

MY BROTHER, MY SELF: AN AUTOETHNOGRAPHY OF SIBLINGHOOD AND  
DISABILITY

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Note: All names have been changed to protect the privacy of individuals.

## **Part I: Introduction**

Sibling relationships are an integral part of the family system. A sibling is often one's first friend, and the relationship may be one of the longest in a person's lifetime. Siblings tend to become closer as other family members age and their extended family begins to decrease (De Caroli & Sagone, 2013), meaning that siblings have considerable influence over each other's lives. Brothers and sisters can be a source of frequent companionship, help, and emotional support. Older siblings represent an important facet of the sibling relationship - as similar to parents they can serve as caretakers, teachers, and models, but they are also, uniquely, a friend as well (Lobato, 1990; Davidoff, 2006). As such, the sibling relationship represents one of the most powerful bonds and human interactions.

When my sister was born I was close to three years old. Perhaps because it was such a momentous occasion in my childhood, despite my young age, I do have memories about that day. I recall my dad picking me up from daycare and taking me to the hospital. I remember playing in a children's area that said it was for children aged three and over, but because I was turning three in two months, my dad gave me the okay to play there. I remember seeing my mom in a small room with a band-aid on her wrist - in hindsight, she was likely in a room that was divided which is why it seemed so small, and had medical tape to support an IV on her hand, not a band-aid. But that's about it. I don't remember anything about my sister as a baby or as a toddler, I only know what I see in pictures or home videos, or what I hear from my parents and other family members.

I do remember that very early on I was clearly told that I was responsible for my younger sister. As the eldest sister it was my job to look out for her, to always include her when I was with my friends (even when I didn't want to), and share any gift or treat that I may receive. When I was around seven my sister and I were playing with our older cousins, and they thought it would be funny to lock my sister in a closet and turn out the light. In hindsight it certainly wasn't a funny thing to do; unfortunately, sometimes children don't think about the feelings of others and act in thoughtless and cruel ways. Likely because I wanted to be accepted by my "cool" older cousins, I went along with it. When my sister was let out and ran crying to my parents, it wasn't my cousins that they were mad at - it was me. As her older sister, I should have done my job - I should have stood up for her and protected her. My parents continued to reference this incident for several years after it occurred.

When my brother was born I became the older sister to two siblings. I was nine and a half years old, much older than when my sister was born, so I have many more distinct memories of him growing up. I vividly remember the day when my parents told me I was going to get a younger brother. After picking my sister and I up from Hebrew school, they took us to Pizza Pizza for lunch where they shared the news. We were both very excited. When he was born, the kids in the neighbourhood decorated our driveway with chalk drawings and congratulatory messages. Shane was a cute kid - as most children are - with blond hair and big brown eyes. I remember him falling asleep in my arms while I was swinging on the backyard swing. I remember his first steps. I remember his first day of school. That "cute kid" has now grown into a gangly teenager. My parents

didn't need to tell me of my role to look out for him; our large age difference instilled a sense of responsibility and protectiveness from an early age.

I am very happy that I have a close relationship with both of my siblings. The relationship I have with my brother, however, differs from the relationship that most individuals have with their siblings. This is because my brother is labeled with autism spectrum disorder (ASD). ASD is defined as a lifelong neurodevelopmental syndrome that affects the manner in which an individual communicates and relates to other individuals and the world around them (Lord et al., 2000). According to the National Epidemiological Database for the Study of Autism in Canada, ASD is one of the most common developmental disabilities. In Canada, 1 in 94 children is diagnosed with ASD (Autism Ontario, 2016). This biomedical definition has significant importance, as less than thirty years ago, the accepted view was that autism was a psychiatric disorder caused by "refrigerator mothers" and their cold, distant parenting (Davidson & Orsini, 2013). However, it is important to note that currently "what we know about autism is deeply embedded in a series of historical, social, cultural, and discursive contexts" (Davidson & Orsini, 2013, p.24). Autism is still often presented in troubling ways, as something that can be "caught" or somehow caused by vaccines. Claims that autism is caused by vaccines were rampant in the media, and trustworthy sources were often credited (Davidson & Orsini, 2013). As such, responses to autism are often framed in polarizing ways - sometimes it is regarded as a neurological difference to be celebrated (neurodiversity), and other times it is viewed as a disabling condition. Further, as stated by Stuart Murray (2012): "if we're honest, the fundamental observation that we might

make, the ‘central fact’ about autism with which we should probably start, is that we don’t know very much about it all.”

I can only speak to my experience as a sibling of an individual with autism. Although research on parents of an individual with a disability is significantly more available, sibling-disability research is an emerging field. Initial research in this area mainly focused on psychological outcomes of the sibling without the disability (Breslau, Weitzman, & Messenger, 1981). There is much less published research on the relationships between siblings, or furthermore, research that sought perspectives from either sibling. Current sibling-disability research does address key concerns and important ways of supporting siblings across the course of their lives (Meltzer & Kramer, 2016). Main themes found in the literature as identified by Meltzer & Kramer (2016) include difficult experiences, beneficial experiences, contributing factors, support and interventions, and caregiving.

Additionally, when researching this topic, I had trouble finding published articles that were written by a sibling. I believe this is a significant omission as it leaves out the lived experiences of disabled and able-bodied siblings. Carolyn Ellis, an esteemed qualitative scholar, “focuses on writing and revisioning autoethnographic stories as a way to understand and interpret culture and live a meaningful life” (University of South Florida, 2015). Her writing on autoethnography has had considerable influence on my choice to use this method. I relate to much of her motivations behind this method as well as her approach. Much of her research has been situated in interpretive and artistic representations of qualitative research and Ellis (1997) discusses the absence of lived

experience within research, stating that “the reality was [*sic*] that few scholars included [*sic*] connection to lived life as one of their goals (p.122). Furthermore, according to Ellis (1997), lived experience is important because it “adds blood and tissue to the abstract bones of theoretical discourse” (p.117). As such, I will attempt to fill this gap, by addressing my lived experience as a sibling of an individual with a disability. I care deeply for my brother, and thus, witnessing him face various forms of discrimination has greatly upset me. That being said, I have also been privileged to witness and be a part of countless positive and wonderful experiences. For parents, their role as caregivers and as trailblazers in how autism is addressed is marked by their feelings of attachment (Davidson & Orsini, 2013), and furthermore “emotions and affects have begun to occupy their rightful place in the study of autism” (p.9). Even though I am my brother’s sister and not his parent, I too feel very attached and emotionally invested in him. It is this attachment and emotionality that motivates my writing.

## **Part II: Coming to Autoethnography**

I have always loved reading. Throughout elementary school I would often get in trouble for reading books under my desk in class. In one classroom I even had to have my desk moved away from the bookshelf - it proved too great a temptation. I devoured books, mostly young adult books as well as biographies and autobiographies, and of course the “Harry Potter” series. The biographies that I read were often of film stars that my mother admired and would pick up at garage sales. Before high school I had read multiple biographies including those of Marilyn Monroe, Judy Garland, Barbra Streisand, Liza Minnelli, and Shirley Temple. Before the existence of Netflix and YouTube, on

many a school night, I would stay up far too late consuming novels, and won quite a few summer reading contests at my local library. I had one teacher in grade seven take particular notice of my love of reading. This teacher often suggested more mature books for me, moving me away from teen romance novels that admittedly lacked substance.

School assignments where I had the opportunity to write were always my favourite, and I excelled in language arts. In high school, one of my favourite classes was Writer's Craft. In this class I had the opportunity to write poetry, short stories, one act plays, and children stories. My favourite to write was short stories. I even thought that one day I would write a fiction novel of my own. As I continued throughout high school, however, the sciences seemed like a safer more stable route, especially considering the pressures put on me by my traditional Russian-immigrant father. Moreover, because of my brother I was determined to learn more about disability, and science and health seemed to be the only way to do so. But even though I was taking science classes such as Biology and Chemistry, as in elementary school, I continued to excel in Writer's Craft throughout high school.

When it came time to apply to post-secondary school, I knew I didn't want to do a strictly science-based program that dealt with minute concepts and biological processes. I not only found this difficult to study, but I also found it incredibly dry - I was more interested in people and their experience with disability, which appears to be a common trend for siblings of those with disability. In their study on the subject, Dyke et al. (2009) discuss that the siblings are more likely to pursue careers in medicine, education, and associated health fields. This certainly holds true for my sister and I. My sister is



presently studying early childhood education, with a plan to specialize in teaching young children with disabilities. I am currently studying Critical Disability Studies, and hold a Bachelor of Health Sciences. I think this partially stems from the sense of responsibility I feel towards improving circumstances for, not only my family, but other families with children with disabilities as well. Having a brother with a disability has resulted in many difficult experiences. I know that this is not solely related to the disability itself, but to how current policies as well as individuals view disability. It is difficult to constantly be stressed about how Shane's day at school is going. It is upsetting that I can count on one hand the number of birthday parties he has been invited to and still have fingers to spare. It can often feel as though no one knows and can understand what I am experiencing, and this has made me feel very isolated. I feel as though I need to do what I can to mobilize my knowledge and my experience to help other families, not only to ensure that these experiences are lessened, but also that they feel less alone. These feelings of isolation were a significant struggle for me. Presently, I try to be much more open; however, these feelings still persist to a lesser degree.

The health sciences program at The University of Western Ontario took an approach to health and well-being that was different from the other science and health programs I applied to. This program prided itself on maintaining the biopsychosocial model of health, in which psychological and social factors are considered in addition to biological factors. In this way it seemed ideal. I was fortunate to receive several post-secondary acceptances, but Western was the one I wanted most - and the acceptance that came last! Core courses in this program included the Personal Determinants of Health,

Social Determinants of Health, Introduction to Ethics and Health, Health Policy, Healthcare Law, Health Promotion, Health issues in Childhood and Adolescence, and Health issues in Aging, in addition to more traditional courses such as Biology and Anatomy. I did enjoy these classes, but I still had a love of reading, and so I took The Storyteller's Art Part I and Part II as electives. Knowing that I wanted to learn more about disability led me to take courses through the rehabilitation sciences module, in which I took classes such as Physiology, Introduction to Speech and Language Disorders, Enabling Health and Well-Being through Occupation, Health Conditions and Disease in Rehabilitation and Rehabilitation for Childhood Disorders. These courses did instill the importance of a dynamic interdisciplinary, client and family-centered approach in rehabilitation. Within these courses, though, while they did not conform to a strictly medical model, disability was viewed as always needing a form of rehabilitation. We discussed autism in rehabilitation for childhood disorders, however, it was within a discussion of other common childhood disorders, symptoms, and possible treatments. I was struck by the absence of lived experience. Although we were taught to consider the individual experiencing the disability or illness and not only the biology, this was done solely through case studies. We never did in-depth readings that truly looked at the human experience of disability. For this reason, although I enjoyed my courses, I had a hard time relating what I learned in classes to what I was experiencing at home. Ellis (1997) exactly echoes my feelings, stating that: "for the most part, I could not connect my life to what was being taught in classes" (p.122). Unfortunately, somewhere along the

way, I lost my passion for reading and writing. I had seemingly endless readings to do for school, and therefore reading during my free time became unappealing.

My first exposure to discussing disability with a narrative focus occurred when I took a class during my undergraduate degree entitled Health Related Quality of Life. One of the assignments was to read *Tuesdays with Morrie*. In this book, Mitch Albom narrates his time spent that he spends with his former sociology professor, Morrie Schwartz from Brandeis University, who has amyotrophic lateral sclerosis (ALS). This was definitely my favourite assigned reading, and I easily read the entire story in one sitting. I viewed this assignment as a random, unusual one, though. I didn't make the connection that this form of writing can have a significant contribution to our knowledge of disability and disability experiences. Ellis (1997) states that "social science education did not prepare [her] to write from the heart, touch other people, or improve social conditions" (p.128). I certainly feel this way about my health sciences education. Even as I write this paper, I find it a struggle to truly explore and expose my feelings, rather than stating facts and distancing myself from my writing. This is unfortunate because many students such as myself enter health sciences with the motivation to improve social conditions, however, we are given a limited perspective on the means to do so.

While pursuing my master's degree at York University, one of the assigned readings for my class entitled Indigeneity and Disability was "Dishinikawshon Jesse: A life transformed." This piece contained different vignettes written by Thistle (2015). He describes himself "as an aboriginal man amputated from my Michif clan at the age of three,

I am, just by being, a rejected part in the Canadian “system.” [...] “a young man without identity, without mode or instruction; by age 21 I had become homeless and an addict, and was in and out of jail” (p.69). Even though the content itself was harrowing, this was one of my favourite readings from this class because of the way it was written. It was extremely captivating, and I quickly became engrossed in Thistle’s story. I read the entire article in one sitting, a rare occurrence when I am reading articles for class. I enjoy reading narratives such as this piece, not only because I find them interesting, but also because they give personal insight into issues that I may have only read about in a more factual way. Furthermore, because the writing is so evocative, the content has stuck with me much longer than most non-narrative style readings.

In discussing the use of autoethnography as a methodology, Holman Jones, Adams, & Ellis (2013) writes that:

Autoethnography creates a space for a turn, a change, a reconsideration of how we think, how we do research and relationships, and how we live. These stories constitute a narrative of coming to an experience and moment in time when excluding or obscuring the research felt uncomfortable, even untenable. (p.21). One characteristic that binds all autoethnographies is the use of personal experience to examine and/or critique cultural experience. Autoethnography is the use of personal experience and personal writing to:

(1) purposefully comment on/critique practices; (2) make contributions to existing research; (3) embrace vulnerability with purpose; and (4) create a reciprocal relationship with audiences in order to compel a response (p. 22).

Ellis (1997) further states that her goal for using “stories that focus on the self in a social context” (p.117) is to “try to connect social science to literature, academic interests to personal ones, emotions to cognition, and social life to the concrete living of it” (p.117). This explanation coincides with my motivation for employing this methodology in this paper.

In addition to the aforementioned reasons, another motivation I have for writing an autoethnography is to share my personal experiences in order to create a connection and a response with the reader. I hope that by writing in this way, this paper and topic will be more evocative and interesting. When discussing traditional research, Ellis (1997) questions: “how could those outside this tribe [of academia] connect their lives to what we were doing?” (p.122) In accordance with this, I hope that by using this method, those who have similar experiences to mine, whether or not they come from academia, can relate to my writing, and feel as though their own stories are valuable and can be shared. Ellis also discusses this, stating that she used an “autoethnographic voice that concentrates on telling a personal, evocative story to provoke others' stories” (p. 117). By establishing a connection with the reader, I hope that the reader will be more likely to care about my writing, and as such, this paper will be more memorable and likely to affect change. Moreover, writing my major research paper in this way seems like an ideal way to not only incorporate my passion for writing, but also a way to add lived experience to sibling-disability research.

When discussing this project with family and friends, I was often asked how this differs from an autobiography. Therefore, I feel as though it is important to distinguish the two. Holman Jones, Adams, and Ellis (2013) differentiate autobiography and autoethnography in the following way:

If an author experiences an epiphany, reflects on the nuances of the experience, writes to show how aspects of the experience illustrate more general cultural phenomena and/or to show how the experience works to diminish, silence, or deny certain people and stories, then the author writes autoethnographically. If an author writes to tell a story to illustrate a sad, joyful, or problematic experience but does not interrogate the nuances of this experience in light of general cultural phenomena and cultural practices, then the author writes autobiographically (p.22-23).

In accordance with this explanation, I will share personal stories and experiences, as well as analyze these stories.

There is significant apprehension associated with this form of writing. I have said for some time that I want to make a positive impact in some way on those with autism and their families. Who's to say that writing about my own experience will be of interest to anyone? Who cares about what I have to say, and more importantly, will it mean anything to anyone? Why will my story make any difference? My instinct is to feel that it is almost arrogant to write solely about myself and my personal experiences. Ellis (1997) provides a counter to this feeling, stating that "autoethnography should be self-absorbed. If you're not absorbed with the topic of your research, how can you write well about it?" (p.122) I am certainly absorbed with my topic; I love my brother, and want the absolute

best for him. She further states that “my hope was that readers would see my "self absorption" as an avenue to learn from exposure to candor and vulnerability” (p.130). I share this hope that my absorption will serve a purpose.

In addition to sharing my experiences, I also feel uneasy about sharing my thoughts; there are certainly others who are much more educated and experienced than myself. I find myself at times doubting the validity of my opinions and criticisms. Ellis (1997) writes about this as well, and states the following when discussing her experiencing writing autoethnographically:

The exposure had to include betrayals, uncertainties, and self doubt, including doubt about what I had written. I wanted readers to trust that I had started with what I didn't know and discovered what I did know through the process of writing. I never pretended to have it all worked out, nor to suggest that the finished product disclosed the bare truth (p. 130).

As such, even if I am not entirely confident in what I'm writing or feel as though the reader may not understand, I will still include it. The truth of my story as I know it is that it is imperfect, incomplete, and perhaps contradictory, but it truly represents how I feel and the realities of being a sibling of an individual with disability.

As important as I have shown incorporating lived experiences into writing to be, writing using this method is emotionally draining at times. The stories and moments that I'm discussing are often upsetting to think about, much less write about. Writing about these instances brings negative, stressful, or confusing emotions to the surface. The

peculiar thing was, when my writing was the most emotional, I have found I am able to reflect and disclose these experiences with the least effort. My thoughts would seamlessly pour out of me and onto the page. Despite this, at times I needed to take a break and either step away from the computer to take my mind away from the situation. Additionally, because what I'm writing is so connected to my personal life, when negative things were occurring in my personal life, I found it difficult to remove myself and write in a positive way.

Ellis (1997) discusses the implications as well as benefits of emotional writing. When discussing her writing about experiencing loss, she states that:

The moves in and out of these emotional situations were painful yet therapeutic. They allowed me to experience emotionality safely in my office, often reminded by a phone call or a click of the computer key that I was not actually in this situation. If the emotionality became too intense, I could stop and return to current time, a safety valve I did not have while engulfed by the epiphany of the initial experience. This "safety" gave me confidence to explore each incident as fully as I could, and to pay attention to what was most upsetting and least resolved. I concentrated on the singular loud voice screaming inside my head or the raw fear gnarling within my gut. Then, embracing the multiplicity of selves that all human beings harbor, I tried to bring to my consciousness the contradictory and ambiguous thoughts and feelings (p.130).

While writing I have tried to keep these words in mind and use my emotions in order to make my writing stronger, I will also ensure that I critically reflect on my experiences and my feelings associated with these experiences.



### **Part III: The Sibling's Role**

A few years ago I joined a sibling support group for adult siblings of individuals with disabilities. This group meets approximately every month, and has informal discussions about the goings on in our lives, and of course our sibling's lives. I have found attending the sibling support group and talking to other siblings of individuals with disabilities to be especially helpful, supportive, and even therapeutic. The social worker who conducts these meetings herself has a brother with a disability, and so she truly understands, and even shares her own experiences, frustrations, and joys. When my sister returned home from living away for school, I brought her with me to one of these meetings. She also enjoyed the meeting and continues to attend even if I am unable to go. As we are the youngest in this group, it has been extremely valuable to hear from others who have already experienced what we currently going through. Additionally, it has been beneficial to attend this group as I have made friends with others who, because of our shared experiences, can connect with us on deeper levels, as well as provide support. Members of this group have often remarked on the significance of having these discussions with others who understand their unique perspective and can relate in ways well-intended friends and partners cannot. Within our discussions, common themes often emerge that are unique to siblings, such as holding different opinions from our parents on how to best support our siblings.

As I have lived with my brother for almost his entire life, I not only have an intimate perspective into his daily life, I am intertwined in it. I contributed to his care beginning in my early adolescence, doing things such as taking picking him up from

school, preparing him meals, and getting him ready for bed. I attribute this more to our large age gap, though, rather than him having a disability. Care is something all people, both disabled and non-disabled, need; when my sister was younger, I assisted with her care as well. That being said, siblings of individuals with disabilities have also been shown to contribute to care across the life course, and are often expected to contribute to care as older children and in adolescence. In adulthood, siblings without disabilities are often expected to step into the care roles previously held by parents (Heller & Arnold, 2010). According to research by Coyle, Kramer and Mutchler (2014), although many adults with both intellectual and developmental disabilities (I/DD) live independently in their own homes, and others live in group settings, the majority of adults with I/DD live with a family member. Approximately 75% of adults with I/DD live at home with family carers, usually parents, and 25% of these carers are over sixty years of age. As such, many adults with I/DD will continue to rely on family carers in later life, and the siblings will increasingly take on the role of primary caregiver as their parents age. Most parents prefer and expect that a sibling or another family member will assume these responsibilities once the parents are no longer able to provide care. These assumptions are often made without any formal arrangements, however, and sometimes without an in-depth discussion with the sibling who is to provide care. This article does not mention whether or not the sibling with the disability is involved in any discussions. The limited empirical research of sibling expectations does suggest that 44- 60% expect to assume primary care responsibility (Coyle et al., 2014).

For siblings of adults with a developmental disability, a key issue is planning for this transition when parents can no longer provide care. As discussed, many families do not make concrete plans regarding future living arrangements and financial plans. Particularly when the sibling has an intellectual disability, adult siblings without disabilities may become increasingly concerned with financial, advocacy, guardianship and caregiving issues (Heller & Arnold, 2010). In a 1994 study of siblings of adults with disabilities who were living in the parental home, Griffiths and Unger found that about half of the adult siblings said they would be willing to take on a caretaker role in the future, but parents reported that they were reluctant to cast them in this role. This may make the transition to sibling-as-caretaker a more complex process than when families have agreed on a plan well in advance of parental illness and death.

I have discussed with my mother, although informally, that if something were to happen to her and my father, I would assume responsibility for my brother. This is partially attributed to the fact that I am the eldest sister, however, his disability does play a role in this. This is because if something were to happen to my parents, I would not want anyone to make decisions for Shane that would not be in his best interest, and I wouldn't want to risk him being placed outside our home. The difficulty with being an adult sibling is that even if I have well-intended but differing opinions from my parents regarding Shane, my views will always be second to theirs. This can be frustrating, as due to our age gap I have always taken on more of a mothering role than a sister, but as I am not the parent, my views are still not given as much weight. I understand and respect that this is the way it must be, however, it is difficult because ultimately I will undertake the

main role in assisting Shane to make decisions in his future, and advocating for him when needed. Additionally, I personally struggle at times with balancing the role as a caregiver and a sister. When I leave the home for an extended time, I am always worried about how Shane is doing- I even annoy my mom with my constant calling to check in. I am thinking about applying to study abroad, however, it would be difficult for me to not be home and know how he's doing. My mom tells me I need to stop worrying and live my life, but Shane is my life. When he is unhappy or having a hard time, so am I. Because my wellbeing is so tied to his, I need to be able to do whatever I can help.

Additionally, while researching supports for siblings, I found the Sibling Leadership Network (SLN). SLN is a national non-profit with state chapters created to support siblings of people with disabilities and provide a stronger voice for siblings. The SLN's mission is "to provide siblings of individuals with disabilities the information, support, and tools to advocate with their brothers and sisters and to promote the issues important to them and their entire families" (Heller et al, 2008, p. 4). Although SLN is based in North America, anyone with a Facebook account can join the Facebook group. There are different groups targeting different ages, and I joined the group for twenty-somethings called Sib20. Within this group, siblings share joys and frustrations, as well as provide resources and support.

Spaces such as this Facebook group and the sibling support group are important because within these spaces, across age and geographic location, siblings who share a

unique commonality can connect, understand, and support each other. At both the support group and within the Facebook group, siblings have expressed on multiple occasions that what they are sharing they haven't said to anyone before, and they wish they found the group sooner. These sentiments are significant because they highlight the feelings of isolation that can occur when one has a sibling with a disability. There are countless resources and outlets for parents (and with good reason), but it is much more limited for siblings, and furthermore, much harder to find and access the resources that do exist. I often have felt quite isolated in my experience as a sibling, and this has left me feeling dejected and helpless, and as though no one understands. As such, these spaces play a critical role, because they have shown me that I'm not completely alone.

#### **Part IV: Grappling with Perceptions and Expectations of Disability**

Although support groups have mitigated feelings of isolation in my life, I immediately feel a different energy as soon as we leave our home. When it's not only our immediate family present, I at times feel as though there is pressure for Shane to not act autistic. By this I mean not to be too loud, not to ask too many questions, not to jump too much, basically not to do anything out of the ordinary that would draw attention. A particular instance comes to mind that illustrates this. A few years ago, my family attended the wedding of my first cousin - a rare occurrence, as I have a very small amount of family in Canada, let alone in Toronto. It was the first wedding that myself and my younger siblings had ever attended. Both my sister and I came home for the weekend from University to attend. My parents had planned a trip to Disney World at the same time, and adjusted their plans so they could come back less than twenty-four hours prior.

It was a significant event for our family. I recall there being some concern from extended family about how Shane would be during the ceremony, which myself and my immediate family brushed off. At the wedding, my mom ran into an old family friend who she hadn't seen for about fifteen years (read: since before my brother was born). She was excited to meet Shane and see my family. During the ceremony itself, perhaps because of the pressure to be quiet, Shane sat cuddled on my mom's lap. When he is feeling anxious I have noticed that he often wants to hug or cuddle. The same can be said for numerous other individuals, as human and/or animal touch can be very comforting. Was he making any noise or disturbing anyone in any way? Absolutely not. Did people stare anyway? Absolutely. So much so that my mom felt the need to say to her recently-reunited friend, "My son has autism." This instance was uncomfortable, and stuck with me for some time after, even though Shane was doing nothing wrong. As stated in *Worlds of Autism* (Davidson & Orsini, 2013), "sometimes so-called autistic behaviour can be just as "random and casual, as open as any other behaviour" (Murray, 2012, xii) and of course just as challenging to understand" (p.2).

Another instance that has been burned into my memory occurred several years before this. My family is Jewish, and my parents immigrated here from Israel before I was born. We grew up in Etobicoke, in which there is no significant Jewish community. It's very important to my parents that my siblings and I have some connection to our Jewish heritage, though, so both my sister and I attended Sunday school from kindergarten through to grade ten, which was as much education as the Hebrew school we attended offers. I don't remember exactly when Shane started his Jewish education,

but it was after I had finished attending Hebrew school, but was still in high school. Knowing this, the director of education at our Hebrew school asked me if I would like to provide support to Shane in the classroom if so, I would receive volunteer hours towards my high school diploma. This wasn't an unusual request, as many other graduates were also volunteering in classrooms, so it was an easy decision for me to support him in the classroom. One Sunday, I was with Shane and we ran into one of the teachers I had had when I was much younger. I introduced her to Shane and she said something along the lines of "it's important to look at someone when you're being introduced." He didn't respond, and it somehow became clear to her, perhaps from his body language, that he was "different." Upon realizing this, she said to me "it's really great what you're doing." I was caught off-guard; this was the first time someone had said something like this to me. It turns out I would hear similar sentiments numerous times in the years to follow. I wanted to say to her, what is so great about it? I was volunteering to fulfill a requirement for my high school diploma, as all those in high school must do. Did she say this to everyone else who was volunteering?

"It's really great what you're doing."

"You're an amazing person for working with those kids."

"That's hard work, not everyone could do that"

These are sentiments I often hear when discussing my studies, or my chosen career path. It is not something that I know how to comfortably respond to. I usually just

give an awkward thank you. Currently I do respite work, and although I know it is not done with malicious intent, when myself and the other workers are out in the community with the children we support we are told this constantly. I previously worked as a one-to-one integration worker for children with disabilities at various summer camps throughout the city. I explained to those who I was closer to that it was not the actions of the children I supported that made it “hard work” -it was often the actions of others. The camp counselors who completely ignored the person I was supporting and myself, or the supervisor at one camp who critiqued me for letting the individual I supported take a break, telling me I needed to use more “positive reinforcement” in order to ensure that they fully participate in all camp activities. From my more recent experience working with autism, I now can assume she was discussing one of the strategies used within Applied Behavioural Analysis (ABA). However, at this time I had no knowledge of ABA, and this was not a position where ABA was required of me. Additionally, we were not disturbing anyone, and this supervisor had no knowledge of why I made this decision, and yet they still chose to reprimand me.

Paradoxically, although it is a much less frequent occurrence, there have been instances in which people look to Shane to act “autistic.” For example, at several attractions such as movie theatres, theme parks etc., if you are with someone with a disability, you can be admitted for free as a caregiver. In order to take advantage of this, I took Shane to a water park not too far from us this summer. At the gate I told the attendant that I was with someone with a disability. She asked if I had an “Access 2



Entertainment” card.<sup>1</sup> I replied that I did not, and then the attendant stuck her head out a bit and took a look at Shane. I remember wondering, what exactly is she looking for? Did she even know what she was looking for? As if on cue, Shane did a couple big jumps, and that was it, we were in. I’m not saying the attendant meant any harm, but I found the occurrence noteworthy nevertheless. What would she have done if I was with someone with an invisible disability? Autism itself is not always visible.

Now that I have worked in employment positions supporting those with autism for some time, I have grown accustomed to the frequent stares by those in the public, but I still don’t think it’s right. Human diversity exists and will continue to, and this needs to be accepted. However, I previously was not so confident in this. It is shameful to think about, but I definitely have tried to stop Shane from running or jumping when out in public, even if he was not bothering anyone. I was uncomfortable with the stares, and because of this I didn’t let him be himself. I was also uneasy about even telling others that I had a brother with a disability. A particular instance from my first day of university illustrates this. During one of the “icebreaker” games designed to help us get to know the people in our dorm, we played a game called ‘two truths and a lie.’ To play this game, participants take turns stating three facts about themselves; two facts are to be truthful,

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<sup>1</sup> The Access 2 Program is a collaborative partnership between Easter Seals and over 500 movie theatres, cultural attractions, entertainment venues, and recreation facilities across Canada. Designed for people of all ages who have a permanent disability and require the assistance of a support person, the goal of the Access 2 Program is to improve social inclusion and provide access to entertainment, cultural and recreation opportunities and experiences without any added financial burden. When an Access 2 cardholder (the individual with the permanent disability) presents their valid Access 2 Card at any participating venue partner, their support person receives free admission; the cardholder pays regular admission.

and one is a lie, hence the name. Once an individual has stated their three facts, the other participants try to guess which one of the facts is a lie. It's a fun and simple way to get to know a new group of people. Even though this game took place close to seven years ago at the time of this writing, I haven't forgotten this event. This is because one of my floormates' facts was that her brother was a little person. I was so struck that she chose to share this, especially on the first day. This is because I myself felt apprehensive about disclosing my brothers' disability. I felt as though it was something private, although it is just one aspect, albeit a potentially significant aspect, of someone's identity. I actually brought up the incident to her not that long after, although when I did bring this up to her I was intoxicated. It is somewhat shameful to think about, but at that time and age, I didn't feel as though I could discuss this with her while sober.

My guarded feelings towards sharing Shane's disability were, and continue to be, complicated. Part of it is that I have strong protective feelings towards my brother. This in part stems from our age difference, and in part from his disability. An unfortunate reality of having a sibling with a disability is that when you mention your sibling's disability to your friends or partners and they meet your sibling, it can shed light on undesirable aspects of their characters. Although I have been fortunate not to experience this myself, I have heard stories from others of friends or partners who react in a negative way, to such an extent that it has caused them to leave their current partner. While such an experience would be difficult, I would say that finding out this information is not necessarily a bad thing. I do not want to associate with individuals who hold ableist views, regardless of my experience with my brother.

Although one would hope that this form of rejection would be an extreme occurrence, Shane faces constant rejection in other ways. I have seen him experience rejection from his peers, teachers, and even family. Shane really doesn't have friends his age, despite being active in extracurriculars and attending facilitated friendship groups. It's very upsetting. As discussed, I have also witnessed people in public stare at him and even give dirty looks for simply stimming.<sup>2</sup> My brother is the most caring and fun fifteen-year-old I know, but he is far too often judged, and too seldom given a chance. Bearing witness to this has certainly added to my feelings of protectiveness; I don't want him to be rejected more often than he already is.

Additionally, I have found that my generation, being so wholly surrounded by social media, has a tendency to put forth an artifice that our lives are perfect. We're constantly being surrounded by such flawless depictions of others and their lives, and the pressure that this has placed on younger generations has been well documented. On Facebook and Instagram, we only post photos in which we look our absolute best, and don't disclose how many tries were had in order to get the "perfect" photo. If it doesn't get enough likes, it's deleted. We work hard to convince others that our friends are perfect, our relationship is perfect, our family is perfect. The end result is that it's exhausting. In all of this, it can be easy to remember that no one's lives are as perfect as they are depicted to be. Real life is complicated, real life is messy. That's what makes it *real*. And I need to remember that that's not necessarily a bad thing. I don't need to act as

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<sup>2</sup> Stimming is shorthand for self stimulation, meaning receptive body movements such as rocking and hand flapping

though my life is so perfect. It's okay to talk about your struggles, your family's struggles. In fact, I really think that honestly talking to your friends is a good thing. It'll bring you closer, and make you feel less alone. When my family is going through a hard time, especially if it's concerning my brother, it can feel very isolating. It can feel like no one understands, and no one can help. However, what I have to come to realize only really within the past year, is that you can't expect your friends to understand what you're experiencing if you never tell them about it. Moreover, if I keep to myself the significant injustices that my brother and my family has experienced, then there is little hope that change can occur, and my brother and others will continue to experience this. Therefore, it is important to speak up, to not be complacent, and to keep talking. Myself and others need to tell our stories to anyone who will listen. I hope that telling my stories will help make others aware of important realities, and help to bring about change.

Furthermore, I found that in the past when sharing my brother's disability with friends I would also mention how good he is with dates. Shane has always been very good with dates, easily remembering the birth and death dates of innumerable celebrities, as well as the release dates of countless films, including if they had a limited release and when that date was. Additionally, if you tell him a certain date, for example if I were to tell him my birthday January 1, 1993, he could very quickly tell me what day of the week that was. Although having this ability is something notable and unique, I was not stating this to my friends exclusively in order to share something cool. Upon reflection, I realise that I was stating this as a way to make his autism seem better. I don't know why I felt that I needed to do this... Perhaps I felt as though it would help others accept his

differences. However, as I stated I don't want people in my life who are ableist, especially my friends. It has taken time to come to this realization, but I do know that there is absolutely nothing wrong with Shane. The issue lies outside his autism, the issue is how others perceive and treat those with autism. If I want to change this and aid in promoting disability, I can't keep acting this way. Although it did come from a good place, by being hesitant to share this with others, I was in fact promoting others to treat his autism as something undesirable, and something that ought to be kept secret. Since that time, I do try to be less closeted about my brother's autism and share this more freely, without mentioning his unique abilities, unless it is relevant to the conversation.

Not too long ago, after visiting some friends in London, Ontario, I received a ride back to Toronto with an individual named Fred who also had come to London to visit that weekend. Fred and I had met briefly a couple times as we had many mutual friends in London, as we both went to Western University, hence us both coming up the same weekend. The drive was about two hours long, and as we had not talked much before, we generally made small talk. We discussed where we were from, what we had studied at Western, and so forth. As often occurs when talking to someone around my age, he asked me if I was currently working or studying. I told Fred that I was currently working on a Master of Arts in Critical Disability Studies at York University. When further discussing this program, he asked me what I am writing about. I told him that my brother has autism and that I am writing about my experience as a sibling of someone with a disability. He then asked if I had seen the video about the autistic artist who drew an unbelievably

accurate large-scale drawing of the New York City skyline following a short helicopter ride. He was talking about Stephen Wiltshire, who drew an eighteen foot drawing of this skyline after he spent a mere twenty minutes in a helicopter flying over the city. Stephen produced his longest ever panoramic drawing in May of 2005. Again following a short helicopter ride, he drew the Tokyo skyline on a 52-foot canvas within seven days. Since that time he has drawn Rome, Hong Kong, Frankfurt, Madrid, Dubai, Jerusalem and London, all on giant canvasses and with extraordinary accuracy and detail. In 2006, Stephen Wiltshire was awarded a Member of the Order of the British Empire for services to art (Daily Mail, 2009).

I had in fact seen this video, my introduction to psychology professor had shown the class this video when I was in first year. It is likely that this is where Fred has seen this video, as Introduction to Psychology is the most popular course students at Western take to fulfill this requirement. The Professor had shown this video while discussing savant syndrome. It is noteworthy that Fred's next thought after I mentioned my brother's autism was to talk about an individual with autism who has an extraordinary ability, when in actuality savant syndrome is rare, and only a small percentage of those with autism possess such extraordinary skills (Osteen, 2013). Perhaps this is because when the media depicts those autism in a positive light, it is mainly of those who have these "superhuman" abilities. Furthermore, as noted by Osteen (2013), "even if, as one study suggests, a higher percentage of autistic people process such extraordinary skills, the main problem here is not accuracy. Rather, it is the implication that [...] autistic people are only valuable if they are geniuses (p.262).

The most well-known autistic savant is a fictional one, depicted in the film *Rain Man*. This film received overwhelmingly positive reviews, and with the help of its star Tom Cruise at his peak popularity, was the highest-grossing film of 1988. This film won four Oscars, including Best Picture, Best Original Screenplay, Best Director, and Best Actor in a Leading Role for Hoffman. *Rain Man* also received an additional four nominations (IMDB, 2017). *Rain Man* stars Tom Cruise as Charlie Babbitt, a young, selfish fast-talking car salesman who, after the death of his estranged father, discovers he has an older brother, Raymond Babbitt. Raymond, played by Dustin Hoffman, is described as an autistic savant, to whom his father has left his three-million-dollar estate. Charlie feels cheated by this, and essentially kidnaps Raymond from the group home where he has been living for several years. Charlie asks Raymond's doctor for half of the estate in exchange for Raymond's return, but he refuses. Charlie then decides to attempt to gain custody of his brother in order to get control of the money. They spend a week together driving to Los Angeles, and develop a relationship in the process.

The character of Raymond was created after one of the writers met Kim Peek, who was known as a “megsavant” due to his exceptional memory (Weber, 2009). In this film, Raymond indeed exhibits impressive savant abilities. He has an amazing memory, memorizing several books, including the phone book, at a remarkable speed. He wins Charlie \$80,000 in Las Vegas at Blackjack through his ability to quickly count cards, even the casino's six-deck shoe. Raymond can also instantly calculate complicated mathematical equations in his head. These are just some examples of the savant abilities Raymond demonstrates in the film. Unfortunately, due to the influence of this film, some

individuals are now under the impression that all individuals with autism are also savants. This notion is also depicted in a scene in *Rain Man*, where a physician, upon learning that Raymond has autism, asks Charlie if Raymond has any “special abilities” and that he “wants to try something.” He then proceeds to whip out a calculator and ask Raymond complex mathematical questions, to which he easily answers. In actuality, the estimated prevalence of savant abilities in individuals with autism is 10%, whereas the prevalence in the non-autistic population is less than 1% (Edelson, n.d.). It is certainly distressing that in *Rain Man* a physician, whom one would assume would at least have a general knowledge of autism, plays a role in perpetuating this stereotype. Furthermore, it feels as though the film is overly pushing Raymond’s savant abilities on the viewer. It is as though the film portrays Raymond having these multiple superhuman abilities as a way to redeem Raymond for being autistic.

Due to its critical acclaim and two hugely popular co-stars, *Rain Man* continues to be one of the most prevalent films depicting autism, and for many people it serves as their first exposure to autism, as well as the autism savant phenomenon. When discussing my brother’s ability with dates, I have had people exclaim “like rain man!” I remember first watching this movie with my parents and being moved to tears by the end. The popularity and critical reception of this film likely contributed to the big budget Hollywood films depicting disability that followed, such as *Forrest Gump* (1994) and *I am Sam* (2001). Both films, like *Rain Man*, received Academy Award nominations, with the former receiving even more Oscars than *Rain Man*. Clearly, movies with this subject matter are very well received. However, perhaps due to having a family member with



autism, and studying disability through a critical lens, upon viewing *Rain Man* more recently it is clear to me that despite these accolades, this film is problematic. This film depicts autism in a very stereotypical formulaic manner, and consequently perpetuates untrue stereotypes. Furthermore, Raymond's character in this film is underdeveloped and undergoes very little growth. The use of Raymond and his disability in this film is to act as a foil for the growth and development of the non-disabled character, Charlie.

In *Narrating Autism*, Osten describes a set of rules that fictional narratives depicting autism tend to follow, and this depiction of autism is problematic because it “collapses autism's diversity into a menu of formulas” (p.261). Osten discusses how *Rain Man* adheres to these rules. The first three rules he defines are as follows: *Rule #1: The autistic person must be a savant*, *Rule #2: The autistic person must be charmingly quirky but not too severely disabled*, and *Rule #3: the autistic person must be a catalyst to advance, or a yardstick to measure, the natural progress of nonautistic characters*. These tropes are clearly evident in *Rain Man* as well as other narratives that depict characters with autism. I would also posit that these tropes can extend outside of fictional narratives. I feel as though in order for Shane to be accepted by much of society, he needs to adhere to this formulaic depiction as well. My conversation in the car with Fred, in which his first thought when I mentioned that my brother had autism was to bring up Stephen Wiltshire, demonstrates his learned association with autism and *Rule #1: The autistic person must be a savant*.

My brother is currently fifteen, and with this age he can often be as my mother likes to say, a “nudnik.”<sup>3</sup> When he’s acting this way, teasing me, talking about inappropriate things to get a rise out of me, I have to remind myself that most fifteen-year-old boys can be immature and annoying a lot of time. It's not because he’s autistic - it's because he’s a teenager. My sister and I do not have a medical diagnosis, and we most definitely gave our parents more than our fair share of trouble as teenagers, and would argue with each other constantly. We actually rarely got along until I left for university and we had some space from each other. Despite the fact that Shane can get on my nerves, him and I actually get along much better than my sister and I did when she was his age, although this is perhaps due to our age difference. The issue is that although I am conscious of these realities, I have found that others often are not, and associate any undesirable behaviours as stemming from his autism. As such, I find that because of his autism, he is, ironically, held to a higher standard of behaviour than others his age. There is pressure on him to always act nice and sweet, and by extension, there is pressure on my family to ensure this as well. In reality, no one is sweet and nice at all times - but that doesn’t seem to matter in Shane’s context. If he is viewed as “moody” or “mischievous,” instead of others taking a moment to think about why he is acting this way (e.g. typical teenager), or further being accepting of human difference, his behavior will be attributed to his autism. If he is categorized in this way, from my experience, he is less likely to be accepted by others, and people such as teachers and other educators will be less likely to want to work with him and believe in him. Therefore, I believe that Osten’s identified

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<sup>3</sup> Yiddish word meaning a pestering, nagging, or irritating person

characteristic of an individual with autism within a narrative: *Rule #2 the autistic person must be charmingly quirky but not too severely disabled* (p. 262) also applies outside of fictional narratives. In order for someone with autism to be given a chance they have to adhere to this, and if they don't, they will be written off or ignored.

### **Part V: The Educational Experience**

This section I already know is going to be the most difficult to write - I have been putting it off. This is because I can say with complete certainty that my brother's schooling has been the most substantial source of stress and where we have experienced the most issues relating to his disability. Knowing how draining writing this part would be, I tried to keep in mind what the words of Ellis (1997), and resolved "to explore each incident as fully as I could, and to pay attention to what was most upsetting and least resolved" (p.130). Additionally, I tried to view the writing process as a cathartic way to work through my feelings, and attempt to let go of some negative emotions associated with these experiences. Unfortunately, I know that our family's challenges with Shane's schooling are not isolated, nor are they in the past.

There are currently significant issues surrounding education for individuals with disabilities. The recent World Report on Disability reports that:

Children with disabilities are less likely to start school than their peers without disabilities, and have lower rates of staying and being promoted in schools. Education completion gaps are found across all age groups in both low-income and high-income countries, with the pattern more pronounced in poorer countries (World Health Organization and World Bank, 2011, p.11).

These statistics are troubling because receiving an adequate education is a necessity for ensuring an optimal financial future for all individuals. Specifically, with regards to individuals with disabilities, the unemployment rate is higher than the rest of the population (Torjman, 2001). Although many factors including accessibility issues in the workplace and attitudinal barriers of employers certainly contribute to this, the inadequate educational system plays a large role. I strongly desire for my brother to be employed in some way after high school. I know he is more than capable of being employed, but I also that both completing and succeeding in high school is necessary to his goals. School is also important for numerous other reasons, such as forming relationships with others and discovering new passions. All children in Ontario are required by law to attend school or receive education, and all children have the right to attend public school (Lattanzio, 2013). In Ontario alone, there are at least 334,000 students with special education needs currently attending Ontario's publicly-funded schools. Therefore, at least one of out every six students has an identified disability (AODA Alliance, 2016). Due to this large number of students, I would hope that there would be significant provisions in place to accommodate, protect, and provide the opportunity for the inclusion of these students in Ontario's public schools. Indeed, significant legislation does exist in this regard within the Federal *Charter of Rights and Freedoms*, Ontario *Human Rights Code*, and the duty to accommodate and ensure accessibility for Ontarians per the *Disabilities Act* (AODA), and the Education Act. At a global level, education for individuals with disabilities is also addressed under the United Nations Convention for the Rights of People with Disabilities.

Section 1 of Ontario's human rights law, the *Human Rights Code* ("the Code") states that: "every person has a right to equal treatment with respect to services, goods and facilities, without discrimination because of race, ancestry, place of origin, colour, ethnic origin, citizenship, creed, sex, sexual orientation, gender identity, gender expression, age, marital status, family status or disability" (Human Rights Code, 2016). With regards to individuals with disabilities in the education system, this is addressed in this section, as education is a service within the Code (Ontario Human Rights Commission, n.d.). Therefore, individuals have the right to equal treatment in the education system without discrimination due to several factors, including disability. Section 10 (1) of the code provides the following definition of disability:

- (a) any degree of physical disability, infirmity, malformation or disfigurement that is caused by bodily injury, birth defect or illness and, without limiting the generality of the foregoing, includes diabetes mellitus, epilepsy, a brain injury, any degree of paralysis, amputation, lack of physical co-ordination, blindness or visual impediment, deafness or hearing impediment, muteness or speech impediment, or physical reliance on a guide dog or other animal or on a wheelchair or other remedial appliance or device,
- (b) a condition of mental impairment or a developmental disability,
- (c) a learning disability, or a dysfunction in one or more of the processes involved in understanding or using symbols or spoken language,
- (d) a mental disorder, or

(e) an injury or disability for which benefits were claimed or received under the insurance plan established under the *Workplace Safety and Insurance Act, 1997* (Human Rights Code, 2016)

However, despite these laws, current policy, and the numerous students with disabilities, these students continue to experience discrimination. In fact, disability continues to be the most frequently cited ground of discrimination under the Ontario Human Rights Code (Ontario Human Rights Commission, n.d.).

The means through which students with a labeled disability such as Shane receives education is often through “special needs education”, or “special education”. Special needs education is defined as ‘educational intervention designed to address special educational needs’ (Florian, 2007). Arguably the most significant international document that has ever appeared in the field of special education (Ainscow & César, 2006) is the UNESCO Salamanca Statement, which affirms that:

Regular schools with this inclusive orientation are the most effective means of combating discriminatory attitudes, creating welcoming communities, building an inclusive society and achieving education for all; moreover, they provide an effective education to the majority of children and improve the efficiency and ultimately the cost-effectiveness of the entire education system (UNESCO, 1994, ix).

Despite the fact that this statement was made over a decade ago, current education practices are far from inclusive. From as early as daycare, and even within Shane’s current classroom which is specifically for students with ASD, there have been significant challenges.

My sister and I both attended a community daycare close to High Park, which is where my parents had their first apartment when they came to Canada. I enrolled when I was about eight months old after my mother had found a job, and my sister enrolled at six months old, which was the amount of maternity leave given in the mid 1990's. My parents and I moved to a house in Etobicoke shortly before my sister was born, but we still both attended that same daycare until I aged out. When this occurred, both my sister and I switched to a school that was a short walk from our house that had a daycare within the school. I attended school as well as daycare afterwards, while my sister, who was still too young for school, attended preschool at the daycare. We both stayed at the daycare until my dad was laid off from his job, which was about a year before my brother was born. When Shane was born, maternity leave was extended to a full year. At age one, even though we were living in Etobicoke, he attended the daycare in High Park that my sister and I first attended as infants as well. This is because they were unable to get a spot at the daycare that was in our current school, but our previous daycare did have a spot for Shane. After about half a year, my mom was laid off from her job, and so he was pulled out of daycare and stayed at home with her. When she was hired at a different job about a year and a half later, the daycare that was in my elementary school had a spot for Shane, and my parents enrolled him there. This was very convenient for our family, as I was twelve by then, and so I could pick him up myself when I was done school and take him home. He was at this daycare, the same daycare my sister and I attended for at least three years, for probably two months before the daycare tried to kick him out.

Shane was almost three years old when this occurred. I tried to decipher the exact timeline with my mother while writing this, and she helped me to the best of her memory, but stated to me that she has repressed much of this incident. At this time, Shane had a limited vocabulary, and was not toilet trained. Based on my experience working at a daycare, it is not that unusual for kids to not be toilet trained yet at this age. I don't remember exactly what the incident was that triggered this situation, but I believe he pushed another child off a slide. While I am not condoning his actions, given that he was of such a young age, the reaction of the daycare was disproportionate. Again, based on my experience working at a daycare, if this were to occur, especially with toddlers, more of the onus would be on the staff to provide closer supervision, rather than the child to not misbehave. After this occurred, the day care began to film Shane in order to build a case that he was violent. We had to get a doctor's note stating that he was not violent, and pay a lawyer to write an official notice to stop them from filming him. My parents chose to pull him out of this daycare, and we were lucky to get a spot at our former daycare in High Park, where Shane had briefly been as an infant. No other incident occurred. The same daycare teacher who had been instrumental in toilet training my sister and I, declared that "no child of mine wasn't going to be potty trained," and did the same for him. Shane's official autism diagnosis came around this time, largely prompted by his limited vocabulary for his age. My mom became unemployed again, which unfortunately proved necessary, because she would drive him to this daycare after his morning kindergarten class. When my sister and I were in kindergarten we would go to the daycare within the school after, but obviously this was not a possibility for Shane.



Fortunately, Shane flourished at this daycare, and attended until he too aged out. I think his daycare experience really highlights the difference when childcare providers truly care and want you to succeed, instead of kicking you out when a problem arises.

After that Shane's schooling went fairly well for some time. After kindergarten he attended an ASD classroom in Etobicoke. This program went up until grade five, with two classes - one for grades one to three, and another for grades four and five. This program took place within a public school, and as such was governed by the *Education Act*. The *Education Act* presides over the delivery of publicly funded elementary and secondary education in Ontario. Its purpose is to "provide students with the opportunity to realize their potential and develop into highly skilled, knowledgeable, caring citizens who contribute to their society". Under the original *Education Act*, public school boards in Ontario were not mandated to provide educational services to students with disabilities. In 1980, however, an amendment to the Act was introduced, being the *Educational Amendment Act* (Bill 82). This bill required that the school board provides these services (Lattanzio, 2013). Section 1(1) of the *Education Act* defines an "exceptional pupil" as one "whose behavioural, communicational, intellectual, physical or multiple exceptionalities are such that he or she is considered to need placement in a special education program". This Act stipulates that the Minister of Education is responsible for ensuring that all "exceptional pupils" in Ontario have access to appropriate educational services and placements within the public school system. The ministry is also responsible for providing a way for parents and guardians to appeal special education placement, and all this must be available without the payment of fees.

This Act further states that the Ministry is responsible for ensuring that school boards have procedures and standards for identifying students with special education needs (Ontario Human Rights Commission, n.d.). Clarifying this provision, the Court of Appeal stated the following:

The Minister's obligation is to ensure that appropriate special education programs and services are made available to exceptional pupils in Ontario. This can entail an obligation to ensure that a group of exceptional pupils has available a particular special education program or a service only if it is the only appropriate program or service for that group. If there are alternatives, the Minister is not required by that section to ensure the availability of any specific program (Lattanzio, 2013).

Furthermore, public schools are provisioned by the Canadian Charter of Rights and Freedoms in addition to provincial laws. Section fifteen of the Charter, which came into effect in 1958, states that "every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability" (Malhotra, 2012). This includes the right to education.

Shane was always a happy child, and he very much enjoyed his class, and outside of the classroom he also participated in track and field. I vividly remember his grade five graduation. My mom, my sister and I all attended. It was during the day, and we didn't mention it to my dad. This is because at all our graduations throughout the years, he would be upset if we didn't win any awards. My dad meant well, but he has very high

expectations for his kids. I attribute this to his childhood; to put it mildly, his parents didn't believe in him. My paternal grandparents had rough childhoods themselves; my grandpa lost his parents when he was five and lived on the streets for a short time until a neighbour took him in. My grandma lost several siblings, as my grandparents are Jewish and lived in the Soviet Union during World War II. When my dad's family moved from Russia to Israel when he was fifteen, his parents sent him to military school instead of high school, where the focus was more on trades and discipline. Eventually, he decided he wanted more for himself and went to school to college to study to be an engineer, despite only completing formal schooling up to grade eight. This shocked me because my dad is the smartest person I know. He's very well respected for his knowledge at his job, and as such has survived several rounds of layoffs that his company has experienced. He can also fix pretty much anything, and when I ask him how he knew how to fix a certain thing his answer is always "physics." He's the go to guy for fixing cars, cell phones, and computers for several family members and family friends. As such, I think because his parents had close to zero expectations for him, he has such high expectations for his children, and always encourages us to succeed, sometimes more than we wish. That said, I definitely wouldn't be where I am today without him.

All of that being said, we thought it best that he didn't attend as he was at work, and we were certain Shane wouldn't be winning any awards. During the awards portion of the ceremony, when presenting the literacy award, I distinctly remember the teacher saying, "teaching this guy to read was like teaching a cat to swim." She went on to say something along the lines of now this individual not only can read, but chooses to read on

his own and even write. Sure enough, it was Shane. Being the jokester that he is, when he was presented the award, he punched the air ala *The Breakfast Club*, which got big cheers from the crowd. My sister, my mom and I all cried, and it was such a proud moment that, in hindsight, I wish my dad was there for. His award is framed in his room, and he is the only Pervin sibling to receive an individualized award. I am so thankful to his teachers for not giving up on him, and a particular educational assistant (EA) who made it her mission that Shane would learn to read before graduating elementary school.

For middle school, Shane entered another ASD classroom at a different school. When he started there, it was the first year that this classroom had run. Although this school as well as the one he previously wasn't around the corner as was the case for my sister and I, they were still in our area and, further, he had a bus that took him to school and back. Although there were sometimes issues with the busses as they picked up other students from multiple schools, when this occurred he would take a taxi cab that was sent by the school at no cost to us. This is due to the *Duty to Accommodate*, which was released by the Ontario Human Rights Commission (OHRC) in March of 2001. As the name suggests, this document outlines the policies and principles regarding individuals with disabilities and the duty to accommodate these individuals. These principles apply to several public services, including education. The principles of the duty to accommodate are as follows: respect for dignity, individualized accommodation, and integration and full participation. Education providers are mandated to provide accommodation in a manner that most respects the dignity of the student, unless doing so would result in undue hardship. There are strict guidelines for determining whether an accommodation

would cause undue hardship, and they are as follows: cost, outside sources of funding, if any, and health and safety requirements, if any. It is up to the service provider to prove that undue hardship exists in carrying out an accommodation, and they must provide objective and quantifiable (where possible) evidence to support this claim (Ontario Human Rights Commission, 2004).

When providing accommodations, privacy, confidentiality, comfort, autonomy, individuality, self-respect and self-worth of the individual receiving accommodations must be taken into consideration. The principle of individualized accommodation entails that there is no set method for accommodation, every person with disability is unique, and therefore has unique accommodation needs. The principle of integration and full participation has three steps: design by inclusion, removing barriers, and accommodating remaining needs. Design by inclusion entails that for students with disabilities in public schools to have equal access to education, programs, services, as well as the academic facilities themselves must be designed and structured in a way that promotes maximum inclusion. For example, in order for the curriculum itself to be inclusive from the outset, materials should be developed in a way that is compatible with screen readers. This is referred to as universal design, and should occur unless doing so would result in undue hardship. In regards to removing barriers, students with disabilities often face several barriers within the education system. These can include systemic, attitudinal, and physical barriers. The duty to accommodate entails that those in the education system work to eliminate barriers in order ensure equal access for all students, unless doing so would result in undue hardship (Ontario Human Rights Commission, 2004).

If there are persisting needs that exist for students with disabilities that require further accommodation to ensure integration, even after the first two steps “design by inclusion” and “the removal of barriers” have been implemented, the third step of the principle of integration and full participation for the remaining needs to be addressed. These need to be addressed, again providing that this does not result in undue hardship (Ontario Human Rights Commission, 2004).

The AODA (2005) contains protocols around accessibility in education and with educational materials, which extend the Duty to Accommodate. The purpose of this act is as follows:

1. Recognizing the history of discrimination against persons with disabilities in Ontario, the purpose of this Act is to benefit all Ontarians by,
  - (a) developing, implementing and enforcing accessibility standards in order to achieve accessibility for Ontarians with disabilities with respect to goods, services, facilities, accommodation, employment, buildings, structures and premises on or before January 1, 2025; and
  - (b) providing for the involvement of persons with disabilities, of the Government of Ontario and of representatives of industries and of various sectors of the economy in the development of the accessibility standards.

Section fifteen of this act sets out provisions with regards to educational institutions i.e. schools:

15. (1) Every obligated organization that is an educational or training institution shall do the following, if notification of need is given:

1. Provide educational or training resources or materials in an accessible format that takes into account the accessibility needs due to a disability of the person with a disability to whom the material is to be provided by,

i. procuring through purchase or obtaining by other means an accessible or conversion ready electronic format of educational or training resources or materials, where available, or

ii. arranging for the provision of a comparable resource in an accessible or conversion ready electronic format, if educational or training resources or materials cannot be procured, obtained by other means or converted into an accessible format.

2. Provide student records and information on program requirements, availability and descriptions in an accessible format to persons with disabilities.

(Accessibility for Ontarians with Disabilities Act, 2005).

I admit I don't know as much about Shane's experience when he first entered this classroom, as I was away for school in London, Ontario when he was in grade six and seven. I do know that when I was living away from home, there was an incident in which a student reported seeing Shane's teacher be physically abusive towards him. Shane was not able to confirm or deny this, the police were involved, the teacher was removed, and we actually never found out the results of the investigation. Unfortunately, we would

come to experience a similar incident in high school. However, I do know the replacement teacher Shane had as a result of this incident was lovely. I met her when Shane was in grade eight, as I had moved back home that year. At his class's graduation, his teacher cried and took pictures with her students, and it was evident the affection she had for them. As is common with most schools at the end of grade eight, Shane's school held a graduation dinner and dance. The school sent home a form asking if Shane would attend, and what he would like to eat at the dinner. After talking about it with Shane, my parents wrote on the form that he would not attend, as Shane did not show much interest in going, and as it was after school hours they didn't want to put more work on Shane's teachers. Not long after, we received a phone call from Shane's teacher asking why he wasn't attending. When my mom explained her reasoning, she said of course Shane should come and celebrate with the rest of his cohort and she would be more than happy to keep an eye on him. The fact that she cared enough to call and insist that he attend was heartwarming. Further, this teacher gave Shane Dr. Seuss's *Oh the Places You'll Go* with a beautiful inscription as a graduation present. She also called to wish him a happy birthday (in July), and called later in the next school year to see how he was liking high school. She was not only a great teacher while Shane was in school, she went above and beyond outside the classroom as well. She made Shane's middle school experience a great one. He loved school, and we are forever grateful he has her as a teacher. My mom has mentioned to me that there is a parent in her parent support group whose son currently has her as a teacher, and she speaks very highly of her as well.



In the summer leading up to high school Shane was very excited. This was significant, because Shane loves summertime and having time off from school. As we got closer to the start of school, Shane was counting down the days. Unfortunately, Shane's first year of high school was a nightmare. His class was also a class specifically for students with ASD, and additionally he attended certain classes with the rest of his cohort. Not unlike Shane's previous classes, this class had one main teacher, and a few different EA's. I cannot remember exactly when the problems started. The main teacher in the classroom was quite sick, and as a result he was often away. Perhaps because of the lack of support, when he was away was when we would have the most issues. The EA's would constantly call my mom to come pick up Shane for various reasons. For example, on one occasion Shane had a runny nose and did not want to study and they called my mom to pick him up. When she got the phone call, she initially thought that he was seriously ill and that's why they had called. Imagine her surprise when it was merely a runny nose. Shouldn't the EA's have attempted to motivate Shane to study, perhaps not to the level he usually does, but in some level as to not waste the whole day? As a result of this, whenever Shane has a runny nose he refuses to do any work, and demands to be sent home. Each time, the EA's, instead of working to resolve this, would call my mom to pick him up. I am sure that in the past he has had a runny nose at school, but we never received a call to pick him until his experience in this high school classroom. It was ridiculous, and hindered his learning. This situation was upsetting, because of course we wanted him to remain in school with his peers. It was also isolating, because we didn't know what to do about it, and further we didn't know who to turn to for advice about

what we could and should do about it. It felt as though all we could do was hope the situation would improve. But instead it got worse.

We began to get calls from the EA's to pick Shane up constantly. It seemed as though any time Shane would act out, however minor, we would get a call to pick him up. It got to the point where we were getting calls constantly, sometimes multiple times a week. It was very frustrating, as my mom would have to stop whatever she was doing to go pick him up, as well as call the bus driver so she would know not to pick him up. My mom had difficulty making plans for her day and getting her work done, because she knew she had to have her phone on hand and not be able to count on Shane being at school all day. This happened less when the teacher was present, but he was away more often than not. This was concerning because this did not occur at Shane's previous school. Shane began expressing that he hated high school, which was upsetting not only because he previously enjoyed school, but because of how much he was looking forward to starting high school. I didn't understand why the teacher and EA's were not working to manage negative behaviours, instead of calling for him to be picked up. Furthermore, constantly calling my mom to pick Shane up unfortunately reinforced his negative behaviour, as he was being rewarded for acting out, because he understandably would rather be at home than at school. It was also disheartening because when he was sent home, he was falling further behind in school. After a few months of this, my sister expressed this to the EA, and the EA became very defensive, stating to her "well do you reward him at home?" This was not only uncalled for, but unproductive. What was most devastating was that after being sent home for acting out, Shane told me, crying, that an

EA told him “don’t come back tomorrow.” How can he be expected to flourish in school if an EA, an EA who works with students with autism, no less, tells him not to come back? What a stark difference from Shane’s EA in elementary school who made it her personal mission to help Shane to learn to read, who believed in him, and pushed for him to succeed.

The attitude of the EA’s also made myself and my family feel very alone. Shane has certainly become more irritable and moody now that he is a teenager, and furthermore, high school is certainly much tougher academically than elementary school. I find it difficult to grasp that it has become so much more drastically difficult to educate him from the year before, though. Gone was the warmth and support we felt from Shane’s previous school, which I believe has been most detrimental to his success. Instead of his teachers working with us to figure out strategies to mitigate his challenging behaviours, we felt as though we were the only ones who wanted him to succeed. When the school year came to a close, it was a relief. We knew summer wouldn’t last forever and that he’d be back to school soon enough, but it was an immense relief nevertheless. Additionally, at the end of the school year his teacher told us that he would not be returning the next year due to his health issues. Therefore, we knew that next year there would be a change. We didn’t know if it would be for the better, but we were happy about the promise of a departure from the previous year.

As stated earlier, inclusive education for those with disabilities such as my brother is also addressed on a global scale. The Convention on the Rights of Persons with Disabilities (CRPD) guarantees educational rights for those with disabilities, and article

24 lays out specific obligations pertaining to education. The CRPD was the fastest negotiated human rights treaty in history and came into force on May 3, 2008, as the eighth major UN human rights treaty and the first of the twenty-first century (Hansen & Malhotra, 2011). This article mandates the right to an inclusive education system (Lattanzio, 2013), and states the following provisions for ensuring this right:

In realizing this right, state Parties shall ensure that:

Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;

Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;

Reasonable accommodation of the individual's requirements is provided;

Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;

Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion (United Nations Department of Public Relations, 2006).

The CRPD was ratified by Canada on March 11, 2010 and therefore it should significantly affect policies and practices pertaining to students with disabilities in

Canada henceforth. Unfortunately in reality, it has not had a significant impact on current policies and practices (Hansen & Malhotra, 2011). On a positive note, in accordance with both the *Charter* and *Human Rights Code*, in recent years the Ontario Government has placed an increasing emphasis on the inclusion of students with disabilities in mainstream educational settings (Lapofsky, 2016).

## **Part VI: Conclusion - Going Forward**

A few months ago, I began an employment position in which I support an individual with autism in recreational activities such as trips in the community, as well as programming within the centre. Having experienced such negative reactions to Shane's behaviour, I have really been struck by the approach and attitude of the centre towards autism. For example, if a staff knows that the individual they support has difficulties with transitions, they accept it and try to mitigate this as best they can, instead of seeing it as a hindrance. If an individual is having an especially hard time and acts aggressively, instead of saying that someone is acting out or misbehaving, the term escalation is used. At the end of every shift we have a debrief where we discuss how our day went. During this time, I have heard staff members express sadness and empathy that the individual felt frustrated to the point of an escalation. Additionally, when an escalation occurs, staff members still work to the best of their ability to ensure that the escalation did not define the rest of their day. This resonated with me, because in Shane's experience, he would constantly be told by his school that he behaved badly. Last year, this would mean he would be sent home- his behaviour was certainly never met with empathy for Shane's feelings. How is it that in this part-time position, the students I work with who have

significantly less training and make much less money, have a better attitude towards autism than the professionalized EA's and teachers in Shane's ASD classroom? Shane, and all those students in a similar position, deserve better.

CBC recently reported on the issues relating to supporting students with ASD at school. The article discussed results from a new survey released by the Ontario Autism Coalition (OAC). This study surveyed 165 parents of children on the autism spectrum. Better training for educators and more support at school for their children are just some of the things that these parents are calling for. This survey found that 72 percent of kids with autism don't get the help they need at school. About 60 percent of the parents who responded were told by a professional that their child required one-on-one support from an educational assistant assigned exclusively to them, but only 17 per cent say their child has that support. As a result of the issues Shane was having in his classroom, we requested for him to have one-to-one support as well, but were not provided this support because he was not classified as a "threat." This seems ridiculous to me; clearly things were not going well at school, yet he has to have "threatening" behaviour in order to be granted more support? Additionally, with regards to the OAC survey, almost 65 percent of respondents "felt that their child's teacher did not know enough about autism to effectively support their learning." The OAC recently held a protest outside of Queen's Park, in hopes the Ontario government to address these issues. In a statement sent to CBC Toronto, the Ministry of Education says it's "committed to providing dedicated supports to students with autism" and for the past year it has "been consulting with parents,

experts, teachers, educators, as well as members of the Ontario Autism Program Advisory Committee to better understand how to best support these students."

Parents have been raising these concerns for some time. Years ago, the Ontario Government included a general requirement on the issue of within the Integrated Accessibility Standards Regulation (IASR), which became law on June 3, 2011. Section 16 of the IASR, Training to Educators states that:

16. (1) In addition to the requirements under section 7, obligated organizations that are school boards or educational or training institutions shall provide educators with accessibility awareness training related to accessible program or course delivery and instruction.

O. Reg. 191/11, s. 16 (1).

(2) Obligated organizations that are school boards or educational or training institutions shall keep a record of the training provided under this section, including the dates on which the training is provided and the number of individuals to whom it is provided.

O. Reg. 191/11, s. 16 (2).

(3) Obligated organizations to which this section applies shall meet the requirements in this section in accordance with the following schedule:

1. For large designated public sector organizations, January 1, 2013.
2. For small designated public sector organizations, January 1, 2015.
3. For large organizations, January 1, 2013.

4. For small organizations, January 1, 2015.

O. Reg. 191/11, s. 16 (3).

(4) In this section, “educators” means employees who are involved in program or course design, delivery and instruction, including staff of school boards; “school board” means a board as defined in subsection 1 (1) of the Education Act.”

Half a decade after that provision was enacted, though, there is no indication that there has been any change regarding this issue (Accessibility for Ontarians with Disabilities Act Alliance, 2016), and clearly according to the OAC survey parents still have serious concerns.

Shane had a great summer. He went to camp for the first time, spending two weeks kayaking and canoeing. He went biking, swimming, to the beach, to Canada’s Wonderland, Wet ‘n’ Wild, the Canadian National Exhibition, the Art Gallery of Ontario, and more. He also utilized photoshop to make lengthy PowerPoints and movie quizzes featuring hundreds of movie posters. When the summer drew to a close, Shane began having trouble sleeping. He also began acting overly defiant and even aggressive which he hadn’t done in months. My sibling instincts tell me it is no coincidence Shane began acting out and expressing anxiety as the new school year approached.

At the time of this writing, Shane has been back at school for three months. He has a new teacher who is always there, and seems to believe in Shane. Shane still does not enjoy high school and has trouble being motivated to study. We also unfortunately had a repeat incident of someone reporting seeing another staff physically hurting Shane,



requiring the school to involve the police. The first time I wrote it off as a one-off, but it is very troubling that we have encountered this a second time. It's certainly not fun to receive a call from Child Protective Services. It resulted in a very stressful few days for my family, and an emotionally challenging time for me. I'm happy that I did open up to my friends when this occurred, and I'm lucky to be friends with very supportive people. I do want to credit the policewoman who did the initial investigation, as she has a son with autism herself and made the process much less stressful than the last time. Unfortunately, Shane has begun to at times act aggressively at school. It seems to occur when he has to get off the computer and do school work, which is something we haven't experienced with him before. When we get the phone call that he is having a bad day, I have trouble doing anything productive and am overly emotional. I know I need to work on self care and mindfulness, and that reacting in this way doesn't help anything. Even though his behaviour is worse than last year, though, his teachers are not asking for my mom to pick him up, which is such a welcome change. His teachers do seem to want to find strategies to better motivate him, so I am hopeful. It is still upsetting, however, because when he is at home he is so sweet, fun to be around, and certainly never aggressive. I do understand that high school is a stressful time for many students, but I wish I knew what stressed him out so severely that causes him to act this way at school, and furthermore, I wish I knew how to alleviate it. Additionally, although as I've stated I am trying to be less closeted and more open, even with my close friends I have trouble discussing this even though it greatly upsets me, and frankly, I could use support. By talking with my friends throughout the day and not mentioning what is going on, I know

I'm being fake and putting up a front, but my protective instinct is kicking in again, and I don't want my friends to view Shane in a negative light. On a recent rough day, I posted in Sib20 for the first time, asking for guidance. I only got one response: "I don't have any advice, but my sister does the same thing." The response really made me feel less alone, and I'm glad I posted it, even to only get one response. It would be incredible if this writing would help just one person feel less alone, and that someone else understands what they're experiencing, just as that one person who responded to my post did for me.

Even though he can get on my nerves at times, I love my brother more than I can put into words. He is so incredibly smart, so funny, so sweet and has such a caring heart. If he does something wrong, no matter how minor, he is very remorseful and never wants anyone to be upset with him. I love the person he is. I love all the noises he makes, even if his jumping does wake me up when I want to sleep in. He's also simply fun to be around, and my favourite times are when all of us siblings are together doing things that we all enjoy, such as playing the Wii or jumping on the trampoline. Shane also has great taste in films and music, and as such has exposed me to amazing classic artists and movies that I may not have otherwise been interested in. It is such a blessing to be his sister, and I have learned so much and am continuing to learn from him. His autism is just one part, albeit a significant one, of his identity. When others are dismissive of him, when others don't see and further don't want to see what I see in him, it's devastating. I don't know if circumstances will improve at school. I don't know what lies ahead for him, and I hate that and worry about it much more than I should, even though I know that worrying to such an extent is unproductive. Additionally, even though I am nearing the

end of this writing, I still have significant doubts about whether anyone will care about what I have to say, let alone if writing about my experiences will help anyone, help to change anything. But I have to hope it will. As Butler acknowledges:

Perhaps most importantly, we must recognize that ethics requires us to risk ourselves precisely at moments of unknowingness, when what forms us diverges from what lies before us, when our willingness to become undone in relation to others constitutes our chance of becoming human (Butler, 2005 p. 136).

What I do know, is even if this writing doesn't have any impact at all, it will only fuel my drive and motivation to work to make things better for Shane and others like him. I'm his protective older sister and always will be.

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