,
Who has gone without.
I know what it is
Not to be cared about.

To reach out to
A family under pressure,

Generosity of self,
My truest measure.

So, strive on,
Past the fatigue that finds me,
And the reality of challenge.
Working to feel what others see.

Coping

"Believe you can and you're halfway there."

(Theodore Roosevelt)

I have used many tools in coping with my high levels of mental health distress over the years, including common ones like workaholism or avoidance of difficult tasks, and less common ones like dissociation. Dissociation involves the disruption of consciousness, perception, memory, identity and affect (Krause-Utz, Frost, Winter, & Elzinga, 2017; Spiegel et al., 2011), and I am not even sure at times I am doing it. I have used dissociation for as long as I can remember. Whether I am alone or within a conversation, it transports me from the moment I'm living to a place within my mind where I feel both safe and in control. As a child, my surroundings were unsafe, and I used this tool frequently as protection for survival. Dissociation served me well in the past, and those neurological pathways are well ingrained and continue to be used today.

“Where are you right now?” he asked with curiosity. I sat across from him as we got to know each other. I had sought out new treatment for the PTSD symptoms I'd been experiencing for 25 years, after the decades of talk therapy were unsuccessful. In May 2011, I began Eye Movement Desensitization and Reprocessing (EMDR) in the hopes of learning more effective ways of coping with my emotional triggers. EMDR has been demonstrated as effective treatment for PTSD through several randomized controlled trials (Valiente-Gómez et al., 2017). This therapy moment was the first time my dissociation was noticed with kindness instead of frustration at what appeared to be me not paying attention. I had not intended to be distracted by my thoughts of my unborn child Liam, concerns I'd had with my sister's school, noticing the growing trust I felt with this new service provider, and planning a movie night with my partner, all simultaneously running through my mind in those seemingly few seconds. The kindness he showed helped to build a trust and permitted me to learn new skills to cope with the challenges I had faced throughout my life.

Dissociation has transported me to a place where I have control over my thoughts, which has created a platform for my survival. With perceived distress, my mind uses the freeze response, preparing for the flight response, to maximize my ability to get through the environmental distress. The freeze response is not a passive state, instead it is the body’s motor system stopping to prepare for action (Roelofs, 2017). It seems I am always “prepared for action.” I take notice any time in the day when I feel each muscle in my body becoming tense, readying me to escape any danger that may arise. In fact, I can be “resting,” watching a comedy beside my partner, and when I take note, my jaw, neck, shoulders, back, all the way to my feet, are stiff with stress.

Living life as I am is often quite difficult. I live in a chronic state of dehydration due being so busy as to not remember to drink water, I occasionally lose my hearing during high stress situations, and constantly perseverate on issues in our family’s life. To address the high anxiety, I have been known to create comprehensive research binders about problems I am studying or online databases about items we require for our home, such as a new bed for our son. It may seem excessive to others, but this ability to separate my emotion from the issue at hand has allowed me to feel stronger and more prepared.

In learning to cope with the challenges in my life, I have tried very hard to be prepared for anything. But it’s impossible to be fully prepared for the intricacies of finding services. I’ve learned that within each new opportunity for service lies potential discomfort, distress and fragmentation. A new location I am required to be at can have access and inclusion concerns, or a new service provider may be triggered by my way of being. No matter how prepared I think I am, I can become frustrated when the services meant to reach us in meaningful ways lead to additional stress in my family’s life.

As the years have gone on, I have improved my ability to rely on my friends. Calling for support, developing connections, and mutual understanding have improved my life and well-being immensely. Informal and natural supports, such as friendships, decrease depression symptoms and risk (Benson & Karlof, 2009). Developing a close friendship with another mother with young children, one of them on the autism spectrum, was one of the first times I felt truly seen. To have the option to reach out to another person who had or is currently living the realities of my life is emotionally grounding.

Growing a relationship with a friend who deeply understands my reality in parenting my children, who accepts my gifts and areas of needed growth, and remains steady in support during difficult times is an experience relatively new to me. Being able to call upon her in times of distress has dramatically improved my mental health and well-being. This in turn improves my overall coping with life and the challenges of service provider bureaucracy and relationships.

<u>April 2, 2017</u>

Then the Panic Set In (Taylor, 2017)

Welcome old friend. I haven’t sat with you for years. What about today, was today the right day? I guess a panic attack can happen anytime, right? So, why not today?

When you feel your heart start. Your breath erratic. The loss of control. It gets a life of its own.

At school this week, it happened. It’s been nearly two and a half years, but when you have an anxiety disorder, the possibility is always there. Better than several times a day, right? The “you have survived this before. Breathe” so often works. Today? Nothing.

If you’re lucky like me, you have people in your life you can reach out to for help. It’s important... I noticed someone online, who I really adore, and I know really understands me. As I texted with her, she reminded me to come back to my surroundings.

Actual conversation:

“I think I’m having a panic attack.” I told her as I couldn’t catch my breath in the hallway. I wanted to run and hide. I had the good sense to go into a room I knew not many people would be in.

“What colour is the floor?”

“Dirty and needs-to-be-replaced,” then I sent her a picture of how dirty it was. I might have an anxiety disorder but I’m still funny.

She suggested looking at what was in the room I was in. We counted the doors together via text. Bathrooms are gross.

“Can you get to a window?” and I could. So I did. I allowed myself to look at the trees in the wind. Take seconds to be grateful for the sun shining and the snow glistening like diamonds. Coming to the moment brings us out of the panic and out of our body response. This is mindfulness. I can’t focus on my breath, because it will make me focus on my breath! But I can focus on a THING. This brings me back to the present moment. And it is a powerful tool we can use on our own or help a friend if they need support.

Then I could breathe again. And I could return to class.

Why today?

Well, I’m so glad you asked. Why not today?

I am a full-time graduate student in #alltheclasses. I research and study disability in society. So, some stress there certainly. I watched a very well-done movie about adults with cognitive impairments recounting horrific abuse. Again, nothing I don’t know. I work (read: volunteer) at least 40-60 hours a week, supporting my community, with no funding. Why would you do that, you ask? Because I can. We all do what we can, don’t we? And because it’s the right thing to do. Because I don’t want families to struggle like mine.

Mostly, I’m just grateful. I’m here. I embrace my uniqueness. My differences and disabilities. I have so many. I am compassionate and kind to my imperfections. Yes, mindful self-compassion. It is great. And you know what else? They support my connection and empathy to the beautiful people I get to meet in my life. That I’m thankful to know. That make me really thankful to be me.

Using lived experience, especially that which involves families that include disabilities, is an answer to providing a lens to the frameworks of tools created for service providers, such as family engagement practices.

Journey to Acceptance

“A true artist is not one who is inspired but one who inspires others.”

(Salvador Dalí)

Being kind to myself did not come easy and still I falter when things are hard. When I think of how I was raised, like many I was told to, “Suck it up,” and treated as though I should have my problems somewhere else, likely because I contributed to it anyways.

I discovered a local treasure, mindful self-compassion, a course that was both affordable and accessible. The course was offered through an organization associated with a hospital in my city. After looking into the evidence behind the classes, I was intrigued. I attended the series of classes and it felt like running up a hill. It was difficult for me to make the time in my life, which was full of children, school and work while just managing. There was also the difficulty in facing things I had never realized, such as being raised without much kindness from others or myself which affected me much more than I had anticipated.

July 27, 2018

Haunting lies echo in my ears. Once disallowing my inner power, now reminders of who I want to be. “You don’t deserve...” reminds me to be true to my heart, my mind and my soul. To move mountains, I must stay true to my core values and take moments of mindfulness and gratitude.

October 16, 2018 (A. Taylor, 2018)

Be who you are. It is enough.

I have repeated this to myself thousands of times, and yet the feeling of fulfillment is ever-fleeting. Without kindness to myself, how can I be authentically kind to others? Yet kindness to self is the ultimate challenge.

Excerpt from Kindness (Naomi Shihab Nye, 1952)

Before you know what kindness really is
you must lose things,
feel the future dissolve in a moment
like salt in a weakened broth.
What you held in your hand,
what you counted and carefully saved,
all this must go so you know
how desolate the landscape can be
between the regions of kindness.

<u>September 15, 2018</u>

Being kind to myself is a struggle right now. The anniversary of my mother's death is coming and all the planning/preparation (The Winnipeg March for Mental Health has eight confirmed politicians this year!) and distraction has not created the buffer I needed to ride out the waves of challenge. Not even Kit Kats. This is affecting my parenting significantly, and I see my children are feeling my stress. But I feel unable to manage their needs in addition to my own. Mindfulness is eluding me, and I have been unable to sit and even drink a cup of tea without fixating on work. This deep love of my work is both a gift and a curse - and a little more the latter right now.

Becoming

We cannot know what the future will hold. We can become informed on what supports are available and use our instincts to guide us. Through seeing my son in the strength and beauty he possesses, I have been able to see the beauty in myself. I can see that running away or other challenges in our day was a communication, and in fact all his movements are a form of it.

The idea of authenticity is one core value that will be ongoing as part of my journey. The felt sense of being true to myself in my thoughts, feelings, and actions is something I did not have modeled as a child and I have found so rare in this world. Identifying what makes me unique and not allowing myself to feel shamed for it is an integral part of my transformation. As I see myself now, I see someone who is neurodiverse. This is a term I heard in 2016, which positively described neurological differences like the autism spectrum or living with a brain affected by trauma and described to me a normalization of the natural variations of the human brain I live with.

October 10, 2018

The poem "Washing the dishes to wash the dishes" (Thich Nhat Hanh, 2016) speaks to me and my journey in finding the joy in the smallest of details. “If while washing the dishes, we think only of the cup of tea that awaits us, thus hurrying to get the dishes out of the way as if they were a nuisance, then we are not 'washing the dishes to wash the dishes.”\' What’s more, we are not alive during the time we are washing the dishes. In fact, we are completely incapable of realizing the miracle of life while standing at the sink.”

The Next Chapter

“Up, up, up. That’s it!” (Liam Taylor, 2018)

From here, I can only go up, reaching for clarity and offering the insight I possess to those who may carry it forward. This study has given me the opportunity to express the stories from my life, many of which have remained untold until now. Having the space to articulate my realities and how they affect my current lens brings me confidence that offering support can create change in my community, in the hope that one person will read my story and shift the trajectory of their life, impact others, and create ripple effects of understanding.

The life of attending school while working two jobs, experiencing my marriage fall apart over 18 months, and raising four children has not been easy. The distraction from my sadness has been welcome, but there has also been sacrifice. There were many days while completing this project where I used television and snacks to distract my children from my inattentiveness, and days where my children called for me repeatedly while I pretended I couldn’t hear. I have not and could not have done it without the sacrifice of many, which has allowed me to put stories and image to paper, to perhaps shift the landscape of accessing autism services.

As I make the steps forward to become who I am meant to be, within the frame of celebration and honouring my neurodiversities, I am in uncharted territory. I am for the first time in my life creating safety for myself. I no longer feel the need to locate protection for my body and mind from the world, as I find that the strength I needed to survive has been within me always.

The challenge is now how to reconcile the path required of navigating services for my children while embracing the need of community, including the change required for social services. As they intersect, the balance required of being an advocate versus being a mother to children with differences collide. I am not naïve to see that the 2 needs require a different communication style, yet the need to stay true to myself is paramount.

Life is complex and so am I. The impact of my life and not being able to save my mother has launched me into serving my community, but also created the framework of how I interact with service providers throughout our journey. The next chapters look hopeful, with my awareness intact, guiding me to be present to my children, my family, and to the opportunities for increasing core competencies in my community. I feel as though I am now beginning to truly live.

Section 2: The Beginning of a Journey - Accessing Care

Accessing care for my son within autism services did not begin the moment the doctor agreed to refer us for the assessment I requested. The journey began long before then and developed alongside my childhood, my relationship with my mother, and then again, the moment I held my son in my arms. The urge to nurture and protect begins for many of us as children and is engrained over our lives to inform us on how we should be. When I decided to be a mother and bring children into this world, the idea of creating others who will care for the earth and those who make up our community was appealing to me.

For me, becoming a mother is the single most monumental experience of my life. I considered myself a mother as I raised my sister, and yet something happened when I grew my children within myself and brought them into the world. I understood then, that when my mother died, so did a piece of my heart. And too, when my first child came into this world, I was permanently changed. I then understood my mother’s love for me so much more clearly and the reason she sacrificed as she did and even why she is no longer here.

August 15, 2018

Ode to a mother (A. Taylor, 2018)

Breathless,
Mocking Fatigue.
Find the time
Without compassion,
“You must.”
Rest
Is for the weak;

Sleep when you’re dead.
“How do you do it?”
Mindless droning
Eyes drooping
Push on.

During my second year as a clinical case manager, I discovered we were expecting for the second time. It was a wonderful surprise and despite our home life being unbalanced and chaotic, I fell in love with the idea of having another child. But I worked with young complex youth during the day at my job, and in the evening came home to my sister who was at times unstable and I found myself becoming increasingly distressed. One afternoon, I lay in bed, realizing I was losing the baby. Comments from colleagues, family members and even my boss were that the loss was positive, as our life could not manage the addition of another stressor, yet the urge to fill the loss of our unborn child led me to plan to grow our family shortly after. The feeling of loss was profound, and after a lifetime of loss, was too much to cope with. I was overjoyed to discover we were pregnant with Liam two months later. My pregnancy was at first uneventful, in that I was only slightly ill with dull nausea and was able to continue to work.

“Oh my,” I said as the nausea wave was peaking, and I braced myself on the side of the building on my way to a clinical meeting. I cooed to Liam, “Hey my sweet child” and caressed my round belly through my coat. I noticed he was gentle throughout my pregnancy, and in comparison, to his older brother, moved with less force and with more response.

The lingering complications of a lifetime of stress and the body changes associated with pregnancy became problematic approaching my fifth month of pregnancy, and by six months I applied for disability from my employment. I enjoyed the time at home, did creative projects like drawing and painting, renovated Liam's new room, and began to experience a close relationship with my son, singing to him daily and looking forward to his arrival.

Liam has Arrived!

In the weeks prior to Liam's arrival, I prepared meals, placed the final touches in his room, and washed and folded every piece of clothing he would require in the first three months of life. I would catch myself counting down the days until his due date, checking and rechecking, and spoke to him as if he had already joined me in the outside world.

"It's time!" I shouted to T, the phone resting close to me on the floor, unable to hold it. He had taken the children out to give me some time to relax, as the contractions had been going on and off for over 24 hours. I joked and laughed between contractions once we had met our doula at the hospital. Liam was coming to join me, and I was elated to meet and hold him.

August 7, 2011

This is one of the best days of my life! He is here! Our beloved son Liam has been welcomed and my heart sings with love and happiness. I'm not sure I have ever known a deeper love than having these children in my arms. Oh, the plans and hopes we have for him, and the home we have built to help him grow. I love this intensity of connection when we gaze into each other's eyes. As I speak to him, how he hangs on every word. I could bottle this feeling up for the rest of my days and be the luckiest person alive. Discovering his differences as a gift to this world lit a fire in me that would be a blessing in my own journey to discover who I was and what my son could become.

Discovering Difference

"At the end of the day, we can endure much more than we think we can."

(Frida Kahlo, n.d.)

My son and I are two of the approximately 1.8 billion people with disabilities worldwide (Woodman et al., 2014). Not surprisingly, children with disabilities are more likely to have a family history of neurological differences and increased risk for mental health disorder (Bourke-Taylor et al., 2011; Emerson, 2003). Coming to terms with our differences was not a seamless transition from the life I had imagined for us. The hopes I had etched for our family were erased before they could be created into acceptance.

Figure 6: Liam

Pencil on paper 11.5x14"

Liam was born a loving child, with attentive care towards his family and a gentleness that other mothers made open statements about. At a playdate with another large family, the mother stated to me that she wished her son, who was around the same age as Liam, would be more like him.

Liam's large blue eyes promoted strangers to stop in the street to compliment him on his "deep soulful eyes." He would sit contented in my lap on outings and went with me wherever I went, and as long as he snuggled with me in his baby carrier, he would sleep, smile and observe his world. I even took him to comedy nights, and easily reassured staff when they asked that he would be no trouble at all. He rarely cried or was observed in distress. As long as I held him close to me, he was safe.

Things changed when he began to toddle. He was already 18 months when he began to walk. He never spoke a word, except his "sticky" words, where he would hear a word like "hockey" and repeat it dozens of time a day for a week and never say it again. By 18 months, children with developmental and neurological differences often show this within their social, language and motor skills (Lemcke, Juul, Parner, Lauritsen, & Thorsen, 2013).

The need for me to be close intensified, and I noticed he would become upset if anyone other than me fed, carried or played with him for more than moments. I could see his eyes search the room for me if I stepped away. He did not enjoy peek-a-boo as our other children had, unless we were inches away from his face. Arranging to prepare dinner became interesting as I would be required to have him within 24 inches from me, and on a chair on the counter, needing to speak to him and look towards him constantly.

Liam was a danger seeker and I would refer to him as my "danger monkey" as he moved precariously on the edge of decks and ledges without any fear of falling. Walking and balance was still a big concern for him as he showed me it was difficult, yet I often viewed him leaping from the couch to his highchair without looking. I would try to hold my face still as a way of hiding my fear response from him.

With Liam’s increasing avoidance of others, family members began to comment that he must not like them, which only further increased Liam’s distress. He tried relentlessly to connect, but his speech and struggles were getting in the way. “What is wrong with him?” they’d ask when he’d cry for me and did not walk by 17 months. The effects of having no one who seemed to understand my experience was isolating and created a framework of doubts: am I the problem or are the issues in my mind? These questions played on as I worried about what might be the cause and the solution. I felt as though we shouldn’t do anything, including vaccinate, until we knew what was happening.

Making the Decision to Vaccinate

Autism was on my mind, even when Liam was an infant. I had supported children in the community for years, and many of those families included children on the autism spectrum. These children and the effects of autism on their families, along with the associated decisions, were at the forefront of my mind as we raised our children. Then too, the decision to vaccinate was also well considered. I had read in newspapers and saw on television that vaccinations were linked to autism and research evidence-based literature that the link was false.

In the doctor’s office, I sat with apprehension. We had been asked to attend an appointment to discuss future dates and getting up-to-date on Liam’s vaccinations. We had made the decision to vaccinate our first son according to the doctor’s schedule, and with the newer vocalizations from celebrities and friends hesitating and avoiding vaccinations altogether, we started the conversation.

Me: I think I want to delay all his next vaccinations

Doctor: Tell me why (said with flat tone and expression).

Me: I’m scared. I’ve read some conflicting information on vaccinations, and I have seen the complexities within the families I support. Disabilities are so hard to manage, and I just want to make sure we do the right thing.

D: There is absolutely no link, but you can delay them if you wish.

We did delay his 18-month vaccinations, because I considered the ingredients and his already vulnerable body, and I was concerned he would not be able to cope. I took months to gather the facts from the media and medically-sourced evidence and found there appeared to be no link between the vaccinations and the increased rate of autism. In a meta-analysis, Taylor, Swerdfeger, and Eslick (2014) stated that vaccines are not associated in any way with autism. Within five cohort studies that included 1,256,407 children and five case-control studies including 9,920 children, it was found there was no relationship between vaccination and autism (OR: 0.99; 95% CI: 0.92 to 1.06) (Taylor et al., 2014).

I often sat looking into Liam’s eyes and wondered “What do you see?” and “What is your experience?” I felt peaceful and in love with this small being we had created. I look back now and see that he always experienced things differently. The decision to delay vaccination was not a factor in his development, yet it was a factor in my ability to feel in control of my son’s life. This control matters because in nearly every area of my life, in raising my son, his behaviour challenges, staying home with him, and being mainly alone in the world, I was without it. Just as I have been without the sense of control throughout my life, having a child with exceptional needs brings light to all the unresolved pain one may have forgotten. Perhaps I wanted to forget and worked so hard to leave it all behind. Yet pulling in service providers and their contribution to power and control is a necessity. The internal discomfort and fears for my son's future, and if I was researching the right thing or spending time planning in his best interests, ate at my wellbeing. And still, I had to wear a brave face during countless requests for support, being told by family there was nothing wrong with my son, and in fact it was my parenting and me that was the problem.

October 10, 2013

Beyond this moment, I dream of bigger and better times. These hopes sustain me during those dark times. The times that no one is to speak of. I am so tired of this! I feel like no one understands what this is like. I am here alone every day with a child who is in distress (eight hours of crying!) and my deepest pain is not being able to help him. We are expecting, and I am scared as my sickness increases, that I will not be able to keep him safe. I am nearly bedridden and unable to engage him as I was. The medications only make me sleep, which is worse for preventing danger, so I am without any reprieve from being ill. “Oh, how blessed you are” does not take into account that no matter how blessed, pain is still pain and disallows me from saying my truth that I need compassion and care.

And Baby Makes Six

I was in a car accident when Liam was 20 months old and was hit from behind by a two-ton truck. The driver was distracted and hit my vehicle as I was stopped at a red light. The impact would cause my body to go into spasm, including my neck and spine. This made caring for Liam’s needs difficult. During my recovery I discovered I was expecting again and, likely due to the pain and spasms, I was losing the child. The longing for the child I lost surprised me, as the increasing coping strategies I had learned did very little to address the emotional suffering I felt.

The thought of adding to our family began to increase for me daily, even though pregnancy and another child would complicate our family life significantly. Within weeks of losing our baby, we were pregnant again with our sixth family member. My energy levels rapidly declined and my ability to respond with hypervigilance was inhibited. Hyperemesis gravidarum is a relatively rare pregnancy diagnosis that includes high fatigue, morning sickness and vomiting day and night (Lutomski, Mccarthy, & Greene, 2014), which in my case went up until 34 weeks. I spent my days sleeping on the couch, with Liam watching his favourite shows while my legs rested on his lap. This was the only safety measure I could think of that would allow me to know when he got up to leave our home and run into the street.

T and I discussed our social support limitations, the barriers in the system to finding service, and my own limitations as a mother, now chronically physically ill, and we made the decision to seek out daycare. I understood that confirming a spot for a child with additional support needs would be difficult and frustrating, as the waitlist for typically developing children were many years and children with disabilities can get turned away. I was told by daycares I called there was little chance of finding a spot for Liam and a private home daycare might be our only option. The higher cost of private daycares was a deterrent, but as our options were limited, we began interviewing home daycare providers. The fear of disclosing his additional needs were not far from our mind, as we could not live with a denial due to our life circumstances and my inability to carry on.

Liam began receiving part-time care, and within weeks the home care woman noted he would scream “without any reason,” disrupting the other children. Each time she shared this, the fear of being turned away intensified, and my anxiety about how our family would be able to manage the next months grew.

During the pickup time, I would knock hesitantly on the door, playing through the possible scenarios of his day, wondering about what type of challenge he would have experienced and concerned about the conversation I was going to receive upon entry.

Staff member: Come on in.

Me: Thank you. How was his day today?

Liam would crawl to me quickly, smiling a big smile. I would lean down to pick him up and hold him as he gripped onto my body.

S: He just screams so much. The other kids just cover their ears and try to leave him alone. He does not want to share the toys and can't seem to end things when it's time.

Me: I know it can be hard for him when he tries to talk and others don't understand.

S: It's not that. I just smile and nod and say "oh yes…" but he screams anyways.

During the months he attended there, I called my preferred daycare weekly. I believed the quality of care and opportunities to learn would increase in a licensed facility, as I knew the training for staff was often superior to home daycare providers. Social inclusion was going to be a challenge for our son and I wanted to equip our family with the structure a licensed centre could provide to diminish the barriers of loneliness and exclusion Liam might experience in his life (Koller, Pouesard, & Rummens, 2017). Difficulties accessing childcare are common for families that include children with disabilities, with 21.5% of families stating that childcare services or programs had refused to provide care, increasing to 31.7% of children with severe to very severe disabilities being refused (Statistics Canada, n.d.).

November 11, 2013

Things are so hard! I have been to the doctor three times about him missing milestones, and I have this sinking feeling that there is something more going on. What if the gut feeling I have is right and I am missing the window of early intervention by listening to these professionals? I have made another appointment today and I plan to tell him that I will not leave until he refers Liam for an assessment. Must. Gather. Energy.

Seeking a Diagnosis

The significant behaviour challenges were ultimately what pushed us to seek out diagnostics. The behaviours themselves, including up to eight hours a day of screaming, climbing into the freezer, jumping from couch to highchair without a fear response, kicking, hitting and running into danger, were the most difficult for our family, and perhaps especially for me. Keeping him safe was my main priority and it was beginning to wear me down and affect every part of my life, including my mental health. Not being able to look away for fear of injury or death made me feel like if I admitted my distress, I would not be able to keep going.

As a caregiver, my own behaviour and mood would become dysregulated because of the high levels of isolation and managing with hypervigilance the high needs of a child who could not be left unattended for one moment. I would enter the bathroom, and Liam would jump off the couch where he was watching a show, open the door and go out to the street without shoes or a coat, and unaware of the danger of oncoming traffic.

Challenging behaviours are likely the most significant challenge for parents of children with developmental disabilities, with these difficulties often more strongly related to parental stress than the disability or difference itself. And just as populations without an autism diagnosis are affected by parental dysregulation patterns, so too are children with autism; the dysregulation can lead to increased behaviour problems (Granic & Patterson, 2006).

I worked hard to regulate myself and be the calm and doting mother I had dreamed of being. I knew the effects of my responses would help shape who Liam would become and affect his development. Levels of maternal warmth are correlated to increased adaptive behaviour and lower levels of what is referred to as "autism symptoms," as well as behaviour problems, while depressive symptoms and/or criticism are linked to higher levels of child psychological symptoms (Smith, Hong, Greenberg, & Mailick, 2016).

Bigger Than All of Us

After over a decade of working in social services, I had anticipated accessing supports as a manageable task, as I was skilled in knowing where to go and the language to use in requesting service. Nothing could have prepared me for the challenge of accessing service for my son. Having impairments in the family would bring additional barriers that would prevent us from getting help for months and years at a time, waitlists up to three years, and private clinicians too costly for our family to afford.

As I drove to attend to my son having another escalation at daycare, I wondered to myself, "Am I even cut out for this? Why is parenting so difficult?" and tears started to pour down my cheeks. I would daydream about running away to the Barbados, turning up the music too loud, focusing on the instruments, and imagine myself anywhere but here. I wondered if my family was better off without me, because even after a lifetime of social service experience, I couldn’t find the support my son and family required.

But despite my doubts and frustrations, I had to push on in advocacy and get the help we needed, or one of us might not survive, and I was unsure if it would be him or me. I reached out to colleagues who were also service providers in the social services and asked what their experience was with families. I learned these feelings were not uncommon and experiencing fragmentation within the system was commonplace. They pushed me to “follow my gut” and proceed with advocacy in the medical system to seek out a diagnosis.

I was raised to believe that we need to follow the doctor's instructions, as they know best. Yet after inquiring about my son’s developmental concerns for 12 months, I was tired of being told to “wait and see.” I sat in the doctor’s office and told him, “I will not leave until you refer him for an assessment.” I had practiced in the mirror, had encouragement from my supports, and yet I shook and nearly lost my words. To my surprise he agreed, and told me the best and quickest option was to see a pediatric developmental specialist. He explained he would complete the necessary forms and it would be a matter of weeks before we would hear back from the developmental pediatrician with an appointment.

The assessment day came, and we were invited into a small cluttered room, with papers in stacks over two feet high, lining each wall on tables, and a child-sized table near the centre of the room with six blocks upon it. T and I entered the small room after being called in from the waiting room in this downtown clinic. We sat down with our then two-and-a-half-year-old son and were asked a series of questions about him and his developmental milestones. We summarized the escalating behaviours, at times leading to eight hours of distress in this small child, running into oncoming traffic with no fear, speaking only through echolalia, mimicking the same limited words in the exact intonation and tone of the speech he heard, the transitional difficulties and dangerous behaviours exhibited over the years.

Doctor: Here, get him to play with these.

She sat at the child-sized table across from my son and I, with him sitting on my lap. She pushed the five blocks around with her hands, staring at Liam's face. He leaned into me, and I could feel his heart beat quickly against my chest.

D: Get him to do this.

She offered me the blocks and put them together about 12 inches from my face. I handed the blocks to Liam, using my voice to calm him, showing him as the doctor had showed me, and requesting he do the same.

Throughout the short interaction I could see and feel the frustration in the clinician's body and face. Liam looked to me for comfort, and looked towards the doctor as she brought her face towards his own. Prior to leaving, the doctor asked me to speak to her alone, and while T took Liam out of the room, my body shook involuntarily as I sat to hear what she would say.

D: I think Liam has a developmental delay, which means that his speech is delayed by more than 18 months. Eighteen months was the clinical diagnosis marker. He may have a global developmental delay as well, which means a delay in every area of his development, but I haven't seen enough to know that is the case. I can fill out the paperwork and get him into

Children's Disability Services to access support. They would open a file there for him, and he can receive support until age 18, then moving into adult supports.

Me: What about autism?

D: He's not autistic.

Me: Why do you feel he's not autistic?

D: There are many reasons. For instance, his relationship with you. I can see he's very connected to you. Also, he can make eye contact.

Me: He does make eye contact but only to us and when he is seeking reassurance, and I do have a special relationship with him, as I've been home with him every day since he was born.

D: You have to pick your battles. If transitions and turning off the television causes him to have a meltdown, then let him watch it. It won't be like this forever.

She got up, and walked slowly towards the door, and I saw how I had been dismissed. I left the office to find T and Liam, walking in a fog. I replayed her responses and the experience in my mind repeatedly, considering different phrases I could and should have used. I thought perhaps if I had shown her more of my notes, or if I had been more clear and direct she may have understood. Should I have had T direct the meeting and was it me that was the issue, preventing him from getting the diagnosis I knew to be true?

February 16, 2014

What a ridiculous experience. I cannot understand how this came to be. I am so surprised that a specialist can deny a diagnosis of autism because my son is connected to me. I know these characteristics and behaviours do not define autism. The nearly 15 years of experience supporting those with autism tells me there is something else happening for him, yet I must accept the word of someone who has seen my son for a snapshot of his life, a brief 20 minutes, as a judge of his future.

I recall calling a friend and colleague in tears about the developmental delay diagnosis that I was not expecting. She was silent, holding space for me, and told me my son was the same boy he always was. “No one can know what will be for him, no matter what diagnosis or differences he may have,” she said. Yet I began to feel depressed and anxious, perseverating about the assessment, what I should have said and her responses. I began to take the perimeter highway route, so that while picking up my son from daycare, I could cry without anyone seeing my reality of sadness. I walked for weeks in that fog, unable to process the experience, and not having anyone I felt who could connect with my experience.

The developmental pediatrician had not completed the forms she had promised, and I followed up numerous times, as they are required for receiving support through Children’s Disability Services and getting the tax credits from the government. After the third message over four weeks following the assessment, T called me from work, asking why I sounded upset. I began to cry and shared the past month of how the doctor would not respond to my calls, and how the documentation she had not completed was needed to move forward in accessing supports. T suggested he attend the office during his lunch hour and remain there until they completed and handed him the documentation. Bringing the forms that evening was just the beginning, as I had to complete, copy and mail them for review by the Canadian government. This was the first step in getting the children’s disability tax benefits and primary tax benefits that would allow us to fund some of the necessities for our son, and reduce the financial burden placed by the additional costs we had incurred.

Service providers are responsible for a great deal, including understanding the challenges of families, even during times where the family may not be aware of their own challenges. Seeing my body language as I entered, hearing me tell our story of how our family was not sleeping, that our son was actively distressed for more than a year, and that we were struggling, should have elicited a response. I saw a need for prioritization of care and responsiveness to alleviate the distress I know to be a reality for families like mine.

During this time, we continued to take our son to the services available to us. The one-hour every four-to-six weeks was within the hospital, consisting of service providers printing off and explaining sections of a resource textbook to read on our own time as homework. Within each session they would try and fail to get our son's attention, as he looked to us for reassurance that he was safe. These sessions caused high levels of distress, as the new environments were overwhelming, including the sounds, new faces, new expectations and necessary ways of acting, listening and sharing. We were instructed to get him to complete puzzles and follow short sets of instructions. T and I would also be asked a series of questions to update the service provider on the latest happenings of the past month and summarize challenges and growth.

Each appointment took nearly three hours for each round trip. I did not feel they were a good use of our time, yet there was nothing else available to help us support our son's growth. During these sessions, service providers instructed us with such advice as, "Sit with your child, listen to them, be interested, and repeatedly say new words…" which we had done already for several years, daily, without progress. They would slide photocopied textbook chapters over to us while we sat across from them and request us to work on the chapter until the next time we saw them. T and I would review the "homework" once at home and joke about the rudimentary aspects of the information. While bringing concerns up in the session, we would be told this is all there was and we could always pay for private assistance if we wanted something different. Staff would appear rushed, distracted or communicate with a short temper, and overall, I felt as though our son was an interruption from their real work, instead of a family who needed help and their role being to provide this help.

We began to receive some financial support from our family to take Liam to private occupational therapy and speech pathology, which confirmed our suspicion of autism, as both professionals asked why he had not been diagnosed. The conversation of assessment had come up frequently with daycare staff, my colleagues, and families we knew, all carefully hinting about and asking questions referring to autism.

Private support was not what I had hoped it would be. One professional would direct our parenting while in session and appeared short-tempered on many occasions. The impact of curt tone, eye rolls, directive language such as "don't bring that [Liam's bag] next time," and other such communication affected me greatly. As a newly-pregnant young mom with three older children, one of whom did not sleep or eat well and was exhibiting consistent behaviour challenges, it was emotionally difficult to feel the blame, as well as the shame associated with it. Unfortunately, the connection and support of a service provider carrying us to a feeling of safety and care was not happening.

I made another appointment with our family pediatrician and requested support in getting Liam to the lead clinic for a reassessment and was met with refusal. I asked again to meet and brought in documentation from each service provider questioning the first assessment, and our pediatrician agreed to call all the way up to the head of the clinic to get special permission for

Liam to be reassessed there. We were told he had already used his allotment of provincial resources and this was seen as exceptional circumstances, as no family was allowed to receive two assessments, no matter the reason.

My anxiety met me again at the door, as I knew it would be additional months of waiting. Beyond this tactic, if this did not work the way I was hoping, we would be left with private clinicians and $2000 assessments. I questioned myself throughout this time, wondering if I was making the right choice to push on, to demand support for our family who had been in distress now for nearly 20 months. Liam continued to run and we were unable to bring him into public for fear of his safety. I was unable to continue many of the friendships I build over the years and felt increasingly isolated. Over these months, the disparity between my knowledge of my son's disability and the inability for those around me to articulate "disability," "delay" or the like grew. I felt alone in knowing his autism was still undetected.

The day had finally come to meet the new clinical assessment team. I sat down with my folder in hand, including documentation from other professionals we'd seen along the way, articles about autism, a list of questions I had prepared, and a diary of behaviours and concerns. I was shocked that without opening my folder, within five minutes this new professional said the word "autism." She looked at me, eye to eye, and offered compassion and choice.

Doctor: I am seeing he is on the autism spectrum with a global developmental delay. I have a feeling that this is something you already knew.

Me: (nodding)

D: Don't be alarmed by the global delay part. This often comes with autism and means that in many ways there is an 18-month delay in his development. Those on the spectrum often have delays in many areas and can take a bit of extra time to catch up. Do you want to book further assessments and a date for the ADOS (Autism Diagnostic Observation Schedule)? He fits within the criteria for autism as I've assessed him here, so it's not necessary, however I am happy to book him if that is what you want.

Me: What would be the benefit?

D: There would be no benefit. As it stands, he will have a formal diagnosis of autism, and this will allow you to get the funding you need for his services. I can fill out the documents for the CRA (Canada Revenue Agency) to get you the tax credits. I see you already have support through Children's Disability Services, so that will not change. The further assessment will delay accessing support.

Me: Then let's move forward with the diagnosis.

I cannot forget the relief and pain I felt in those moments. Autism, the diagnosis required to receive the care and support our son and our family needed for over a year; the diagnosis that describes his difficulties and differences in a way that offers a reason why, a reason that does not lie in me as a parent and the inadequacies I bear. This was the first moment I felt the challenges our family and my son lived with were possibly not my fault, and they were caused by something else, unrelated to me.

September 28, 2014

She [the doctor] said, "You know he has autism, right?" And all I could do was nod. Tears. I fought so hard for this moment and here I am, lost.

<u>October 14, 2014</u>

She [the doctor] already forwarded the forms we needed to get care for Liam. I feel like I won the jackpot! After years of one challenge after another, I am so so grateful to have someone really listen and follow through. I'd better buy a lottery ticket!

They Call It Autism

My son had finally been diagnosed on the autism spectrum. Autism affects approximately oen in 66 children and youth in Canada, with the prevalence in boys being four to five times more likely (Public Health Agency of Canada, 2018). Of these, 85% of children are diagnosed prior to the age of ten (Vehling, Brownell, Kaufert, Nickel, & Alessi-Severini, 2016).

The autism diagnosis did not bring magic or access to the necessary services in their entirety as I had hoped. Within a week, I received a phone call from the hospital where we had been accessing minimal supports. The service provider stated the service we had been receiving would be removed as his new diagnosis of autism showed his needs were "too great" for the services they had. I was told he required in-home services, which may lead to us waiting 18 months or more. Ultimately, she shared their team had "no idea" how long our family would be waiting for service and there was nothing they could do in the meantime; it was their mandate to remove all children with a diagnosis of autism from their caseload and place them on an indefinite waitlist.

Lack of services and waiting were not our only barriers to living with our son. During these years we avoided all outings or leaving the house with Liam. In our home we could ensure his safety and manage our anxiety and stress levels much more efficiently. At friends' homes, our friends' children could be unpredictable and safety precautions like a fenced yard or baby gates were not a guarantee.

Simple outings like picking up a gift for a child's birthday party began a series of escalations that would derail our family's day and affected any interaction afterwards. As I prepared to get a birthday gift ready for my older son, I helped put the three children into the car, so we could attend a local bookstore to pick up the item. I spoke to the kids about what was going to happen and walked hand-in-hand with Liam, bringing his attention to the treat planned afterwards. While waiting in line I could see that Liam's body shifted from relaxed to stiff and stressed. I lowered my body to his, my eyes meeting his eyes, and I quietly and soothingly spoke, "Hey, Mom is here. I know it's hard to wait, and after we get to the front of the line, we will go for our treat." This type of conversation was typical for us, and despite him having limited verbal communication skills, this would provide the regulation he needed in these moments. We continued to wait, and suddenly he turned from holding my hand, running into the store and towards the door to the parking lot. I jumped from the line and grabbed his body with my arms> He pulled me to the floor, with him now screaming. I spoke softly into his ear, "You're safe" and planned a quick exit. He continued to scream, cry and move his arms rapidly, hitting me in the process. A crowd began to gather, and an older woman walked over to us, stood over our bodies and raised her voice to tell Liam that he was a "bad boy" and should listen to his mother.

Understanding the good intentions of others does not overshadow the awkwardness or alarming nature of these comments.

For this reason and many others, I felt an expectation to stay home with Liam, reasons that included more than family direction and societal expectation. I felt at that time, and still do, that the burden of raising children, especially exceptional children, lies mainly with the mother. I see mothers like me working more than two full-time jobs, raising exceptional children, working out of the home, attending school, and maintaining an illusion of polish. The rawness of life has shown me this illusion is not healthy and by pushing myself to adhere to the highest standards, I will make myself ill.

The timeline for these years can feel like a long series of dates and challenges. I certainly feel that way as I look back to those times. The summary below depicts a clearer image of some of the significant details of 2013 to 2017.

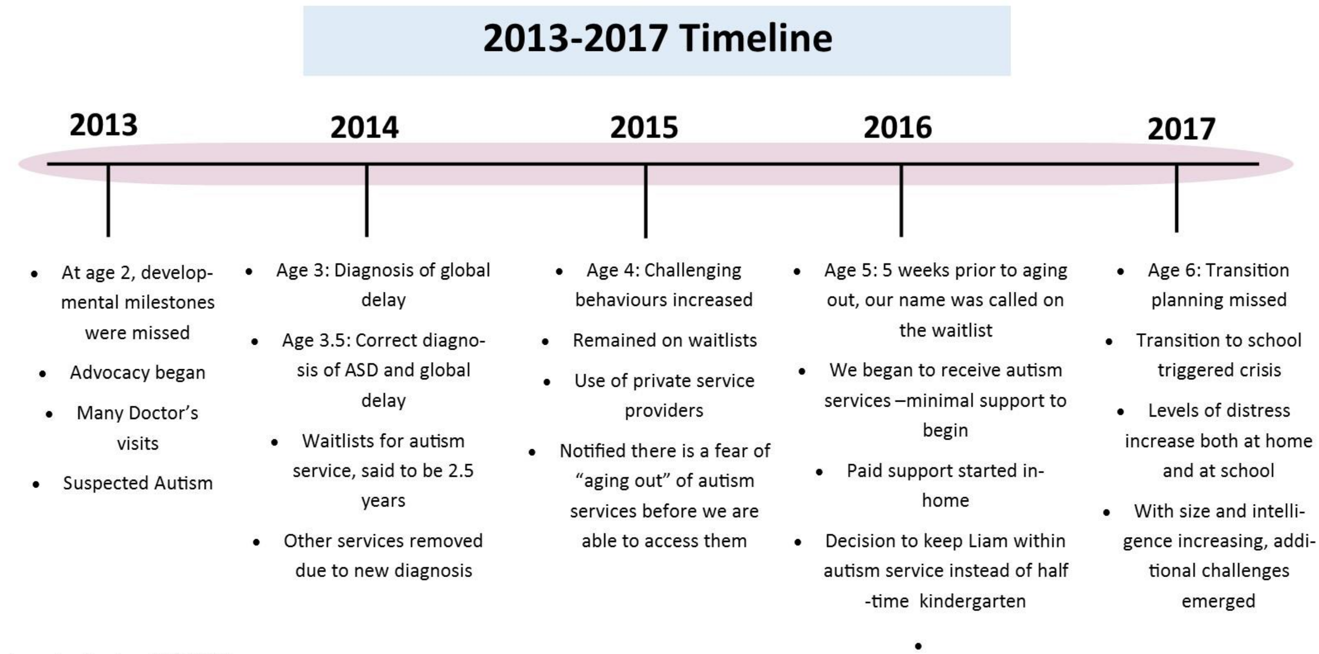

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Figure 7: 2013-2017 Timeline

Finding Connection

Connecting to my son in some ways has come easily and naturally, and in other ways it has been difficult. Liam experiences his world differently and is sensitive to the sounds and sights in his environment, so the way I was taught to guide behaviours, including verbal communication, were not as successful.

Research shows that the attachment and emotional processing in children on the autism spectrum is different from children not on the spectrum (Sivaratnam, Newman, Tonge, & Rinehart, 2015). So too my child responds differently than most, including his facial expressions, body and verbal communication. Since a parent's ability to be responsive is based in the recognition, understanding and interpretation of their child's behaviour, body language, facial expressions and speech, this means a child’s disability can inhibit the parent’s ability, creating increased stress and detachment between them (Howe, 2006).

When the surprise of the autism diagnosis hit me, I was alarmed at the prognosis I was given by the service providers. Thinking for that short time that my son would not live a fulfilling life created negative effects in my parenting. Interactions between a caregiver and a child living with a disability has more to do with the stress and state of mind than the disability itself (Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009; Howe, 2006). The closeness I felt was impacted by the perspective of those around me, including my family and the support system. My inattentiveness and stress also increased his challenging behaviours as he sought comfort and connection. His challenging behaviours exasperated my distress and things came full circle, just as it had with my mother and I, where I felt less close to him due to his increased behaviours. Mothers report less closeness as the severity of the child’s autism or associated behaviours increase (Lopez, 2013). The truth is, I was fully responsible to provide a consistent and attuned response to my son, and within the environment I survived, it was very difficult. It felt impossible.

Decisions for Therapy

The decision was presented, do we want to have full-time behavioural support or a handful of hours of developmental attachment therapies? Mixed messages about the value of each swirled in my mind, yet the decision seemed clear due to how much support was being offered within each choice. I had been previously trained and saw the value in applied behavioural analysis as well as developmental interventions, like attachment therapies, and I did my best with the internal resources I had to initiate both within our home. I needed help and I needed a lot of it. I began the steps to learn more about the details of options available to us.

In the large hospital-like centre, I went to meet and learn with a service provider from the behavioural team. I sat with my newborn in my arms, sharing how Liam runs from us and our home, into the road, and began to cry. She told me the only researched supports for my family were the ones that her team offered, and I could complete all the applications for service and wait for both programs in tandem. We would wait up to two years for behavioural support, and less, although no specified time, for the developmental interventions. I was told if we were accepted into either program, accessing the other would no longer be an option. I was also informed that without completing the forms immediately, I would increase the chances of my son aging out of care prior to receiving any, as he was already three years old. I wiped my tears, soothed my baby who had also begun to cry, and signed the papers.

Immediately after this meeting, I began to research and locate affordable and accessible training. T and I struggled to make the necessary accommodations for one of us to attend while the other managed our growing family. Due to our son’s delay in speech, we were eligible to receive a third option, an intensive intervention to improve our connection to him and increase his verbal communication. We were accepted and began the long assessment process. It was stated to us that if we began with this support we could not receive any behavioural supports, as it was considered to be “undoing” the support they would do. We could do this program, not knowing the benefit it would have, or wait indefinitely for another program that may never come. The risk of aging out of behavioural support and not receiving any help was great due to the 2.5-3-year waitlist, so we agreed to invest our time into the developmental resource.

The sessions were several hours long with up to six weeks in between each session and homework between them. T took time off work, and for many of the sessions we took Liam out of daycare and his routine, to a new location with increased risk and challenge. We managed to keep up with hours of homework each week, seeing no improvement, and coped with comments about our parenting from the service provider each session. During one session while showing a video we made of the joys of interacting with our son, she leaned over and smirked, stating that we were feeding him like a dog. To know why we didn’t leave after enduring these comments is to not fully understand the landscape of service, and if you say the wrong thing, speak up or withdraw from the service, you risk the possibility of gaining no further help for your family. We continued at a detriment to our own mental health and well-being to the hoped-for benefit of our son.

During the time the assessment was being finalized, we were told we would not hear from the service provider for several months to allow them time to complete it. During this time, Liam went into crisis, increasing his behavioural challenges, screaming and hitting behaviours, and decreasing his sleep once again. I called, and after no response, emailed, stating we needed help and Liam was struggling. The email response stated we would have to wait until the new year (3.5 weeks), and the assessment was not complete. The precarious nature of a parent’s mental health with a newborn and three children, two with complex mental and neurological needs, does not lend itself well to waiting nearly a month for support. I felt at that time I was sitting on a ledge, where at any time I would disintegrate with worry and distress.

The following week we got the call that we were accepted into the full-time behavioural support and a team would be trained, and one staff member would attend daycare with him. After discussing it, T and I agreed that not having to book additional time off, removing Liam from his routine, and hearing comments of how we were harming our son with behaviourism would be welcome.

I asked T to call the service provider to tell her we would no longer be working with her, as I felt my capacity for her reactive responses was limited. When I asked him that evening how it went, he shared that she did not respond to his words, except to hang up on him. Months later I saw her in her office building, which is shared by all the local organizations serving families like ours, and the look on her face showed disgust.

Meeting a service provider who shows kindness, sits and gives us time to answer, not expecting us to follow their schedule is a rare blessing. With every meeting I schedule with a new service provider, I must prepare my body and mind. The concern I have is based on the knowledge that my well-being is linked to the care of my son and his well-being. With kindness and compassion, my capacity to cope with the challenges that will inevitably come increases. The opposite also holds true: when I am met with judgments and misaligned expectations, I know I will not succeed.

There were several examples of my needs as a caregiver not being met during accessing autism services for my son. Prior to being invited to receive in-home care, we were told that we, the caregivers, must attend a mandatory training. I had to shift many things around to attend, and although I had had similar training in the past, was told there was, "no way out of it." I attended weekly session for months, learning about positive reinforcement and changing negative behaviours. During these weeks the staff member would routinely share information about "her kids," meaning the children she had once supported in homes, and discuss the value of positive reinforcement schedules, which were to track positive behaviours and use rewards to increase them. Other families said this would be difficult for them due to the number of children in their home and limited time and resources. I also brought up this concern and was told there is a benefit, and we should plan around the difficulties to enact these in our home. One of the moms would frequently walk towards me at the end of the class and say how she was frustrated with the classes and did not find them helpful. She spoke frankly about how these limited supports and being mandated to attend was not a good use of her time, and I agreed.

During one of the last sessions, we went over a chapter near the back of the textbook which explained punishment. The staff member stated that although they do not teach it, this resource is there for us to review. As I looked at the image and read the details, it described a young child, appearing four or five years of age in the photo, who had not listened to his mother. The image was of him sitting on a wooden chair facing a wall in the basement, and the mother’s hand on the door, preparing to close it.

During the months after our “training” period, a provider excitedly shared she had come up with a plan resulting from our previous meeting. We had met one month earlier and discussed the reality of my family’s life, and in honesty, I shared that my ability to enact programming at this time was low despite my willingness being high. I was well accustomed to the benefits of this type of support, as I had offered behavioural interventions in family homes for many years.

She held her papers tightly, leaning over, and slid them towards me. The reward chart was to be put in place, tracking each negative and positive behaviour throughout our day, with tangible or eatable rewards for each positive behaviour (or even those less negative and therefore improving).

Staff member: I have created a token economy for Liam, which you should start today. This will positively reinforce each of his positive behaviours and reduce his negative behaviours. (Showing me the documents), You will keep track of each positive and negative behaviour he exhibits, check them off here, and tally each here (pointing with her pen). He will get a reward for every five he completes.

Me: (Holding my newborn infant) I am concerned I will not be able to do this. I shared last time that with the four kids, two with significant behavioural concerns, that I'm having a hard time doing the basics.

S: (Disdainful look) It'll be great. It'll help both of them.

She then proceeded to explain again why the system she created would be a good fit and shared ideas on how to decrease the several hours of tracking. I could track behaviours for only an hour. As a previously trained tutor in Applied Behavioural Analysis (ABA), I was accustomed to the value of positive reinforcement, yet I hesitated in responding. I had attempted to share my concerns and they were not received well. In the previous meeting I had shared that our family had very limited support, including that I had no family helping us, that my newborn had colic and cried for up to eight hours a day, and I was at home managing the needs of four children while my husband worked hard to pay the bills. I knew the reality was I would not be able to find success in sustaining the plan she had created. I had four children to tend to, not one, and if you implement a plan for one child, including candy and prizes, you must implement the plan for all children. Over the months, the provider repeatedly directed me to implement this plan, and with my communication becoming increasingly stern that this intervention could not work for us, she appeared less and less interested in engaging with me. The once monthly sessions became less frequent and my calls were no longer returned.

I went to speak to her boss, first calling, and then meeting with both the service provider and her boss. I felt intimidated as they sat together, sharing a document from one to the other. I shared about how the experience I had was difficult for me and received anger and escalation from the service provider as her supervisor observed us. I became emotional, as I felt they were on the same side and me on the other. After that meeting I requested a new service provider in writing, directed at the supervisor. Without validating or confirming my experience, I was given another staff contact who was both attentive and compassionate. The following months went without concern, allowing my family to benefit from the skill of the team, and I felt some of the stress dissipate.

Once support is found and systems begin working, this does not mean families are at ease. There are transitions between service providers as they change jobs and between service programs for different ages. As our family transitioned from one service to another and into the school system, there were multiple challenges.

I sat alone, across from three staff members at a large white round table in a basement room to discuss the transition of my son from their care to another's. It was the summer of 2017 and I felt a sense of apprehension and fear, despite having been looking forward to preparing my son for the next stage in his life. As I worked to breathe through my thoughts of our past and previous experiences, I worked to focus on the staff member sitting straight across from me. She smiled, a forced and unhappy smile, and I felt my body stiffen.

Doctor: We are processing the assessment and will have it complete by the end of September.

Me: Are there other documents and support going to the school before school starts?

D: No. They were invited to attend an information session and will come to observe him here.

Me: Do any parents have concerns with not having the assessment done until four weeks after they've begun the new support?

D: (Laughing) Actually, no. You are the only one.

Images of previous years flashed through my mind: the judgment of the staff who told me I treated my child as a dog, the looks of disdain, and phone messages that did not get returned. I felt those experiences in my mind and body as I proceeded with completing an additional hour of conversation, as I knew without it, my son's care would suffer. So often I am in a position of sacrificing my own well-being for the future of my son, and the impact on my health is great. I left that meeting and rushed back to my vehicle in the parking lot. I had difficulty breathing, my heart palpitating, and began to cry.

I have prided myself on emerging from a place of inability to speak about challenge, to being able to respectfully communicate when I know something will not work for me. The energy it takes to share and suggest is energy I do not have to spare, yet as I believe this is how improvements will be made in our system, I find a way. Sharing that a technique and program will not be attainable for me in my current situation is not saying the service provider does not have skill or that the plan is not a great one. Communicating this means that while the plan will not work for me, we need to work together to find an alternative solution to find support for my family. Instead of defensiveness or derision, service providers must show empathy and flexibility, as each family situation and each child is unique.

As a child five and under, Liam was eligible for pre-school support and assessment, and as he began school, he required school-age services and service providers. The pre-school services are designed, in theory, to refer families like mine onto the new waitlist to eliminate excess times without service. This is not always the case, and in my experience, had long-lasting and serious implications for the health of my family. I discovered our family had not had the appropriate referrals done when Liam experienced a crisis due to a poor transition plan and the difficult experience of a new support team and location. Liam appeared overwhelmed with the structure and routine changes from one school to the next, and the communication breakdown between them made our family feel helpless. He would become aggressive at school and communicate his distress by screaming and running. It because difficult for the school to keep him safe, and this translated to him being in distress at home as well.

Another behaviour team initiated contact with us and the anxiety that normally came was diminished, as I knew the staff member who would walk alongside us for the next year. I had met her years prior at a training session for families, and she was calm, open and compassionate. Providing a previously known staff member can be an excellent way to transition families. She and her colleague met me in my home, worked around my schedule and often would invited me to update her on our family’s happenings in a friendly way. They were silent and offered kindness as I vented about the sleepless nights, Liam’s danger-seeking behaviours we lived with, and the concerns we had.

Despite their help, Liam continued to show escalating behaviours in school for several months, including both verbal and physical aggression, and the school not knowing how to handle the behaviours. They shared this via a phone call at my job, midway between client sessions. I looked up the phone number for the intake for the school-age support team funded by the government, which was advertised as allowing for self-referral. I left a message and looked over my notes again to summarize what I would say. I often repeated to myself how I could best articulate my concerns in the most concise and professional way. Several days passed and they returned my call, stating it must be Liam’s physician who refers him, or they could not offer any support. I asked why the online site stated families could refer on their own, as I was concerned about the delay in completing the necessary documents because my son was already in crisis. I was assured this was the way it was done, and it was reiterated the sequence of events had to be adhered to. I called the pediatrician’s office and stated the urgency of the matter, as Liam had been increasing his distress at school and I was feeling increasing worried which was affecting my mental health. The doctor’s administration assured me she would fit us in as soon as she could, and the doctor was accustomed to completing these referrals and would do so quickly. I attended his office ten days later with my son to discuss the need for the referral and the support they could offer.

It was explained this would be a lengthy process consisting of several components, including assessment documents to be completed by the doctor, the school team and our family. Thus, it would be about nine months before we would be seen. Meanwhile Liam was suffering. His sleep deteriorated as he was not able to fall asleep until 11 p.m., waking two hours later, despite him continuing to take the same dose of melatonin that had been successful for over three years. Throughout our many visits over the next several months, T and I sat both alone and with our son and began a trial of three different medications to decrease the symptoms of his ongoing distress. The first two medications were seen within hours to cause increased activity and agitation and were discontinued immediately. We followed up with the doctor each time, giving a detailed summary of what we saw, and met again for another discussion and trial. On the third medication, Liam became physically sick, and again we discontinued the medication.

During this time, a letter arrived, explaining that as we had not called to request any of the services available to us in six months, we would be taken off their caseload. I had not been previously made aware of this requirement and I felt overwhelmed and helpless. The service provider had called two months earlier stating we had not used their service, and I had explained we had been in crisis for some time and I was unable to prioritize this less urgent need.

It was a warm day in the middle of summer as we prepared to finally meet the new team, now 9 months later. We attended with our son and I waited nervously, unsure of what type of support this would be. I had heard mixed reviews of this team due to my involvement with other families and yet was hopeful that our needs would be tended to. Taking deep breaths, we were welcomed with a genuine smile and compassion.

Doctor: Hi there, I am so happy to meet you guys. Hi Liam (looking at our son), come check out all the cool stuff we have here. There is even a big beanbag chair (which Liam ran to). Lots of kids like to sit there. (Looking back towards T and I) I know things have been hard and we’d like to learn more about you, so we can help.

We shared the details of what had been happening since September 6, almost a year ago, and he inquired about the medications we had tried and offered an idea.

Doctor: It just so happens that I was at a conference last week, and they spoke about how children like Liam have benefited greatly from the use of anti-anxiety medication.

Me: Oh! We had tried the other medications because others said they were the best fit. What types of outcomes have you seen?

D: It’s true, for years we’ve been going to stimulant medications, and they can work really well, and for other kids, like Liam, because of the way his symptoms present, this type of medication I’m going to suggest can address the underlying issue. Does anyone in your family use an SSRI (Selective serotonin reuptake inhibitors)?

Me: I do. I have been on [medication] for several years with great success, and noticed a change at the lowest dose, four days after I started taking it.

D: That's great to know. What do you think about starting there?

SSRIs are a type of drug used to treat anxiety or depression and have been proven effective more many individuals, including children (Strawn, Welge, Wehry, Keeshin, & Rynn, 2014). The Doctor further explained in detail what would happen, what we would see and any concerns we may notice. He invited us to call his team at any time, promised to let us know when they would be away, and who to call for those particular days. My shoulders lowered and as we left, I felt myself skip a little. I knew there would additional challenges, yet for now our family had a plan and someone we could call when things got hard. This created a framework for hope that I needed to move forward out of the despair I felt.

The months that followed would bring challenges with additional service providers, so I began to seek out those who would offer our family kindness. The challenges that families like mine are living with may not be something providers are privy to. Part of my story is the underlying grief of the diagnosis, which is triggered and retriggered by interactions we have in the community, within our extended family, in our marriage, with siblings of the child, and within ourselves. To understand me and my experience, you too must hear and see my grief.

Grief

"How futile are words in the ears of those who mourn."

(Helen Keller)

When I received my son’s diagnosis, the despair I felt was severe. I mourned for the life I had dreamed for him from before he was born. I knew life for those living with impairments in a world not made for disabilities was not as welcoming as for those who did not live with a disability. I was aware from families I had known and my own lived experience that things would be more difficult for our family and for him as he grew into a man. The reality is that families like mine are more likely to be a single-earner family, or unemployed/underemployed as the child’s additional needs makes finding daycare or finding time to research and engage in opportunities more difficult (Emerson, 2003). The life I now saw for him as he grew included pain and worry, and I felt such concern for the increased risk he would experience. I knew research stated children with disabilities have higher probability of developing mental health issues as they grow up (Chovil, 2009). The statistics also show an increase in violence and discrimination against those living with a disability (Dammeyer & Chapman, 2018). This was a concern I had while working in the field and was aware of the realities in my community.

Thus, I experienced a painful process of discovery. I felt as though I had failed my son by not getting him help sooner, with our family and his life being damaged due to the inability of the system to provide services for him. Within the stages of the grieving model (Kübler-Ross, 2014), you may expect that I felt denial, yet for me, the denial was years before any diagnosis, when Liam was an infant and everyone in my life told me there was no need for concern. Missing the denial stage upon diagnosis is common, with 85% of parents experiencing this (Allred, 2014).

December 2014

Beyond the Storm (A. Taylor, 2014)

Beyond here, is everything.

This place I’m in,

Is darkness.

The space between what I dreamt for this beautiful child, and the place we are,

in a world not made for difference,

is a feeling I can hardly explain.

The longing-

for a place which accepts the beauty with challenge.

That is everything.

Having so little control over the process continues to be one of hardest things about the grief process and accessing service. The heart of the issue is not my child living with an impairment but wondering why my family needs to be at this high level of distress in a world that is not accepting or encouraging of his beauty. The grief still comes, and it surprises me at times when I least expect it. I have been in a moment of joy at a social event when someone comments on the behaviour of my son, then all at once the grief will meet me again. It is a blow to see the look on their face and to hear the disapproving tone of voice and the cold statements of fact: “Did you see he is hitting that child?” Or I see Liam responding with dangerous behaviour and I am brought back to sadness and hopelessness. Or I hear again, “You have to take responsibility for his learning too” and I relive the blame and grief.

It was April 24, 2018, a warm spring day and Liam wanted to go for a walk. Due to his limited verbal skills, he stated, “Slide” repeatedly, and pointed to the park behind our home. I confirmed the sequence of events we would follow, walking together, holding hands, and playing on the slide. Outings always ended with something he enjoyed as much as the outing in order to reduce his distress in transitioning out of, in this case, attending the park. He nodded, looked into my eyes for a brief moment, and we began walking towards to the park together. We met the fork in the road to turn towards the park, and he directed me with his body to walk away from the park towards the grasslands. Noticing his high energy levels and realizinghe needed redirection was not uncommon. We reached another fork in the road, and again he directed me with “slide” and pointed away from the park. We continued, holding hands again, along the sidewalk for about half a kilometre. At this time, I understood today was different and I had not understood his initial request of “slide.” He pulled me towards the McDonalds, and as I attempted to explain this location did not have a slide, he discovered this for himself as he pushed the door open. His immediate distress took the form of running through the restaurant quickly, finding the door on the other side, opening it and running towards a busy highway. I ran after him, grabbing his body just as he leapt onto the highway, missing a red Toyota sedan which swerved out of the way. I sat on the side of the road, a rainbow of cars streaming past, holding my son on my lap, my arms firmly around his torso. As I whispered, “It’s okay, you’re safe,” I was also affirming this to myself, realizing the impact of what had just occurred. It took me nearly an hour to get him home that day, having to call a family member to help. The impact of such experiences in raising my son are directly related to the nightmare of accessing service for him. As the danger increases with Liam’s age, the need for service and support increases, thus my stress levels also increase which affects the relationships I have with service providers. They cannot begin to understand this story’s complexities. It really began two weeks prior, as his father drove past a McDonald’s with a large and colourful slide, visible from the main street. Despite Liam not saying a word that day when he spotted it or any day in the two weeks between, he processed the information, made connections and acted upon them, navigating successfully to his goal. Liam is capable, can processing information, make meaningful connections. This is normal. Liam's challenge is that he goes into distress and cannot modulate his behaviour. This is what service providers are missing in their assessments and interpretations of who he is and how he will grow. This is also the reality of how we live, and it is difficult to explain it to our service providers who have limited time, limited resources and a heavy caseload.

Within the challenges we face, there is growth. I continue to see the joy in the small things, like the hope that my son can process a serious trauma and learn to move forward.

April 24, 2018

I nearly lost my son today. I replay it over and over in my mind to make sense of it and to learn how to prevent it in the future. I am single parenting again this week, and because it is day 1, there must always be something. As I prepared for one of the biggest career meetings of my life, Liam asked to go to the slide. Today was different as I walked first in the mud, then beyond the slide, and then another as he guided me for what felt like kilometres. As he opened the door to the restaurant, my heart sank into the pit of my stomach. I had not understood him and his distress was immediate at noticing there was no slide... I caught him mid-air as he prepared to run across the frantic lanes of constant traffic. Like a puzzle, my world leaves me guessing, requiring me to be ten steps ahead, or else. And not knowing why I missed it, and how I missed the cues is the hardest thing. Because I almost lost one of the most precious things in my life, my heart; my breath; my own life.

Accessing Support, Living with Disability

There are times that life feels like “too much” and the anxiety becomes overwhelming. Being a mother of children with exceptional needs lives close to the top of your mind always, no matter where you are. The need for work is undeniable, not only for affording a mortgage, but also for speaking to adults about things other than raising my children and to feel value in who I am. The need to be a present mother and have a career pull in opposite directions. Just when you think you have found some calm balance, the waves of panic can come, at times due to a call from the school stating there is a crisis, at other times during a movie about children with disabilities shown during a class at university.

While completing my master’s program coursework, I am working within an impending deadline, but I can see my son requires additional connection to me. Liam will say my name repeatedly, requesting I sit with him, directing me physically to sit on the couch so he can sit on my lap and hold my hand. Similarly, while waiting for service, there is an anticipation knowing some of the pressure will be alleviated from the current situation. Without having any inkling as to when or how receiving help would look like, stress levels increase. The anxiety gets to the point where no matter the distraction, meditation or research, I am unable to comfort myself. And yet I must carry on.

I notice that while giving my best and most patient self to Liam, my other children do not always get the best of me. My limited resources are already spread thin. In our environment of limited social support, tensions with service providers, the negative judgments and frequent misunderstandings, these pressures continue to impact me.

What appears to be “unexplained short-term waves” of intermittent depression, I experience as exhaustion. My body cannot find the energy to cope. These episodes impact my parenting, yet I must somehow buffer this from my child with disabilities. He has so much to deal with and so I must work hard to prevent my inability to connect to him from affecting him negatively.

Service deficits are a part of my life, affecting each aspect of my daily interactions. The service provider not returning my call is on my mind while I am shopping for groceries and as I tuck my son in at night. This phenomenon is attributed it to high levels of service deficits, long periods of waiting, not feeling or being understood, and the confusion families feel (Davis, 2013). Also, service providers all have different opinions and experiences and ways of expressing themselves, which can be both a gift and a challenge.

The energy required to sustain patience in the face of speech, cognitive and neurological processing sensitivities is draining. I experience it in myself and then again through my son’s life. The pressure I feel from knowing that reactivity impacts the trajectory of his life is never far from my mind. The interplay between my son and my own disability creates a relationship unto itself.

Parents of children with developmental disabilities report higher levels of stress compared to parents who have children without disabilities (Baker, Blacher, Crnic, & Edelbrock, 2002; Emerson 2003). A longitudinal study including 90 parents of children on the autism spectrum looked at stress proliferation or how the stressors create additional stressors. They reported significantly higher levels of both anger and depressed mood (Benson & Karlof, 2009).

A study examining the effects of coping on psychological distress and well-being in parents of children with ASD found that both escape, and withdrawal decrease one's positive mood, while regulating our emotions (Pottie & Ingram, 2008). Having social support and worrying about stressors as coping strategies were found to moderate the daily stress and mood relationship (Pottie & Ingram, 2008).

All Things Change

“If you don't like something, change it. If you can't change it, change your attitude.”

(Maya Angelou)

Figure 8: Beauty in the Waves

multimedia

on canvas, 30x40"

Being a mother of a child with disabilities and on the autism spectrum has changed my sense of the world. I no longer see the world nor the people in it with unlimited potential. I do see the good nature of most people, yet I see a lack of knowledge of situations like mine and ignorance that guides their actions.

My sense of danger has changed, in that I no longer look ahead, scanning the landscape for hazards to my own life, but for my son’s. His life and the lives of all my children have become a reason to remain aware of potential hazards, including reading my child’s breathing and body movements to prepare for what he may do next, as well as what he may be thinking or feeling about our environment. My sense of love has grown, and without words, I have been able to communicate with him, sense his longing and his fulfillment. From the look in his eyes and the feeling he shares from his body, I can understand what is happening for him and hear without words what he tells me.

My idea of strength has also adapted as I have walked alongside my son and celebrated his milestones and uniqueness. His strength has invited me to see my own weakness and strength differently in a more balanced and holistic way. From the time he was born until he was four, as he fell asleep I would whisper, "Goodnight my boy. You are a sweet boy; a smart boy. I love you." I would look at him with great care, offering my heart until his breathing slowed and I knew he was sleeping deeply, thinking that if I could understand his strength, then he would too. Throughout this time, I struggled to see my own strengths, often feeling frustrated in what I perceived as my own inadequacies. Relationships remained difficult and I continued to require high clarity in communication. My thinking patterns would perpetually get stuck on ideas, such as problem-solving issues within our home. I started to see that solution-focused activities were a benefit to my family and not necessarily a personal deficit.

There are compounding variables in accessing services that families like mine are contending with. Service providers all have different opinions and experiences, and as a result, families not being or feeling understood are some of the top challenges (Davis, 2013). Within each relationship with our family's service providers, each person has a unique personality with gifts and strengths, needs, opinions, and ways of communicating their knowledge. Having to familiarize yourself with a virtual parade of different service providers is a complication that hinders smooth collaboration and slows progress.

The cumulative effect of years of coping with accessing service, working with numerous providers, and too many negative experiences has had a crushing impact. For example, upon meeting with a newer staff member, she leaned forward and virtually scoffed at the concern I had raised, saying I was the only parent to ever bring this forward. In fact, she laughed. The other two staff members from her team stiffened their bodies, eyes large, breathless, and did not say a word. I sat stunned at her response and realized her casual attitude meant my son was sure to go into crisis. I saved my tears for later, but the blows she inflicted significantly damaged my self-confidence and confidence in this team.

It was little comfort when the next day one of those staff members asked to speak to me alone. He apologized that his boss spoke to me that way and stated he knew of many families who were concerned. He asked me not to say anything to their team supervisor about him speaking to me or about the incident. How can this lack of honesty, this silence to power ever result in effective care? The answer is it doesn’t.

As he started his new school that September, Liam began a steep spiral, out of control and in crisis for most of the year. This could have been prevented with open discussion, including and respecting parental knowledge, and a transition plan that recognized his unique best interests. I see skills and gifts in my son, and I seek care providers who have this positive approach. However, I have learned that each person we meet will either teach us hard lessons or bless us in some way. I am never sure which type of interaction it will be. It is not surprising that I have become hesitant in trusting. I am highly protective of my son, beyond what parents of typically-developing children could understand.

The Upside to Disability

“I am different but not less.” (Temple Grandin)

There is always an upside, at least this is what I like to believe. Deep down, I feel like I always knew Liam best. He needed and still needs me to lean into him, feel his pain and validate his suffering, just as I needed when feeling lost in a harsh and cruel world, and if I’m honest, I still do. I believe that requiring this sense of belonging is one of the things that makes us human. His need for connection may look different than some and perhaps be more difficult to navigate at times, but the needs are his just the same.

Even during the times of pain and distress I have seen my son grow as he notices, remembers and communicates. His growth gives me hope that things will be okay in the future, not just for him, but also for me. As he discovers the strength within himself, I too see my own strength in a new way. Each moment, each day and each significance bring light to the power within by being authentically yourself and owning all the parts, including those areas once considered weakness. The pride for my son grows in intensity as I embrace his differences, which is something many caregivers find as they grow to know their children as *neurodiverse* (Cascio, 2012).

October 21, 2018

Something amazing is happening to me. I feel like I am seeing myself for the first time. As I have been embracing my own differences, to help my children see the beauty in themselves and in their differences, I am truly seeing myself. I can really see how my ADD tendencies give me a magic ability to think on my toes and see things in fireworks. My anxiety disorder allows me to see into others with similar challenges with compassion and deep understanding. Seeing myself this way has allowed me to share my gifts with my children and invite them to see themselves as I see them; strong, vibrant and amazing.

February 2, 2019

Discovering Difference (A. Taylor, 2019)

In reflecting,
Growing up in a world not made to celebrate me as I was,
Did not stifle my creativity as expected.
In raising my children, I discovered a magic.
The treasures in their differences were too in my way of being.
The discovery of my own differences came only while creating the framework of social change for my children,
and them alone.
Throughout providing care in social services,
I emulated the strengths-based perspective I longed for,
Yet could not create for the frame of who I was and longed to be.
My child’s need for a voice,
The creation the change in how others saw him,
Amplified something deep within me.
He required for me to step out of myself,
Into his soul,
beyond current (mis)perceptions of disability.

In his eyes I experienced a joy and beauty of neurodiversity

The neurological difference that I could no longer avoid.

I saw within him, myself,

And the strengths that went unrecognized until that day.

It was then that I was born

And felt who I was,

For the first time.

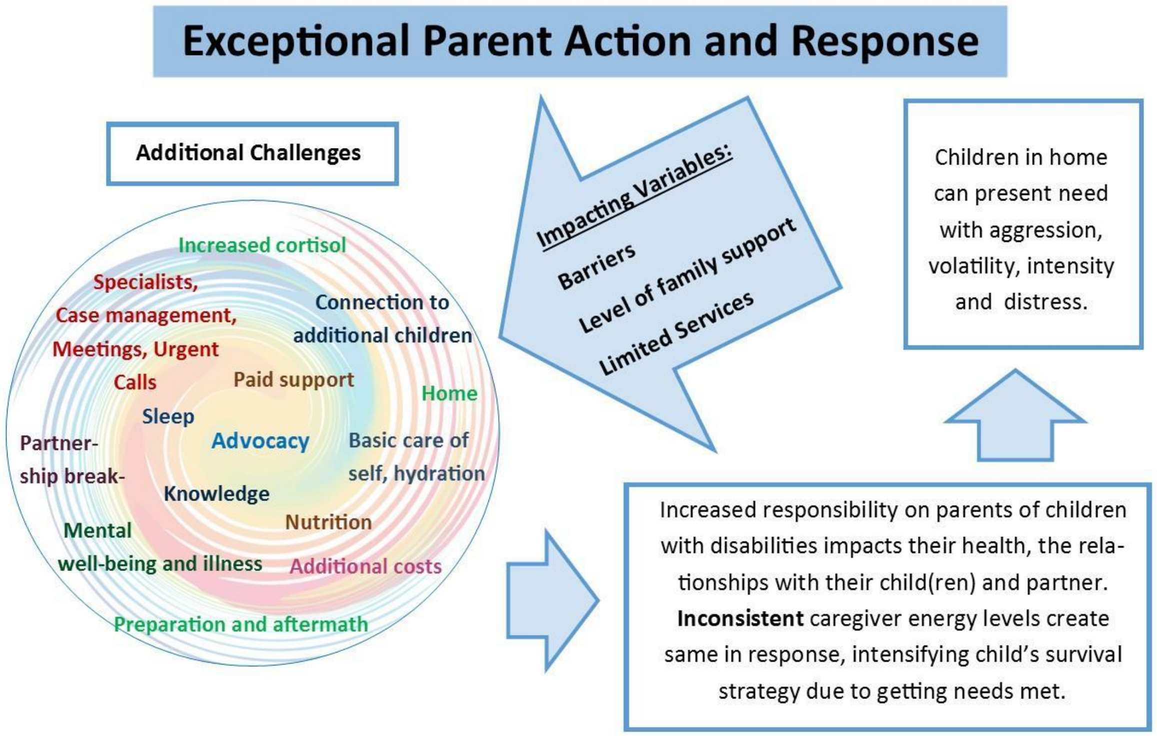
Section 3: Adapting Family Engagement to Include Disabilities

There is a large divide between my family’s needs and the service we receive. The absence of meaningful support impacts families like ours as we live the negative effects despite the best intentions. The details of what families need, of not only to be heard but the opportunity to flourish, is at our fingertips. If we move past the medical model where the impairment or disability is the “real” problem (Berger, 2015) to examine how we can change service itself, we can use the research available and invite families to share how they need change. We can do this by focusing on the details of individual experiences to improve understanding and compassion. The sharing of this knowledge can have a great impact. By accessing parents' voices, we can identify and take into consideration specific strategies that have been identified as either improving or impeding outcomes, which may lead to concrete guidance for clinicians.

Family-centred care is considered most effective in supporting families (Bossard et al, 2014; CAMH, 2012; Chovil, 2009; Dostaler & Cannon 2011; Duchnowski & Kutash, 2007; Emerson 2003; Foster et al., 2013; Kuhlthau et al., 2011; Lindsay et al., 2012; McKay & Bannon, 2004; Ontario Centre of Excellence for Child and Youth Mental Health, 2016; Sloper, 1999; Truesdale-Kennedy et al., 2006). However, within a system that prided itself on providing such care, I felt lost and blamed and defensive. This is not how family-centred care should work. I felt the disconnection between how clinical service providers explain they help families like mine and what is reality. Where is the clear communication of understanding and validation? This experience has been well documented (Bossard et al., 2014; Bourke-Taylor et al., 2011; Chilvers et al., 2013; Collins & Collins, 1990; Cuzzocrea et al., 2013; Duchnowski & Kutash, 2007; Huang et al., 2013; King et al., 2004; Kogan et al., 2008; Lindsay et al., 2012; Shannon & Tappan, 2011; Truesdale-Kennedy et al., 2006). As families, our needs are not being met which is affecting how we experience and continue to access support. And most importantly, it is cheating the children of the care and support they need.

An adapted family engagement plan for service providers to use with families like mine may make the difference necessary for my family to be truly well. Effective family engagement practices have positive effects on the mental well-being of the caregiver (Gladstone et al., 2014), and each child in their family (Bossard et al., 2014). The planning that can be accomplished by using the unique family as a guide to their care offers additional ideas and flexibility in planning, and statistics suggest it may reduce child apprehension via the social service agency (CAMH, 2012). Evidence suggests that meetings are also improved (Foster et al., 2013), as the family feels that strengths, challenges, concerns and cultural differences are accepted, and they feel more respected (CAMH, 2012; Chovil, 2009). Family participation increases which leads to plan buy-in, improving the likelihood of achieved case goals (CAMH, 2012).

In a true family-centred system, the circular action and response system of caregivers and the barriers we experience would inform service providers in their understanding and build compassion. My own life is represented in the graphic image below. My many personal challenges create impacting variables, such as barriers. These challenges affect accessing service and my ability to navigate the system.



Angela Taylor © 2018

Figure 9: Exceptional Parent Action and Response

In my view, everyone should eek first to understand. Professionals who become sensitive to the uniqueness of every family can do a lot to guide us in our journey. In a collaborative partnership, caseworkers and family members are more able to identify a family’s unique needs and develop relevant and culturally appropriate service plans that address underlying needs, build on family strengths, and draw from community supports (McKay et al., 2004).

There is no one-size-fits-all support, and at times individualized and in-home one-on-one services can provide powerful support that parents need (Shilling et al., 2014), with the priority that each family feels supported (Collins & Collins, 1990). As well, having one specific provider to help communicate between the many we have, in addition to streamlining services and sessions, would help maximize my limited resources. The Child Welfare Information Gateway (2016) offers evidence this would increase family well-being. Through these challenges, I find my problem-solving abilities diminish, and with a provider modeling strengths-based decision-making skill, I can be reminded, be supported or learn these skills. This modeling invites an increase in competencies within the family (McKay et al., 2004).

Understanding what families like mine go through can increase empathy. Increasing empathy allows for the shared experience of need or desires between us, creating the emotional bridge that encourages prosocial behaviours and increasing client satisfaction (Weng et al., 2013). A study by Reiss (2017) linked compassion training to increased altruism and neural responses to suffering. By understanding the suffering of others, our ability within our executive and emotional control and reward processing increases (Reiss, 2017).

Having access to a variety of service providers to address the multiple needs of one unique child and their caregivers has felt like magic to my life. Being turned away with nowhere to go or a vague direction has been like a dark cloud over my soul, lingering until I found my own solutions. “I can’t help you with that” is a message family like mine become used to hearing and is compounded into internal dialogue that impacts the direction we take with our children. This affects both short- and long-term care and therefore the trajectory of our child’s life. The magnitude of this is never lost on me, as I navigate both the systems for my son and as I sit alongside families like mine. I need many skills to address the variety of differences that are contained in the beautiful small soul I am in charge of supporting. My child requires a team to work in collaboration to reduce the weight we carry as we move through a minefield of do's and don’t's of service. The contradictory messages of “do listen and do what I say” and the fact that the directions may not be based in evidence but in opinion is difficult to decipher. The truth is, if I am not able to pick apart the rules as a specialist in the field, what hope do other parents have?

The transferring of our needs from one team member to another causes a feeling of being lost. As one service provider ends a relationship or draws upon the expertise of another, the expectation is that I, the parent, initiate, follow up and regurgitate the history of my family, what I have tried and our plan. The realization this may be detrimental to my mental health does not appear on the radar of providers, and that alone is a concern. Not having the comprehension, consideration or compassion that this large burden exists can compound the negative psychological effects on my family. When tied in with a person’s history, for instance my own, the reduced ability to regulate and the increased need for control in a world of chaos can lead to an exaggerated sensation of power imbalance and hypersensitivity in face-to-face engagement. The interactions between service provider and caregiver matter so significantly. They affect more than that day, and in fact can affect me for years after the interaction. The moments of distress of being laughed at are carried forward to new meetings with new professionals in a type of PTSD response, including emotional flooding and reactivity. This in turn creates a new framework for the relationship being built with the new provider. The cycle continues person after person.

The Influence of Stress

“You can’t stop the waves but you can learn to surf.” (Jon Kabat-Zinn)

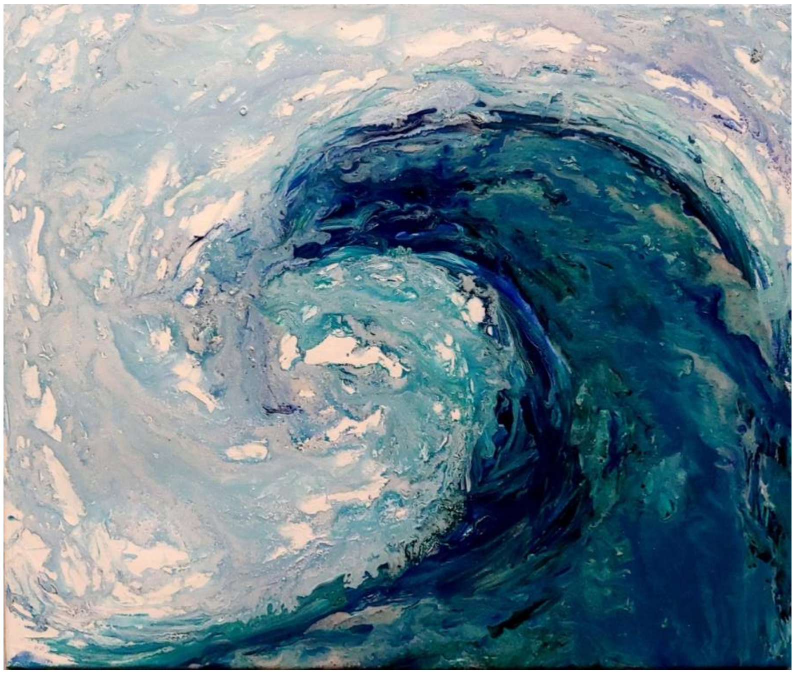


Figure 10: Waves

Multimedia on canvas

12x18”

Children are dependent on their caregivers and other adults in their lives to help care for their bodies and minds. Being aware of the relationship between increased stress levels and brain development is an important aspect of a human's health. The effects of stress on brain development were documented in a longitudinal study focusing on the impact of poverty on children, both with and without mood disorder symptoms, like depression (Luby et al., 2013). Stress, like that caused by living in poverty, has been shown to reduce activity in the prefrontal cortex, which is the processing centre of the brain, affecting self-regulating and calming of self, planning and understanding consequences. Similarly, this negatively affects the person’s ability to suppress amygdala activation during times of distress long term, including as the children aged. The study suggests that exposure to stress over a long period of time sets the amygdala and prefrontal cortex resulting in patterns of emotional dysregulation, correlating with lower levels of physical and psychological health (Luby et al., 2013).

When examining parental stress and family functioning were examined, it was found that higher stress is correlated to lower functioning, and impact children by negatively affecting their cognitive, behavioural and social development (Sloper, 1999). Recommendations included there should be one primary contact for parents to refer to instead of numerous; have parent partnership models where the professional seeks to align with parents, essentially treating them as though they have expertise; and have a coping skills model with a focus on building on the parents' coping strategies. The common theme for these approaches suggests a holistic view is warranted which includes relationship building; a consistent and single point of contact; plans are flexible and individualized; they value the parents' own perceptions and expertise; and therefore, families are empowered (Sloper, 1999).

I continue to hear family narratives of service provision being disjointed and opposing what the studies find as being best practices. My experience is that despite my high level of education and multiple privileges, the services have remained difficult to locate, and once they are located, they are fragmented and difficult to access. I continue to be treated as if I know absolutely nothing about disabilities and do not know what my son needs. This in turn causes me and my family to feel disempowered and thus have the opposite experience of how family engagement practices are intended. I have seen this in many “privileged” families and worry about those who are less able and without the skills and resources to endure the struggle.

The health implications of being under-resourced and in distress over a period of years can also have lasting health impacts. Mothers who care for children with Fragile X syndrome or autism experience more mental health concerns as well as physical health symptoms like headaches and fatigue (Smith, Seltzer, & Greenberg, 2011), which is also the case for me.

March 15, 2018

We are still waiting for support for Liam. I’m told it will be another five months, despite the fact that I have not slept more than two hours a night since late December. I fell asleep last night while trying to stay up to protect him, and I heard a noise that woke me. I felt something was wrong in every cell of my body. I found Liam dangling over the ledge of our deep freezer!

Everything is hard right now. I feel alone. Work is becoming increasingly difficult, and the new job is a steep learning curve. I am struggling. This shiny exterior is becoming faded and I am becoming more and more isolated from my friends. It is affecting my relationships with all the kids, and I’m not sure if my marriage will survive this. All the love and adoration in the world cannot protect my relationships from this sea of pain I’m in. I know things must be able to be managed. I want to believe that God does not give you more than you can bear, but this...it is too much.

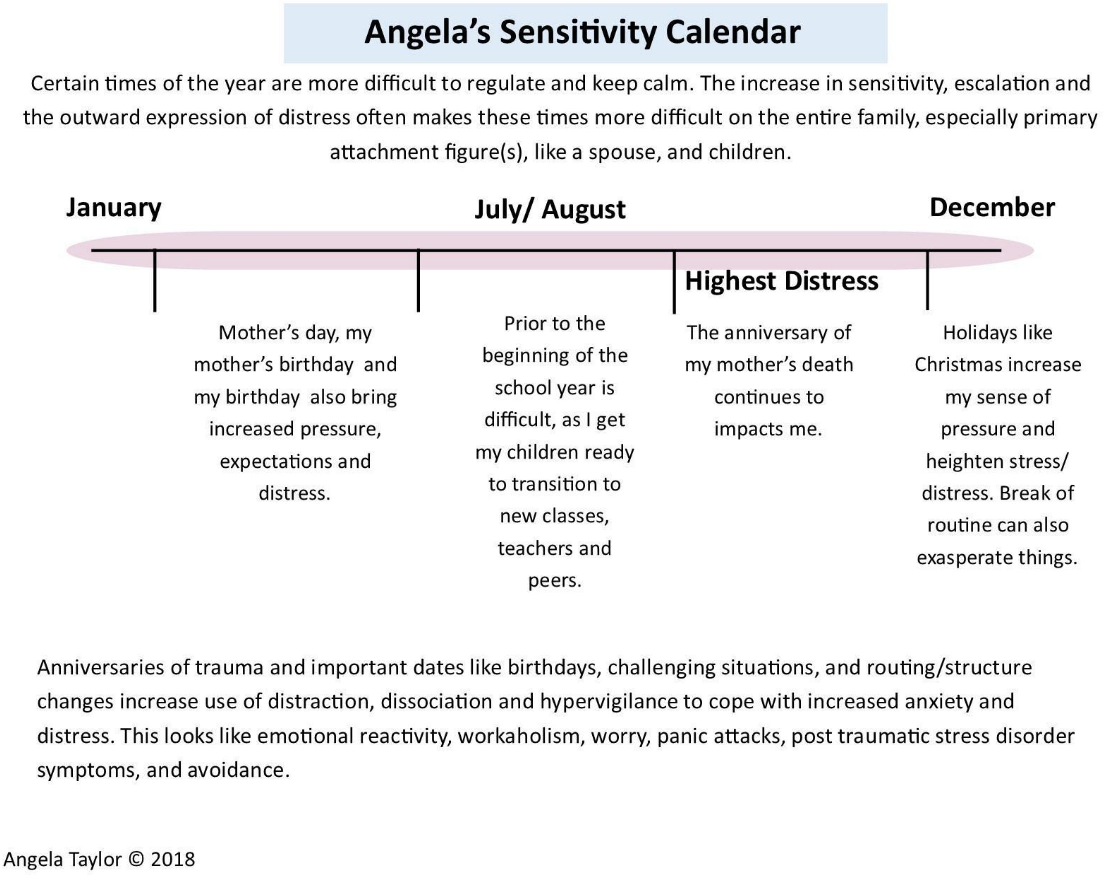
The poem "Wild Geese" by Mary Oliver (1986) summarized what I long to feel and do. Within the actions I never took, there is an emptiness. The front I wear looks strong and bold, and within I am vulnerable and reaching.

“You do not have to be good.
You do not have to walk on your knees
For a hundred miles through the desert, repenting.
You only have to let the soft animal of your body
love what it loves...”

As a parent, I work hard to regulate myself, so I can help my child remain regulated and be a calming presence in his life and be an effective advocate within the maze of fragmented services. This has been with great success and well worth the effort. If I am feeling emotionally activated or agitated, my son will certainly feel it and respond in kind. The sensitivities within a child with disabilities often means a caregiver like me must be aware of our body movements, facial expressions, and the tone and cadence of our speech. I use various forms of mindfulness, such as the "low and slow technique," which invites an awareness of my body and speech patterns to become both lower and slower than my typical way of being. This has appeared to lower his sense of arousal and work to soothe his body and mind, while also keeping me engaged in the process of calm. The cost of this increased parental effort can be exhaustion, increased stress on other relationships, and disconnection between me and the outside world. For many of my parenting years, I isolated myself due to having low energy and limited physical and emotional supports. The effects were compounded year upon year, and it became difficult to see what was happening objectively. And as there are waves of higher and lower energy for all humans, so too this is true for those who are more sensitive or with diverse neurology.

Certain times of the year have remained more difficult for me, while other times of the year are more problematic for Liam. This includes the incorporation of healthy foods, reaching out and receiving support, physical activity, and even vitamins thought to support energy levels and mood. This year I summarized the data I had been tracking in calendar form to show our sensitivities. I used a free online app and my journal, then used a visual tool to explain to others what we experience. During the times of higher sensitivity, the ability to regulate is diminished and reactivity increases, so when something happens, such as a call from a service provider, there will be an underlying reason for the response in addition to the relationship, situational stress and other experiences.

Families like mine all have times of the year they are more sensitive, whether they are aware of it or not. Supporting families to be aware of their patterns can be a tool for us as service providers, enriching our experience together as we align ourselves with the caregivers to provide long-term stabilization. These calendars are examples I now share with those who support us.



Angela's Sensitivity Calendar

Certain times of the year are more difficult to regulate and keep calm. The increase in sensitivity, escalation and the outward expression of distress often makes these times more difficult on the entire family, especially primary attachment figure(s), like a spouse, and children.

Mother's day, my mother's birthday and my birthday also bring increased pressure, expectations and distress.

Prior to the beginning of the school year is difficult, as I get my children ready to transition to new classes, teachers and peers.

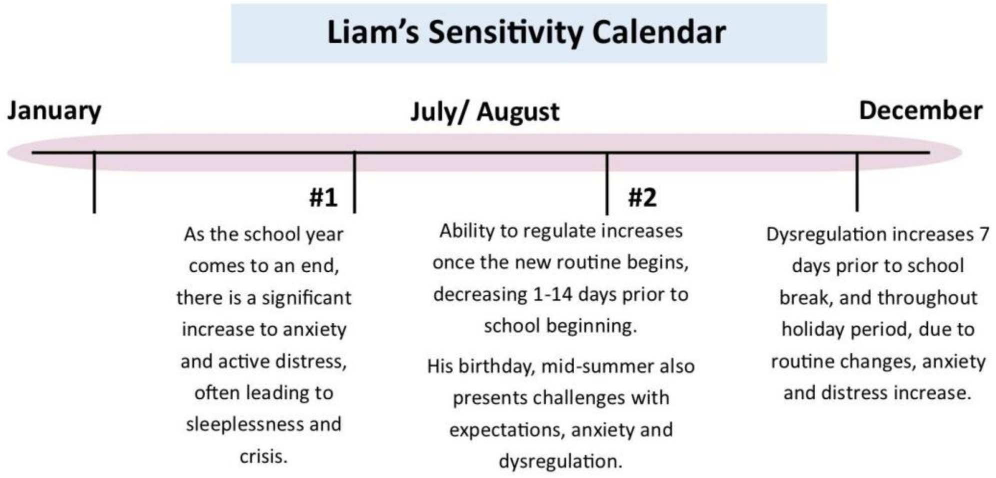
The anniversary of my mother's death continues to impacts me.

Holidays like Christmas increase my sense of pressure and heighten stress/ distress. Break of routine can also exasperate things.

Anniversaries of trauma and important dates like birthdays, challenging situations, and routing/structure changes increase use of distraction, dissociation and hypervigilance to cope with increased anxiety and distress. This looks like emotional reactivity, workaholism, worry, panic attacks, post traumatic stress disorder symptoms, and avoidance.

Angela Taylor © 2018

Figure 11: Angela's Sensitivity Calendar



As the school year comes to an end, there is a significant increase to anxiety and active distress, often leading to sleeplessness and crisis.

Ability to regulate increases once the new routine begins, decreasing 1-14 days prior to school beginning.

His birthday, mid-summer also presents challenges with expectations, anxiety and dysregulation.

Dysregulation increases 7 days prior to school break, and throughout holiday period, due to routine changes, anxiety and distress increase.

Angela Taylor © 2018

Figure 12: Liam’s Sensitivity Calendar

The confluence of stressors in one’s life and in those lives that intertwine can create a cascading effect onto all parts of life, and this is certainly the case for my son and I. Becoming emotionally reactive can have great negative effects on the relationships I nurture, as my tolerance for typical challenge is diminished. Being aware of this has been a gift to my life and my relationships as I can take what I need prior to being overwhelmed or becoming overwhelming. The need for awareness is something I have noted throughout my journey, and I am grateful to have the ability and opportunity to examine the reality of my life and needs. Keeping a similar structure on days that do not naturally contain structure can provide an artificial framework that increases the feeling of safety. This includes all aspects of a day, including what you say to your child when they wake up, opening my day with yoga, providing a blanket every morning to my child on the couch as he begins to wake his mind to the new day, and the times we eat. A similar structure is one way we have found our way.

Finding My Way

On an early fall afternoon, Liam reached up to me, showing me that he wanted to come up. I had been instructed days earlier by a service provider not to “give in” if he would not attempt to use words to communicate with me. I was warned I was going to cause him harm by delaying his development and not attending to his need for “guidance.” I urged him to try to use his words with animation in my face, repeating the word “up.” Instead of speaking, he got frustrated and began to cry, reaching for comfort. Exasperation found me and with the words I heard earlier echoing in my brain, I placed him in his crib, telling him he needed to “use his words.” In retrospect, I know better. My son did not have the ability to speak to me, and I am certain he would have if he could. Instead he cried in confusion, unable to understand what his mother was doing or why.

Raising my children and learning how to support their growth and development has not come easy for me. I have made mistakes and regretted choices I have made along the way. Being raised in violence and being surrounded by many poor ideas about caregiving affected the way I raise my children. My ideas about discipline and learning in general have evolved from my mother’s ideas, including control over others, punishment and even violence. I am not my mother.

I have heard so many contradictory messages about how to do a “good enough” job caregiving my son from the media, family members, friends and professionals. When taking parenting classes, I was instructed to use time-outs as a means to teach children right from wrong, to allow them the learning to “control” themselves. I was informed that time-outs are used to increase positive behaviours and reduce unwanted ones, yet these parenting choices can put some children at a higher risk for negative outcomes (Morawska & Sanders, 2011), as during time-outs children can experience negative self-thoughts, sadness, isolation, fear and being disliked (Readdick & Chapman, 2000). Being spanked was also something encouraged by other parents, yet the research states it can leave potential long-term harm while having minimal potential for positive outcomes (Gershoff & Grogan-Kaylor, 2016). As a parent, these messages were confusing and left me with increased exhaustion. I felt as though I had to adhere to the beliefs and values of what each individual service provider instructed to receive care from them, and with limited options for support, it put our family at a disadvantage. The stress I felt of fitting into the mold of what I was told had removed the confidence necessary for filtering the messages of what was helpful and not. Some of the most helpful advice I received was from other parents experiencing what I was facing, and without messages of empowerment it was difficult to find the energy to locate the resources and answers I needed.

I now understand that Liam's emotional health is tied to his social and emotional environment (National Scientific Council on the Developing Child, 2004), and this includes me and my responses, and as he grows, the long-term effects on his mental health will be evident (Afifi et al., 2017). As a mother, I have been told I am too lenient, too tough, I should punish more harshly or respond only with love. When Liam was born, these messages became louder as his neurological and developmental differences became apparent.

I had to come to terms with messages from well-meaning yet unwanted advisors in every area of my life. Even those I looked up to and admired would chime in, instructing me to be a specific way, without understanding that being instructed had become a way of life for me. This new way of being is not one I had ever expected for myself, nor did I wish for it. Yet here it was, surrounding me, infecting each moment of my day, leaching into interactions with my son and affecting my well-being.

Throughout my time parenting, I have worked to learn how to provide a consistently calm presence, offering attentive guidance when my children are done exploring and require connection. With the memories of "friendly advice" and "expert instructions" no longer directing me, I have found the success I longed for through connecting to other parents raising children similar to mine. So many of us have the same story and we keep it only for the community that understands families like our own.

A Day in the Life: One Parent's Experience

After months of writing in my journal about the hard experiences that I wished service providers could understand, I completed this edited compilation on April 4, 2017. It is a small window into some of my realities of raising my son.

April 4, 2017

My days are long. I'm not going to sugar coat it. This is not what I signed up for. This was not my choice.

My son. Let's talk about him. **He was always loved**. He was welcomed into our family with care and eagerness. There he is. Look at him. Adorable right? I felt so much joy beginning the moment he was born. He had finally come. From that moment on, he and I were inseparable.

Let me tell you about us. The real us.

The Challenge

To know us, you have to know more about the challenge. It's not all joys. **Like any human, and any family, there are things we choose not to share**. The painful stuff. The things that might bring up shame, or make you judge us. I'm going to tell you anyways.

I worry I cannot keep him safe. I worry that if I don't do just what he needs, that I may cause him to struggle all his life. At times, he has run into the road, even with oncoming traffic. So, I never look away. Can you imagine not allowing yourself to blink? But he’s worth it. My love for him has to be enough, right? I don’t tell many people these things. People say the meanest things. I hope you won’t judge me.

You told me that I should not run after him because I was reinforcing his negative behaviours. I didn’t know what else to do. How do you not run after them if they run into oncoming traffic? So, I continued to run. I didn’t tell you. I knew what you’d say.

It’s Morning

I try so hard to keep things calm. The pressure is so high. We have many kids, all with different needs, and it is hard to have a moment to myself to breathe. Can’t imagine? Neither could I, until this was my life. The life I never imagined for myself. But the challenges keep coming. And I have to keep going. For them. No matter how tired I am, or how hard things get.

My child wakes up with **joy every day**. Instead of thinking of when and if this phase will end, I connect with him. Really connect. **And see him**.

Me: Hi buddy, how are you this morning?

Child: Hi Mama. I’m good. I want to go downstairs and watch Bubble Guppies.

Me: Okay love, let’s go watch a show. First snack. Then show. Okay?

He says nothing. **He holds my hand**. I remind him to use the bathroom, or he won't go. We just learned potty training with him and we have to keep it up or things will go back to how they were. We can never fall behind. More pressure. I remind him to wash his hands. Dry them. As I make him breakfast, I am grateful he eats okay. There are only a few things he eats, but that is better than some, right?

Make the lunches, get him dressed, and make sure he drinks his medicine. He has to have it every morning or he has pain and discomfort all day. That was a whole story in itself. All I can say, is that even with the medication he can still have concerns. So we can’t forget. You will see me forget. You will say things like “He had a hard time today. He was in pain. Did you forget to give him his medication?” And I have to tell you that I did forget. And feel horrible. It will sit with me all night. On my mind. That I caused him that. So I can’t forget. It’s important. You see that he’s important to me, right?

Getting ready to bring him to school. Things need to be just so. Can’t forget. As I drop him off, I walk him to the doors and wonder: **Did I remember his extra clothes, his special toys, the special snacks, and the lunch bag?** Did I remember to put on the special socks, with no seams to scratch, so he won’t lash out? As I gift you my child, will he show that he loves me? Will you judge me? I shrink. I feel so small. I feel guilty. Should I have homeschooled him? The uncertainty begins to consume my thoughts and overwhelm my senses.

I had forgotten something else. **It’s the team meeting this morning.** I have to meet with you to discuss his progress. The challenges. You welcome me into the small room, with my son and three others like you. It begins. The anxiety begins too.

You: Has he ever been referred to a nutritionist?

Me: No.

You: I think it would help. He could have support in trying new foods.

Me: Is this something we should have had already?

You: Yes

It feels like a punch to the gut. The guilt, shame and frustration is bubbling up from within me. None of the people who were *supposed* to be helping us for two full years never said we could have this help. You knew he had issues with food and eating, and no one helped us. I know it’s not your fault. You’re just the newest one to help us. I know you have no connection to the others. Your own isolated bubble of information. But it all adds up. I feel crushed. I can’t be angry. There is no place for that.

I remember two years ago when I got angry. When you told me my values and beliefs were not valued by your laugh, and comments at my family’s expense. By the look of disgust on your face. I chose not to get that service after that day. I saw you in the hallway last year and the look of hatred and disdain for me. Because I was to blame.

I must push that away. I have to be a good role model for my son. And what would you think of me if I got upset anyways? Would you not return my calls like the person before you? Would you not follow up on the care for my son? This is my reality. This is my life.

The **power dynamic** is something that weighs heavy on my shoulders. You are above me no matter what I say or do, no matter the power I hold elsewhere in my life, as here I am small. I cannot shake it. I don’t dare bring it up. What would you think then? No matter how nice you are, it’s still there. I tell myself that you have good intentions. I know it’s true. I force myself to care about that instead.

I have to work. It’s a busy day. I think of the email to you I forgot to send, the mail I must answer, and the preparation for the new school year ahead. The waitlists we will be on. The nothing that will be. The new versions of you to work with. To try to communicate with. All so different. “You just don’t know,” you’ll say. Because it’s assumed no matter how much I know, that I know nothing. Six years ago, when you sat in a full room and said my child’s issues were caused by me. I have never felt so alone. The others said nothing. Because there, you were the one with the power. No one was on my side. I push that away.

Things are always so busy. I go to school too, to try to better our life for my family. You say I'm lucky. I know I am, but things are just so hard. I wish I could tell you how stressed I feel. **Like I can't do it.** If you only knew how I live **moment to moment**. I have panic attacks sometimes. I can't breathe. Things feel like they're too hard. But we all have stress, right? We all are busy. That's what you've said.

It's time to pick him up. I have to do it just so. Be right on time. You tell me a bit about his day. All I've missed.

You: He had a good day. He was really hungry today, he didn't have enough to eat. He had a hard time with his friend. There is an incident report here. Can you sign it?

Me: Oh? I'm sorry. I will try to pack more tomorrow. A report? Okay. Can I see?

I read it. He's hit another child. Why can't we help him not hit other kids? Do you think it's my fault? Do you blame me? Will you think it's my parenting? I've heard it all before. I sign it and hand it back.

You: Thank you. Bye.

Me: Thanks. Bye

There is nothing more to say. I should have known he might have a growth spurt soon. As in addition to the exception needs that swirl at the forefront of my mind, there too are his body's basic needs. But we throw out so much food from things he will not eat on certain days or at school.

As I drive home I wonder if the black SUV will pull up in front of our house tonight, if that husky will lunge at us if we try to go to the park, when I will have time or money to get groceries this week.

I rush to make it in time for the other kids arriving home. After school is hard. My husband does not come home until 5:30 and it's only 4 p.m. All the kids are here. Hungry. Needing. I should be doing the paperwork you asked me to do. I pull it out to the table as the kids quickly eat. My daughter spilled her milk. Onto the papers. I take a deep breath.

Me: It was an accident. Let’s clean it up.

She cries anyways. I’m not even sure why. Maybe she can feel my stress. Poor love. I feel horrible. Why can’t I control my stress better? I wish I had family to help me. I wish I had more help. I didn’t know things would be this hard. I recycle the papers. Another week you’ll say I didn’t get it done. Another failure.

Evening Comes

Bedtime. We read a book. **Okay, two books**. His mind can get stuck on certain images and words. I used to get stressed about that. Now I feel like if he likes something, I should use that to my advantage. I look right into his eyes. I feel so lucky he will look into me. I feel like he is so deep. Beautiful. What a beautiful child I have created. Books are done. The melatonin is starting to kick in. He looks sleepy. We give him melatonin every night or he won't sleep. We used to find him on the floor, right on his toys. Up until 1 a.m.

Child: Mom, stay in my bed.

Me: Okay love. Mama’s here.

I watch his eyes close. He startles for a moment, just to see me. He relaxes once he knows I’m there. He’s asleep.

We put a baby gate on his door frame to keep him safe. I know he can remove it, but it makes a loud noise and I listen for him all night to hear it. I know he would be in danger. He’s always in danger.

The Night

I take my medication. My vitamins. There is no time for my own disabilities. No time to get sick. No time for me. Did I even eat? Did I drink enough water? I long for the days when things were simple. When I had time to breathe. You don’t understand how hard this is. How alone I feel. To not be enough. There is no one to sit and just hear me. I block these feelings and thoughts and force myself to make lunches for the morning. Morning will be here soon. I am so busy doing that I forget to be.

I sit with my husband for a few moments before I fall asleep. Things will get better, I think. I should sleep, it’s late and the kids will need me soon.

3 a.m. He’s up. Nightmares again. I go to him. Talk gently in his ear. Lullabies. Weighted blanket. His favourite toy.

Child: Mommy, stay with me.

So I stay. I curl up on a pillow corner and share a small blanket. It's cold. I fall asleep anyways. I’m so tired.

3:30 a.m. My daughter cries for me. I go to her.

Child: Mama. I need you.

So I stay. I cover myself and drift off to sleep. I sneak out of her bed at 6:30 a.m. when I wake to the sun. My son is awake. I can hear him talking about a show he likes in his bed.

Me: Good morning, buddy.

Child: Hi Mama. I want out. I want to go downstairs and watch Bubble Guppies.

Me: Okay love.

As I look into his eyes, I see him. I really see his beauty.

His spirit. And love. And we begin again.

This is a summary of some of my typical life events when providing support for my son. I believe this can help service providers understand what it is like to live my life. Many of the families I support tell me this is also their reality. There are so many things we need as caregivers and our needs often go unmet because we do not have the energy to ask as all the available internal resources we possess go into our survival and the protection of our children. There are so many intricate details in supporting my son that I can hardly begin to tell a new service provider the depth of despair I have felt or the immense hopes and dreams I have for my son’s future. Most importantly, that they, as service providers, play an important role in our survival.

April 2017

What I need:

- Collaboration with the service providers involved with my son.
- Service plans based on our family’s needs and priorities.
- Service providers increasing our family’s capacity to meet our own needs with information, offered in writing.
- To feel heard.
- To be involved in the decisions that affect my family.

Our Barriers:

- Being employed and having to take time off.
- Transportation, cost of gas, parking issues.
- Childcare for our other children.

- Service providers having their own plan of what is needed and how things should proceed, while not including our family's wants and needs.
- Service providers assume that another service provider has completed the necessary referral or told us about an available service but has not checked, and so we go without it.
- Clinical terms and the language used can be confusing or beyond our current capabilities.
- The power dynamic of a service provider having the power and control in the relationship and at times appearing unaware of this issue.
- The stigma associated with mental health and neurological differences or needs.
- Being in a position where it is necessary to trust service providers without having the ability to know them.
- Providers not seeing the cultural aspects of disability and our family’s unique way of being.
- Staff do not appear trained in family engagement or the adaptation for families like mine.

What I wish:

- One main contact person instead of having a dozen staff to keep track of.
- Notification if something is wrong or something can’t be done the way it was promised.
- Flexibility for our family, in responses and scheduling, shown in an understanding way.
- Respect our family’s rights to receive support.
- Accessible and inclusive areas to meet, including toys for Liam and a door that closes.
- Phone calls and emails that were responded to and I did not have to keep such close track and set alarms to notify me to check that the many providers have not gotten back about issues, including urgent matters.

- Prepare for transitions prior to the necessity, with the plan being shared in writing with a timeline.
- Notes being taken and shared with us via email.
- Help us with costs of transportation, parking, etc, when possible.
- Be responsive to and understanding of our family values.
- Parental knowledge and intent being encouraged and honoured.

Most of all, I need to feel empathy and compassion, be treated with dignity, respect and understanding, so I can feel understood.

Seeking Understanding

We are all seeking understanding and to be accepted in some capacity in the relationships we form. In a family, it is not only the caregiver seeking understanding, but all the members of my family. Wolfe et al. (2014) documented that the entire family, including non-disabled siblings, are negatively affected by poor family well-being, further compounded by having a sibling with differences and impairments. My understanding is that it is not the child themselves, but instead the social constructs, such as the poverty, stress and isolation that comes from a society that is not made for differences.

I have felt unfairly treated and hurt by service providers insinuating or outright saying to me that I am the cause of Liam's challenging behaviours/sensitivities. This included specifics including his high levels of distress and his need for space or comfort. The accusations and blame expressed did not appear to be based on research or evidence, yet their opinions were known with clarity.

The blame I have encountered from service providers and educators is not something I have been able to shake free of as easily as I have hoped. I carry a sensitivity to things stated after hundreds of occurrences. Parents like me feel misunderstood by school personnel. We interpret there is a lack of appreciation of the parental stress we carry, the perceived reduction of emotional energy we emit, and the practical concerns like transportation that keep us from actively participating in school-related activities (Duchnowski & Kutash, 2007).

As a mother, I have carried the weight of my child’s needs throughout his life. The strength I possess is of a magnitude I could never have imagined, and it’s heavy to carry it alone. Hedov et al. (2000) studied the significant increase in time spent between a mother and child with impairments, in comparison to children without, with an average of 80% more time spent than fathers in the same family. Mothers like me have overall poorer health and lower self-esteem than our spouses or parents in control groups who are part of families that don’t include disability (Hedov et al., 2000).

The chronic stress throughout my life, including the years spent accessing support for my son’s impairments, has impacted all areas of my health, and I am not alone. The diaries of mothers of children on the autism spectrum, in comparison to those who were not, note acute and chronic stress, and heightened cortisol levels matching increases in behavioural concerns (Seltzer et al., 2009). High stress impacts our overall health and well-being, affects our cognitive performance, and shows increased and long-term cortisol scores appearing similar to combat soldiers, Holocaust survivors, and those diagnosed with PTSD (Seltzer et al., 2009). Addressing the needs of mothers, as well as all caregivers who raise children with impairments like those on the autism spectrum who may have heightened cortisol levels, may increase the well-being of the entire family.

Studies have shown that mothers of children with disabilities have significant negative outcomes related to anxiety and depressive symptoms, as compared with other mothers or the general local population (Bourke-Taylor et al., 2011). I live this. Every area of my life is impacted by my son having a disability, including my ability to be a parent, not only to my son but my other children as well. In an Australian study exploring self-reports, approximately 50% of mothers showed the stress affects a mother’s ability to parent their child as necessary, with 50% also stating frequent interrupted sleep (Bourke-Taylor et al., 2011). Mental health impacts were statistically significant for those raising several children with disabilities, those with younger children (such as under the age of five), a child on the autism spectrum, and those who were aware their health affected their ability to provide care to their child (Bourke-Taylor et al., 2011).

There are significant negative correlations documented for maternal mental health and raising a child with an intellectual disability. For example, Emerson (2003) explored statistics of 10,438 random children’s files (aged 5-15) within England, Scotland and Wales, with the additional sample of 245 mothers of children with differences (opposed to 9,481 mothers who had children without disabilities), had social, economic and stress outcomes reported. The outcomes show that mothers of children with differences were “significantly economically disadvantaged,” with greater social and psychological impacts for these mothers. There are additional specific mental health challenges for males, with increased risks for males experiencing more than one stressful life event, living in poverty or experiencing “unhealthy” family functioning (Emerson, 2003). In a study by Huang et al. (2013), it was confirmed that fathers also have higher stress levels, and lower mental and physical quality of life while raising children with disabilities even though mothers may still do the lion’s share of the work.

Many things impact my levels of stress and the functioning of my family, including my child's type of day, available resources and my health. This in turn affects my son's behaviours and needs, and also affects the other members of the family who are connected and affect each other in action, communication and by simply sharing a space. In a study by Cuzzocrea, Larcan and Westh (2013), interactions were monitored between parent and child, analyzing energy and attention levels, in addition to experiential modality and regulation, and a disparity was noted. Higher levels of parental stress is correlated with lower parenting efficacy, maternal well-being and overall family resources (Cuzzocrea, Larcan, & Westh, 2013; Creswell, 2015).

Relationships with Service Providers

I have sat with several hundred service providers in my life and I'm sure I will sit with thousands more. Families like mine are made to retell their family's story to intake, several front-line staff, and even their supervisor. Studies show that retelling the stories of challenges can be traumatizing to us and our families (Gundersen, 2012). There must be a way to record the family history and pass it along without expecting needless retellings. Building and growing trust takes time, and after a lifetime of experiencing reasons to distrust people, sustaining relationships with service providers is difficult. Starting off with a traumatic family history is not a good way to begin a healthy collaborative relationship.

Taylor and Seltzer (2010) invited 170 mothers raising children with ASD to share their experiences over seven years and found that those with the greater number of unmet service needs showed the least relationship improvement, even if their child did not have additional barriers like an intellectual disability. This impact can last over years, after high school and possibly for their entire life (Tirch et al., 2014).

Judgment and negative experiences of support from those in our environment, including service providers, can increase the risk of depressive symptoms (Smith, Greenberg, & Seltzer, 2011). Shilling et al. (2015) suggest that ongoing service provider training and ongoing supervision can provide effective support to caregivers by service providers.

The truth is there are real limitations to our capabilities as service providers due to many factors. During my 19 years in social services, I have had caseloads that prevented me from connecting with all those I needed to, and due to emergencies, less urgent requests fall off the to-do pile. This is in addition to policy and procedural challenges that are beyond our control. There are, however, many things we can control, and they have significant meaning to the families we support.

There are ways to repair a break in the bridge of communication within the relationships between caregiver and service provider. After a service provider who had worked hard over years to serve our family, showing respect and kindness to me during some very difficult times, she had not responded to an email for 3.5 weeks. I forwarded it back to her and asked for a response and she responded with honesty that she had missed it and apologized. The relationship had been built even though we only had contacted a few times in a few years. But the relationship could tolerate the damage done because I felt respected prior and during the interaction. She also righted it by following up that day and owning her actions. This allowed me to know she could be trusted her communication showed me she was authentic.

May 14, 2018

Trust. Trusting a person with your child is like trusting a person with your heart, your breath, and your life. It takes all I must leave my son, or back away at times, because I feel scared for his safety, and the safety of my heart if anything were to happen to him. Today it happened. A long-time trained staff, who is in charge of my son’s safety, instructed him to come to her in the water and extended her arms. She proceeded to respond to his jump without movement to catch him and he nearly drowned inches from her arms. As I jumped in the pool, all I could think was “Why is she not getting him?!” and I still can’t answer that. The supervisors told me I should have been in the water, or done things differently, instead of saying “I’m sorry” and responding in a way to support wellness and accountability. As usual, I was welcomed by an old friend, anxiety, and fell again into PTSD.

The organization did not follow up with me, or to my knowledge from their delayed responses to my numerous emails, offered training to their staff to prevent this from happening again. The option to escalate the issue within the media is always there, yet the impact on my mental health and use of energy is something to consider. After 12 attempts to reach out to the national, provincial and city supervisors within this organization, I am sad to say there has been no resolve. I read weeks ago that another child nearly drowned at the same facility due to a similar reason, and despite my heart sinking as I let the information seep in, the reality is I feel at peace with the effort I put forward to make a change. I cannot fight every battle, and my son’s current distress is where I must put my energy.

Despite there being services in place to support families like ours, I have yet to hear of a completely positive experience. I have the unfortunate impression that the more service a family needs, the more challenging the experience. The onerous application processes alone often surprise those who have not applied as a consumer of service. Results of a study by Gundersen (2012) indicated that caregivers of children with disabilities fear their emotional triggers, such as having to retell stories of challenge and highlighting the deficits of their child or the inequality of their child versus other children. In the same study, the rejection after sharing their circumstances and being denied services was an overwhelming and significant challenge for many caregivers (Gundersen, 2012).

All professionals are not created equal, and there are as many who struggle as those who are well skilled. During many meetings, I find myself taking deep breaths and imagining my mind as water, both still and smooth, and the words shooting towards me are hardly disturbing the soothing feeling within me. Other times, I cannot contain the tornado of hurt and pain, reacting to the disengaged and disorganized and unfeeling mess within the organizations we are forced to seek resources from. The internal resources that have blossomed throughout my experiences have allowed me to manage through the turbulent waters, and yet do not protect me from everything.

December 2016

I met [service provider] today. She arrived at our home, and sat with me, with care in her eyes. She will be one of the long-term helpers in our family’s life and I felt like she really sees us beyond our current struggle. I told her what has been happening in our life, and she suggested options for us and offered a support person to come to our home each week to allow us to connect with our other children. Oh, dream of dreams! More than the support offered, the compassion she showed gives me hope for our family. To be really seen for our strengths and offered options brings intense joy and hopefulness for my son’s future and gives me the energy to move forward on this long road of advocating for his needs.

The reality is I will continue to be affected by my history and the path I have journeyed with my son. It’s not all bad. I have expensive opportunity to learn and grow, which has allowed me to feel things I never dreamed of. I feel useful and have a great sense of pride in seeing the strength in myself as both service provider and family member who is working to change the landscape of disability in Canada. I believe together we will make the differences we seek to see. I believe we will get there.

March 23, 2019

I sat with my colleagues today and began to share the depth of pain families like mine feel when we are turned away from service. I realized then it was without words and simply a deep sense of felt emotion that I could articulate the despair, fear and frustration of what being told "We don't have the capacity to support you" does to the psychological well-being of someone even as privileged and connected as I am. In situations like this I often think of the families who do not have the loud and bold voice I have, and perhaps the impulsivity of my neurological differences with ADHD playing a bigger role that I'd like to admit. The fact is, I know a large proportion of the professionals in my city, and I have some skills in articulating my needs in a way professional can hear because I have been one for 19 years. The families I tend to sit with do not have those same experiences. They are at a disadvantage, and that is never far from my mind.

What Can Service Providers Do? Increasing our understanding of families that include children with disabilities is a big part of the solution to adapting our practice. By increasing family engagement, we can improve the mental health of caregivers (Gray et al., 2011) and the child's mental health (Bøttcher & Dammeyer, 2013).

Family engagement is the active partnership between families and service providers. For service providers, this means listening to families, engaging in reciprocal communication, and involving them in all decision-making where the family's involvement is meaningful and has purpose. The service provider develops the relationship by focusing on listening (Bossard et al., 2014; Chovil, 2009; Ontario Centre of Excellence for Child and Youth Mental Health, 2016).

Within this practice, we will develop a better relationship and have more success with the family as they feel we see their strengths, challenges, concerns, and cultural differences and are accepted (CAMH, 2012; Chovil, 2009). There is increased family buy-in and more options to choose from when we include families in the decision-making and include them throughout the process (CAMH, 2012). Families are more likely to commit to achieving case goals when they help to make decisions about a plan that will affect them and their children (CAMH, 2012). The meetings themselves will be better, as the partnership developed between the family and service provider increases overall engagement, resulting in more constructive meetings and more positive outcomes (Gladstone et al., 2014). We are able to offer more targeted services in a collaborative partnership. Service providers and family members are better able to identify a family's unique needs and develop relevant and culturally appropriate service plans that address underlying needs, build on family strengths, and draw from community supports (Pinsoneault & Fiermonte, 2013). Lastly, the family is more likely to be preserved (CAMH, 2012).

Beyond that relationship, the family leaves the interactions being better equipped to make decisions. Involvement in a strengths-based decision-making process where approaches to problem-solving are modeled gives family members new strategies for communicating and problem-solving (Pinsoneault & Fiermonte, 2013).

January 10,2019

I've been thinking a lot about what has been the most supportive to my family and I as I have navigated this minefield of services over the past years. As I reflect, I see that during the beginning of a relationship with a new service provider, the details set the stage for the course of trust and our work together. I recall a new provider offering tea and a chocolate she had, asking, “How are you?” and the impact it had on me. There was a bridge created during the session, where I felt like that this was more than an interaction necessary for employment and instead seen as a human being with needs.

There are many ways to create a welcoming atmosphere, and each time I have appreciated the intention of connection and care. I am often overwhelmed during clinic meetings despite my calm appearance. The times where a service provider shares that they plan to take the notes and offers a choice of copying them or typing and emailing them to me has reduced my anxiety immediately. This has allowed me to focus more on what is being said and problem-solving, rather than tracking what is shared at the meeting. Similarly, the follow-through is important in regard to offering notes or completing a task. If there will be a 3-week window of waiting, the issue ends up being added to my complex set of challenges, increasing fatigue and distress. Further to this, offering options has also had a meaningful impact. For example, as a provider states 2 options in how notes can be shared, when and where we can meet, and what steps to take next, I have felt the power shift. Within those moments there is a sense of control offered to me, for which I feel the effects throughout my day and beyond. This sense of power is so often removed as I am dictated instructions with deadlines or felt demeaned in social and personal interactions regarding my child. As a service provider, I am met with thousands of invisible interactions which existed prior to joining a team. Each time I meet a caregiver or youth I note this to myself, inviting me to bring my best to the table and letting go of the baggage I can only impact going forward. This has also intensified the importance of listening first. As a parent, I have a high need to be heard. The sea of invalidation and blame I navigate in every area of my life causes deep internal struggle for me. I require simplification and validation that although you may not know what I am going through, you can help create space to catch a breath.

There are ways to simplify my experience as I receive information within our interactions. When you are communicating with families that include children with disabilities, and the distress they may be in, imagine receiving that same communication on your worst moment of your worst day. This may be how it is taken. For instance, by sharing that you need them to follow through on a task, it may be interpreted as demanding or insensitive. While living through high levels of stress and hearing a suggestion, I can interpret it differently than intended, and again more intense than if I had had enough (or any) sleep, had even moments of self-care in the week, and the like.

As well, within the communication, keeping things as simple as possible. This includes more than removing complicated instructions and clinical language and includes the specific details of a resource for a youth or caregiver, pulling information from other service providers when possible. As an example, it was meaningful for me to get a completed social story to read for my son about staying safe at the park with suggestions on how to integrate it into bedtime, and not helpful to be directed via email to complete one. I had to then research what it was, where to find the details of what to do, and then create time to find images, the correct wording, create it and print it. In the end, of the social stories created, only one was enjoyed by my son. Imagine that I had created 4 hours within my life to create the book, only to have him throw or ignore it. The experience was defeating and removed motivation to follow through with the additional suggestions by that service provider as I felt it was not worthwhile.

In comparison, when a service provider spends the time to gather and share resources with me, I feel respected and validated in my reality. The reality is that I do not have 4 hours to pull from other necessities. This means my children are often going without, and worse yet, it often means I experience less rest and may be a poorer parent due to fatigue.

The ABCDs of Adapting Our Practice

The ABCs of adapting family-centered care invites service providers to a framework to customize each experience for families that include children with disabilities. The A is for attitude, meaning that our history affects how we see and experience our life. Being aware of who we are and why we are this way can help us be even better at our job, and maybe happier in our lives. The B stands for behaviour, because our actions impact our life and those around us. C is compassion, because kindness and understanding is important as we work with others but also as we support ourselves. Lastly is discussion, as communication and the words we use impacts our relationships. The ABCD framework can be used as we prepare to meet a family for the first time, or prior to a session for a family we have known for some time. It invites awareness and compassion to be emitted within the interaction and in our relationships.

Attitude. To increase awareness of our attitude, we can consider the unique situation a family may be in, with the limited or extensive knowledge we might have about them. This includes: How would I feel in this family’s situation? Why do I think that? What am I assuming? My assumptions may be affecting them. How is my own history and worries affecting my attitudes? Does my attitude support me to have a positive and empathic professional relationship with families? What are the barriers this family faces (Chochinov, 2007)?

Behaviour. Being aware of our attitudes can have a positive impact on our behaviour. Showing kindness in both small and large ways can build a positive relationship. We can do this by giving our complete attention, offering to provide notes, understanding how difficult things must be, and asking if anything needs to be repeated, as well as inviting the caregivers to ask additional questions or request clarification in the future (Chochinov, 2007).

Compassion. Compassion can be considered to be the awareness, understanding and felt sense of suffering, its causes, motivation and intention to alleviate it (Tirch et al., 2014). For some, compassion comes very naturally. For others, for a variety of reasons, it may need to be nurtured. We may have found ourselves in a difficult situation in our lives, which may have helped us feel care and compassion to ourselves or others. We can increase our compassion by creating opportunities to get in touch with our own feelings, seeking out information (such as personal or written stories that share about the vulnerability of every human), experiencing a degree of identification with the family's experience, and receiving formal training (Chochinov, 2007). We show compassion by taking time to be with a family, and by the look on our face and either spoken or unspoken communication, acknowledging the person beyond their situation and the felt sense (Chochinov, 2007).

The Ontario Centre of Excellence for Child and Youth Mental Health (2016) published a summary of things service providers should be aware of prior to working alongside families that include children with disabilities. Families can be scared, so creating an environment to feel safe and comfortable is important. Caregivers need to feel free to be honest without the fear of incrimination (there will be limitations here due to safety). Families can also be misinformed or confused, so we service providers must ensure they have all the information about what is being discussed while remaining factual and eliminating any judgment. Caregivers are often isolated and connecting them with other families going through similar circumstances can be meaningful. The caregivers also feel overwhelmed and isolated by the lack of information and available resources. There is also the feeling of intimidation by the unequal power within the dynamics of the relationship. No matter what one's day job is, within the room the service provider sits as a helper, and they hold the power there. Families have felt blamed and disrespected by school personnel (and other service providers) and have experienced poor service numerous times prior to the opportunity to sit with you.

Discussion. Within communication or discussion, there are meaningful ways you can acknowledge the person you are supporting. Stating "This process can be hard. I will do whatever I can to help" and "What do you need more information about?" can begin to create a bridge of connection. Additionally, "Tell me about your child," "What should I know about your family to help me provide the best support?" and "What are the things in your life that are most important or that worry you the most?" can invite a truer sense of knowing what that caregiver and family need from us as service providers (Chochinov, 2007).

Inspire

"Never doubt that a small group of thoughtful, committed citizens can change the world;
indeed, it's the only thing that ever has."
(Margaret Mead)

I founded Inspire Community Outreach (Inspire), a grassroots social service charity in Winnipeg, Manitoba, Canada, in the summer of 2013, with the hope of raising money to support youth through other local charities. Inspire was born out of seeking out service for my own family after not being able to locate supportive services for my children. Preventing crises for families like mine, where children are placed into foster care or other types of long-term harm being done within families, was something I felt I needed to address. I ruminated over this question, “How can I provide stabilization to complex families not receiving the care they require?” And in September 2018, our team launched the In-home Family Stabilization Unit, bringing interdisciplinary care to the homes of families who are unable to get their needs met elsewhere. The culmination of my life's dreams and work met here, and the magnitude of the difference I get to make is never far from my mind. Sitting with families that include children with diverse needs and disabilities is the most meaningful thing I have had the pleasure of doing. To offer compassion and the opportunity to be seen is something I know is necessary. The opportunity to feel hope, to feel truly understood and to have someone listen to all of the fears in a way that catches them without judgment is the ultimate way to make a difference in a family's life. The experience heals, affects and creates layers to who I am, every time.

The intersectionality of Inspire, my history and parenting is complex. The evolution of the support we offer has been and continues to be guided by community narrative, with interactions with families being the foundation of each step we make. The life-work balance I seek is difficult as I am driven internally to support community through accessing service, providing service and being an ally to those who are in need. I was not able to save my mother and parenting my son through accessing service has been difficult, but through supporting community, I can feel connective and in control, contributing to the change I wish to see.

Inspire is the stillness I have sought throughout my life. The peace I feel as I create meaningful change in a family's lives transports me to a calm and powerful place that only art can depict. Through my work I can enact my vision of the social model, where all differences are seen only as limitations in society (Berger, 2015; Siebers, 2008). We may all require support, and yet the power lies within us and always has. As I reflect on all that I have done, I am humbled by the insignificance of one person's journey. No matter the intensity to which I live and the fullness I now experience, I am one part of life’s puzzle, offering only a small part of what is necessary.

Looking Onward

The procedures in acquiring autism (and other) services are complex, even for those who feel well-equipped to manage most of life’s challenges. As a skilled clinician and specialist in the field, I have felt the tremendous weight of hopelessness in being turned away from service without options or being put on waitlists for years, without a plan of what to do in the meantime. The barriers as I see them are numerous and appear insurmountable as a single service provider, and yet I also know the great impact I can make as a single support in a family’s life. This contradictory reality is something that as service providers we wear as part of our position as a helper.

The inside experience may feel overwhelming to digest, yet I believe it is important to reflect on the truth behind the scenes, as this is not something often shared in mainstream training or consultations. To share the deepest truths within my home is a gift to empower service providers to integrate compassion and understanding into their practice to better serve this population. The disconnect between what is best practice and the reality of service affects families much more than we let on, and without that knowledge, there is very little that will change.

As a parent I will tell you what I need and that I am not receiving it, and as a service provider I understand we are limited. To balance this, we can offer compassion first, both to the caregiver, then to ourselves.

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