Identity of Disability

A Modern-Historical Comparison of living in North American societies with deafblindness

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The unLibrarian

A *MySillyWinks project*

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INTRODUCTION

Anne Sullivan truly inspired me and entranced me in her life including her accomplishments. She found a way to communicate so eloquently with the world in her letters, hands, and speech. Of utmost inspiration to me is her valedictorian address to the Perkins school for the blind in 1886, she said that "We can educate ourselves; we can, by thought and perseverance, develop all the powers and capacities entrusted to us, and build for ourselves true and noble characters. Because we can, we must"[1]. Anne Sullivan was a woman with complex social and health conditions who taught her deafblind ward, Helen Keller, language to communicate (verbal, physical, and written). Their history takes place in the United States around the 1900s. Her story led me to taking a look at disability through history and how far we have (or not) come in history in the treatment and experiences of people with disabilities in North America.

Anne Sullivan grew up at the end of the 1800s, into the 1900s, with her parents and younger brother on the American Eastern seaboard. Whereas I grew up with my parents and younger brother with my paternal grandparents and uncle next door, on the Canadian Eastern seaboard at the end of the 1900s, into the 2000s. We both grew up with lifelong complex health conditions and a strong desire to not just survive as a person with disabilities but to contribute to the advancement of society.

I will be elaborating on the various information landscapes that are regularly negotiated in life regardless of historical timeline: living with disability including education, employment, transferable skills. financial, health, information, patient, and

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[1] To read the full speech, you can read it on the Perkins Institute Website: http://www.perkins.org/history/people/anne-sullivan/valedictory-address.

social arenas. The literature presented here will demonstrates the models that anyone can easily employ in any interaction with children with complex health needs. This book is more than personal reflection: a method of releasing the info intake during my time spent with amazing research teams as a doctoral librarian on defining the concept of Children with Complex Health Conditions (CCHC) (I send a special thank you to Shelley Doucet and Rima Azar and their amazing teams). The work with them is in addition to what I learned and read during my tenure as a medical education librarian who also liaised for physiotherapy, leisure and tourism, psychology, family studies, and assisted the nursing librarian upon request. Everything presented here is in light of research that I read while defining who are children with complex health needs. In completing the conceptual analysis[2] and other systematic reviews[3,4,5], I screened tens of thousands of research articles and read thousands of full text articles. I always felt that disability fell into a grey area in their research and so I present in this manuscript. Even after putting down the pen officially in 2019, I have continued working on this idea – I could not let any of it go to waste. In the third year of my doctorate, while grieving from my Uncle ending his own tragic life by fire, a few months

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[2] Azar, R., Doucet, S., Horsman, A. R., Charlton, P., Luke, A., Nagel, D. A., ... & Montelpare, W. J. (2020). *A concept analysis of children with complex health conditions: implications for research and practice*. BMC pediatrics, 20, 1-11.

[3] Ward, S., Bélanger, M., Donovan, D., Horsman, A., & Carrier, N. (2015). *Correlates, determinants, and effectiveness of childcare educators' practices and behaviours on preschoolers' physical activity and eating behaviours: a systematic review protocol*. Systematic reviews, 4(1), 1-6.

[4] Doucet, S., Curran, J. A., Breneol, S., Luke, A., Dionne, E., Azar, R., ... & Binns, K. (2020). *Programmes to support transitions in care for children and youth with complex care needs and their families: a scoping review protocol*. BMJ open, 10(6), e033978.

[5] Reid, A. E., Doucet, S., Luke, A., Azar, R., & Horsman, A. R. (2019). *The impact of patient navigation: a scoping review protocol. JBI Evidence Synthesis*, 17(6), 1079-1085.

after Nannie passed in 2017, I picked up a biography on Anne Sullivan - it was the very first time I felt I could relate to someone historical. I have experienced intense isolation and depression in my life, due to my own lifelong disabilities and life circumstances. I have resolved in my heart that everyone around me really did everything they thought they could for me growing up and my heart will always remember that. Now, as an adult, I can use these experiences and knowledge to help others.

I was born in the early 1980s, in a smaller part of Canada, where cultural norms are delayed. I identify way more with Gen-X than millennials and had a lot older generation influence. I also realize that I am telling a story to prepare young ones of what lies ahead as adults to help paint a picture of what is has come to pass. All the while, also hopefully making someone feel less alone and isolated in their world. Personally, I hope that today's children with lifelong, complex heath conditions will grow up with the ability to self-culture in ways that allows them to flourish in life without the isolation and vulnerability that is experienced by many people who have disabilities, suffer from chronic health conditions, and face the likely development of mental issues due to disabilities and so much more. I truly believe there is always a way to thrive in life: just have to figure it out. Out of simply wanting to figure it out, you know that you always will, each and every time. Let me show you a few life examples with legacies worth sharing.

It took me a while to figure out how one can explore the concept of identity in disability when there are few that "make it" and historical figures are difficult to locate with disabilities. I came up with the idea of writing about this historical figure whom I had come to admire (Sullivan) and tell my own disability identity story. In my mind, I created a way to time travel in writing this book, to create multiple dimensions to best explore identity. Time travel in the science fiction fashion is yet proven. That said, time travel happens every day anyway: through books. When we read, we travel to another time and dimension. While each book is an experience in time travel for the reader, not every book actual involves time travel. Whereas, this book uses time to compare, contrast and learn from two points of history: around the 1900s and around year 2000. When you read this book, you are creating a third, a perfect trifecta of points of view: which is a mix of your own timeline and life experiences. I do not know you or your situation, but rest assured I wish you the best in your life and hope reading this book constructively influences your own perspective of your use of technology, your perspective on struggles with disability, and living life well despite it all. Hold on, let me turn around that kind of ableist dialogue. Rather, I say living well while maximizing it all!

FRAMING IDENTITY THROUGH APPLICABLE THEORIES IN SOCIOLOGY & LIBRARIANSHIP

What's your identity? Every marginalized person is asked to "identify" on self-declaration forms. The first time I was asked to identify as disabled was when I was applying for bursaries and scholarships at the end of high school. I remember one of my first academic encounters with the concept of identity and labelling in undergraduate studies. In my later sociology years, I took many deviance centred courses where I better understood the concept. For example, on page 287 of Deutschmann (2002), they use a blind population example to demonstrate a consequence of labelling as per Scott (1969): "the disability associated with visual impairment is a learned social role, one in which the individual learns incapacity and dependence" (p. 287). Whoa. Hold on.. who the heck teaches incapacity and dependence? How I person identifies depends on the definitions of those around them, which are usually the people on which they depend for support, if not survival. This view of disability threw me off, I was all of the sudden an imposter. So, I learned, you have how the outside world labels you and you have your own internal identity. Oh, and you are at the mercy of your learned roles. Fun, oh, what conflict. I continued in my studies, not understanding the effect this lesson had on my internal dialogue.

Until attending university, disability was simply lived. It was not really identified, personally. In high school, all of the sudden was being asked how my disabilities limit me and how I plan to thrive with disabilities as long as I got *x* accommodations. The accommodation experiences I had up to this point was a cros-hearing aid system from 1992 (Grade 2) and regular testing with APSEA. I had zero idea how to talk about my disabilities – they just were. I had to ask my doctors who all said I no limitations with my disabilities on all the forms. I had to be functional enough to be deemed able to work and study but also disabled enough to warrant additional financial support and equipment. I had to learn how to apply for government and private funding, all of which seem to use varying application methods. I did get into university where I studied social sciences then later librarianship. To me, disability was a baked in process to life that is completely normal and natural but never operationally discussed. So, I start with where I did in learning about disability: academically. I apologize for this in some ways, yet I wish to normalize some of this vocabulary so that others can learn it without the necessity of university scholarship. Books and self-learning go a very long ways in developing one's own self-culture. I was a very curious mind, so it really was necessary, for me, to attend university in order to further my education, knowledge and abilities. I had read of many girls in books, by authors such as Lucy Maud Montgomery, who often followed academic pursuits: I was not alone in this Maritimer way of learning – leave my home to pursue higher education and job opportunities Ontario to make better sense of the world only to come back home later feeling even more confused. But, when it all makes sense, eventually, positive changes happen.

Identity development is a fundamentally social process, and identities are formed through mirroring, modeling, and recognition through available identity resources, and so it is imperative that able-bodied professionals (i.e., rehabilitation professionals, therapists, teachers and caregivers) working with individuals with disabilities also become aware of this developmental process to be able to better support individuals along this journey. Identity has several components of interest in theory:

- Sensemaking
- Symbolic Interactionism
- Communities of Practice
- Value
- Literacy
- Stigma and Labelling

Let's work our way through each theme, one by one.

SENSEMAKING

Really, we all just want to make sense of the world! A commonly encountered theory is Dervin's Sense-Making. The central activities to sense making are "information seeking, processing, creating and using" (Savolainen, 1993, p. 16). The product of this process is sense. Sense includes explicit knowledge and an individual's tacit knowledge. Sense is needed when there is a perceived information gap in a given situation. This requires gap-defining and gap-bridging. Sense-Making is sometimes considered a conceptual tool rather than a theory (Tidline, 2005). However, Savolainen (1993) gives an epistemic expansion on sense-making as a theory. Sense-Making gives voice to the users in operationalizing their information-seeking sequence and information needs. According to Dervin, all information is subjective as it is a construction created by human observers. Information seeking and use are processes taken to construct sense. Once an adequate level of sense has been made in the mind of the information user, they can continue on with life (Bates, 2005). This uphill battle happens repeatedly. So, what does it take to make sense of a chaotic world of information? Literacy learning and Resilience. The task for people with disabilities to achieve sense in their worlds is monumental.

SYMBOLIC INTERACTIONISM

Symbolic interactionism focuses on communication, the subjective meaning that people attach to their circumstances, how people help create their social circumstances, and the interactive process in which meanings are handled and modified (Brym & Boutilier, 2001; Gray, 2013). It is through these interactions that people assign value to ideas. Social constructionists assume reality is created through the interactions and beliefs of people; that the reality is a product of the social processes (Neuman, 2003). Social constructionism implicates a shared system of meaning that is generated in a given culture (Brym & Boutilier, 2001). Constructionism is aware that knowledge is constructed by humans by inventing concepts, models and schemas to make sense of experiences which are continuously tested and reconstructed (Schwandt, 2000). Symbolic interaction is similar in that meaning is constructed based off individual and mutual understandings. Essentially, all interactions create mutual/collective symbols. These created symbols gain value depending on the social interactions, especially within a community.

COMMUNITIES OF PRACTICE

Which brings us to Wegner's (1998) dimensions of communities of practice: "mutual engagement, a joint negotiated enterprise, and a shared repertoire of negotiable resources" (Holmes & Meyerhoff, 1999, p. 175; House, 2003, p. 572). Of importance here is the "shared repertoire of negotiable resources" which consists primarily of English resources which has been constructed through the minds of community and individual. Language phenomena are "always embedded with a context of meaning and a context of functionality" (p. 120). So, the linguistic resources are negotiated through specialized terminology and linguistic routines within a group, a community. "Communities of Practice" theories look at the practice or activities involved in language structure, discourse and interaction patterns (Holmes & Meyerhoff, 1999). These interactions are part of distinct social processes in learning and made more meaningful by way of intentional subscription to particular communities of practice, often as it aligns with ones' own values.

VALUE

Assigning value to absolutely anything, including communication methods, can only happen once it has been comprehended by oneself. Value can be explained and promoted by outside influences to gain buy-in on their own values and ideas. The reputation of the provider of the information also affects value of information. Value is also part of the analysis and processing of information as well as facilitation of its application. Value is defined by the benefit to the user, according to Matthews (2013). He refers to this as *value-in-use* or *utility theory*. In the utility theory, the effects, benefits and impacts are left aside and focus is placed on the "wants, usefulness, satisfaction, demands, and so forth" (p. 92) of information. The notion of convenience and satisfaction is seen as "the quality of information content is much less important than its convenience" (p. 92). Convenience refers to where to search for information, completing the search process and being satisfied with the source. Herbert Simon (1976) coined the term *satisficing* in focusing on the theory of convenience and satisfaction users assign to information (Matthews, 2013). Satisficing is that "in decision making, people make a good enough decision to meet their needs and do not necessarily consider all possible, or knowable options" (Bates, 2005, p. 4). In essence, satisficing is based on the *Principle of Least Effort*. Matthews and Simon both acknowledge information overload as a real barrier for information users and people will take the shortest route possible to get the information, they need to simply achieve the outcome the desire faster. So, how a person with disabilities goes about making sense of their world? If people tend to take the shortest route possible, how does this work for people with disabilities who have to double down their efforts to get similar results as a neurotypical person.

LITERACY

Literacy is another social process that can be investigated through the sociolinguistics lens. According to Damico and Ball (2008), *literacy* is a manifestation of language use; it is "a symbolic practice linking written linguistic code with attitudes, ideologies, and other aspects of human social action and epistemology" (p. 119). Literacy activities are even more powerful when there is a situated context, practical objectives/goals and a purpose to the interventions, which is easier to access within communities of practice.

In many studies that I have read over the years, a mentor made literacy skills acquisition more accessible to the deaf/blind individuals. However, many deaf/blind people do not have access to training or the resources to purchase a computer to access the internet (Watters, Owens & Munroe, 2004). Disability mentors in this day and age are being pushed online. In many cases, a mentor made learning more accessible to the deaf/blind individuals. I believe the element of mentorship is overlooked in many of the reports and statistics on ICT and the deaf/blind population. Indeed, many deaf/blind people do not have access to training or the resources to purchase a computer to access the internet (Watters, Owens & Munroe, 2004).

Literacy is important for everyone, even for someone who is deafblind as it allows them to “exchange information & ideas and develop relationships that would otherwise be out of reach” (Miles, 2005). The National Information Clearinghouse on Children who are Deaf-Blind that is managed by the Helen Keller National Centre has several patient pamphlets available on this population, including one on literacy. In their January 2005 issue, Miles paints a picture of a deafblind person who has access to vast stores of information through the internet where the “person is practically not handicapped” (p. 2). This is a dangerous illusion as there are predators online as well. Really though, it is simply undreamed-of having access to information through the internet than even 10 years ago. Opportunities provided through literacy are increasing all the time as technology develops and society embraces literacy for everyone. This transmission of knowledge informs larger society of a nearly invisible community, as a by product.

Health Literacy

Health literacy is important in public health. Health literacy acknowledges the negative impact to being unable to access, understand, and share information. For some populations, health literacy interventions are very time consuming and intensive (Dennis et al., 2012). Health literacy is defined as “the ability to obtain, integrate, and appraise health-related knowledge” (Keim-Malpass, Letzkus, and Kennedy 2015). So, if a translator or interpreter is needed, it takes much longer to transfer the information from the doctor to the patient. The same study defined health literacy is a key indicator in preventing adverse health outcomes such as morbidity, ability to take prescription medications, more unexpected hospital and doctors' visits, and more expensive care in general. Then there is the idea of a "collective health literacy" in which all people responsible for the care of the child, including the child themselves be health literate. This included parent, siblings, family members, educational staff, and such. I enjoy the idea of a collective health literacy becoming a form of social capital, which can have society-wide implications, at multiple levels (health, education, and familial). I actually support this idea because it creates an important support network that a child can access at any given point for guidance and receive understanding care. A large component of advocacy is health literacy.

STIGMA AND LABELLING

In academic literature, when talking about high level concepts like disability as something that can be applied to a person, it is called labelling. Labeling is studied to identify a person's perception of a particular concept, like disability. It is in studying the label that signs of stigma can be found as labels are often negatively viewed, like any stereotype. Unfortunately, with labels come a long list of stereotypes, lists of characteristics if you will. Disability is a label and there are many stereotypes surrounding disability dialogues.

In Lalvani (2015), it was found that the parents worried about the impact of the label of disability as it alters perceptions of the child. Parents who worry about the stigma around disability are worried about how the label reflects on them as much as their own children. Parents who worry about the stigma around disability are worried about how the label reflects on them as much as their own children. Parents react diversely to having children with disabilities, and it varies depending on the health of the parents as well. Children learn from their environments. This is where it is important for children to be surrounded by other people to expand how they consider themselves in life.

The more specific the label, the more worrisome parents were of their child being pigeonholed by the negative societal perceptions of labels. There is a difference in feeling generated form synonymous labels like autism versus “mental retardation”. The word retarded often led to angry reactions because the parents could see so much more in their child than the label even remotely gives them credit for in their beautiful lives. On the flip side, teachers found the labels helpful as it helped them guide the child’s education. Which brings us to the label of “special education”. The term special is often used to describe people with disabilities, particularly developmental and intellectual disabilities.

But really, how do you know you are disabled? Who decides that? Who do you think should decide that: doctor? social worker? government? teacher? yourself? parent? employer? private insurer? Who ultimately decides that? Can it become a tertiary identity upon external decision? Is the decision internal?

Some folks believe that everyone has a disability of some sort. While it is true for most people I have known, this is seriously ableist. Personally, I had the pleasure of then of asking who they think is willing to foot the bill for accommodation devices. There are a wide range of abilities. The problem comes in when you are discriminated against based on your inability to do something even if you had the right devices and technology support. Disability is expensive and that’s what scares people about being disabled: how in the hell will I ever afford this?

There is a fine line between diagnosis and label. Society and medical professionals have one idea of how disability and a particular diagnosis should appear. Then there is the lived experience. Then once that diagnosis is fully onboarded by the patient, it becomes a key personal descriptor and an access card to health communities. Finding others who “suffer” similarly gives a sense of peace and surrounds you with people who understand rather than attack. Otherwise, having a diagnosis or disability on your own makes you feel like you are in an open field, naked and exposed to any attacks, whether unintentional or on purpose.

How disability is defined is dependent on the personal opinions and professional attitudes, including one’s own. The shy reality is that neurotypicals look to the person with disabilities for cues on how to interact. If the person with disabilities has a deep assumption that all neurotypicals will be rude and not understanding, then this will most likely be their experience until they encounter someone who is grounded in kindness. If a person with disabilities feels comfortable in their own, then it will be a different experience. Some healthier coping mechanisms are humour without being self-deprecating and education without being condescending. I believe that self-advocacy training is key in building these healthy mechanisms.

PEOPLE WITH DISABILITIES

In this book, I will be speaking very generally about people with disabilities, but I wish to clarify a few specific populations that I will be focusing on in some sections with which I have experience. For the purposes of simplicity, I admit my own bias as I am personally deafblind, have severe chronic pain, am autistic, and am diagnosed with major depressive disorder (MDD) and complex post-traumatic stress disorder (cPTSD). I have mobility and strength issues in addition to being a redheaded female. So, I am referring to those with disabilities in a very broad fashion to those with sensorial, physical, emotional, or intellectual disabilities. My coverage of disability in this manuscript is all-encompassing to all who relate. I believe there is a distinct similarity between those with childhood and lifelong disabilities and those who are traumatized: both cases create a neurological divergence. Thus, on a hierarchal level above, neurodiversity covers all the brains that have developed contrary to how a person is supposed if they had all their faculties and a bubble wrapped life. But that is simply not realistic. Some are lucky and others count their luck.

In reality, disability simply has an interdisciplinary nature. Disability is so damned subjective that it is absolutely in the eye of the beholder. Disability starts very young for some and for others it happens later in life. Here, I am talking about disability for life in this article, from birth onward. With the way my brain works, I cannot help but look at the spectrum of life. All of history matter as much s today. Especially if we want to have a desirable future. We have gone from walking to the post office to send a telegram to direct messaging with a device that fits in our pockets. In stories, throughout history, there is an element of government intervention, learning, advocacy, and persistence. The saying “the more things change, the more they stay the same” resonates in my mind when studying living with disabilities. Question is by how much and in which ways? Comparisons over time is one way to tell.

An article surfaced from 2017 on Disability Identity. It was so spot on to a lot of research I found too: “individuals with disabilities are dually navigating both the internalized understanding of said impairment or label in addition to society’s broader meaning making around this disability” (Forber-Pratt, Lyew, Mueller, Samples, 2017, p.18). The authors highlighted the important role that able-bodied professionals have when working with individuals with disabilities as it is a developmental process that needs to be well supported wherever possible. Health professionals are the most consistent people in the lives of most people with disabilities. Yet it is almost as if the systems were designed to create inconsistencies to reduce reliance; our systems are full of silos and fractures.

One way by which this happens is through terminology decisions, which creates divisions, different idea camps. Every organization and government seem to have their own working definition of disability. I will not get into all of them here. But suffice for me to implore you to ask any organization with whom you interact what is their definition. It is complex. For example, the term, "multiple impairments" was only recognized in by the Canadian Revenue Agency only within the last 10 years. Defining “children with complex health needs” and synonymous terms is within the last one to three years worldwide. So, all of this jargon surrounding disability is still relatively new and in very fluid motion. One can, nor should ever, assume.

There is a very long history of people with disabilities fighting for par, which Universal Design attempts to achieve. Information and communication technology advances have changed the landscape and tools available to people with disabilities greatly over the years. People with disabilities are more engaged citizens than ever thanks to social media. Oh, disability is quite a complex experience. This complexity does not stop theorists and social scientists from attempting to categorize disability with models though.

In recent years, terms have started to be developed to encompass a large section of paediatric population that “have or are at risk for a chronic physical, developmental, behavioural, or emotional conditions and require healthcare services beyond that required by children generally” (Keim-Malpass, Letzkus, and Kennedy, 2015). The same study stated that this population represents 40% to 70% of pediatric healthcare expenditures. Keep in mind, this group is all children, so they are at the mercy of their caregivers and the institutions who look after their health and welfare. I will add that health care practitioners play a role as they can positively affect resilience through trusting relationships, positive role models, and access to health care, education, and social services (p. 733).

MODELS

There are two commonly known disability models: social and medical. According to Goering (2015), most people tend to subscribe to the medical model of disability where "the main disadvantage [many people with disabilities] experience does not stem directly from their bodies, but rather from their unwelcome reception in the world, in terms of how physical structures, institutional norms, and social attitudes exclude and/or denigrate them" (p. 134). In the social model, the greater population and institutions are held accountable for being open minded to providing accommodations and creating more inclusive frameworks. In a world where the disadvantageous experiences by people with disabilities is not due to their bodies but rather with how well they are accepted by accessible physical structures, institutional norms and social attitudes. When the body is seen as the main source of disability, it fits the medical model of disability whereas the social model accounts for accommodations and inclusive environments.

DEAFBLIND POPULATION

Of course, the population nearest to my own characteristics is the deafblind population. In Canada, 11 persons per 100,000 persons live with deafblindness (Watter, Owens, & Munroe, 2004). However, using a broader definition of deafblindness, which means impairment but not necessarily complete loss the numbers become 232 persons per 100,000. Age ranges varied with seniors (70%), under the age 45 (15%), and ages 45 to 64 (15%).

Individuals who are deafbind are categorized into deafblindness, dual sensory impairment, dual sensory loss, combined vision and hearing loss and more (Larsen & Damen, 2014). Distinctions are made between early onset (or congenital) and later in life acquisition. For example, communication and language acquisition is often considered to be more severe with early onset (Larsen & Damen, 2014). Early onset is considered before two years old.

The absolute best description of what could possibly be occurring with the other senses in a person who is blind is from the 1951 edition of the Book of Knowledge in a "wonder questions" section found on page 1638 of volume 5 &6:

> *"Why are blind people so quick at hearing?*
>
> *The simplest answer to this question would be to say that blind people listen more attentively to the sounds around them. An ordinary person who has all the senses of sight, smell, touch, hearing and taste receives a tremendous number of impressions from all sorts of sources which are conveyed to the brain by special nerves and give him the ideas that he identifies with all those sensations. Now, if one of the organs of the senses, such as the eyes cannot receive impressions from the outside world, the brain has fewer message to attend to, and so has more time for the rest.*
>
> *Thus, in a blind person there are no means of getting all the information that comes to an ordinary person through sight. If he wants to know how near he is approaching somebody walking toward him, the best means he has of judging that is by listening to the sound of the other person's*

> *footstep. He cannot see the distance that separates him and the other person. In this way he forms a habit of listening intensely for all the sounds around him; and so, we find that blind people become extremely quick at hearing. In other words, their sense of hearing is very highly educated".*

Further, the Encyclopedia Britannica (Hoffman, 2016) describes the deafblind population in detail and that the causes of deafblindness vary among the population. Causes identified were: premature birth, genetic syndromes, and illness such as rubella are common causes. It could also be resulting from a combination of accident with one sense and illness of the other. This population has the most diverse communication methods, often in combinations. They associate with communities related to one or both of their impairments and mainstream society. Due to the diversity, individuals who become deafblind later in life may feel disoriented. The article finished by saying that the community of their choice is based on accepted communication method of the community (Hoffman, 2016).

Larsen and Damen consider DB be considered as a spectrum disorder with four components:

1) sensory medical and functional component,
2) an ability or functioning component as well as both
3) a chronological and
4) developmental onset component (p. 2575).

Therefore, Larsen and Damen suggest that in articles that refer to the deafblind population, it should be made clear: the definition used, the aetiology, severity of sensory impairment, mobility, access to information & communication, age of onset, communicative development at onset. In 1995 the Department of Health in the UK established a legal definition of deafblindness: 'A person is regarded as deafblind if their combined sight and hearing impairment cause difficulties with communication, access to information and mobility. This includes people with a progressive sight and hearing loss.’ (Sense, 2019).

Individuals who experience early on-set deafblindness are often developmentally affected, worse so with severe impairments. It is assumed that the two impairments inhibit the compensation of the other. Early on-set can affect the cognitive, language, social, and emotional development. If the sensory impairment occurs before two years old, they say that there is a loss of basic learned skills required in life. Thus, they only develop through the senses that are not impaired. Therefore, there is suspected a lack of access to sensorial information and are often delayed to their peers. On the upside, early-onset individuals develop mental representation skills. Also, with the appropriate environments, in which they have alternative access to information, they can thrive. Jan Van Dijk (1937-) is renowned for his work with deaf blind children and the link to rubella. He proposes that is the inability to organize senses of vision and hearing that hinders someone who is deafblind. Through ordered information, the child can anticipate and interact with the information. The key is not creating labels but the social interaction between two people having a conversation about objects, activities and emotions (Tait, 2014). It is this social interaction by which we learned of Helen Keller with her teacher, Anne Sullivan, when these two people connected over water.

The deafblind population can easily blend in with society just as much as they can be ostracized, even unintentionally due to the design of the world’s activities. They are a particular population who have access to many different forms of communication as well as complex health needs who require various assistive devices, such as the internet (Watter, Owen & Munroe, 2004), hearing devices, mobility supports, specialized glasses, assistive animals and more just to be able to interact in society.

CANADIAN STATISTICS ON DISABILITY

Statistics Canada (2012) stated in their report that the severity of disability often increases the difficulty of making certain kinds of work unsuitable and require to limit the number of hours they work or may require other workplace accommodations. In general, only ~62% of people with disabilities, ages 25 to 54 participate in the workforce. They are also often expected to end their working life at 55 or even 57 if you look at the government program eligibility criteria. Of course, women experience higher rates of unemployment to men (13.4% to 9.5%). They are more likely to work part time, as women tend to in general. Access to information helps people with disabilities to develop self-determination, self-advocacy, there is a lack of support experienced by deafblind youth who do not expect to work and be able to participate in society (Hersh, 2013). Near half of those with disabilities perceived labour force discrimination in that they felt disadvantaged due to their condition or felt that they were perceived to be considered disadvantaged by the employer.

Surprisingly, given the numbers above, nearly 28% of women with disabilities reported wages or salaries, only a few points less than men. Women were less likely to be self-employed though (7.7% and 12.5%). The rest reported assistance of sorts in 2012. Unsurprisingly, however is that women with disabilities have a lower average income compared to all three other cohorts (women without disabilities and men with or without disabilities). In Atlantic Canada, where I live, women with disabilities reported on average 30,290$ personal income, versus women without at 33,930$. Imagine! I achieved a position of making up to 84,000$ a year at the time of my departure before burning out to rebuild my life. In Canada, the average income increases as a household, but dives deeply if the women with disabilities lives alone (by choice or situational). I somehow broke the glass ceilings; it can happen.

It is here, in employment where life as a person with disabilities, who, if they managed to achieve a certain level of education, becomes a missing puzzle piece: in the labour force. The statistics surrounding people with disabilities in Canada tell a less than successful story. Although, I am one of 14% of those with disabilities who hold a bachelor's degree, the number decreases with higher education and severity of disability (Statistics Canada, 2012). The worse the disability and quality of life is, the fewer folks make it. People with disabilities often require more time or a modified schedule in order to complete their work (Statistics Canada, 2012). Then there is the issue of paying for assistive devices. Statistics Canada (2012) reported that 80% of those with disabilities require assistive devices and 27% of them said they did not have a needed aid. Cost is often cited as a barrier to obtaining aids. We will return to the cost theme again later.

Of course, as common sense predicts, as the severity of the disability increases, as do the associated costs. I am also one of the 86% of women who use prescription medications at least once a week – mine is medical marijuana, which is never covered under any benefit plan anyway, so this is out of pocket regardless. Hardly any articles that I have read in my tenure take the time to even begin to talk about financial implications of disability given the societal attitudes and institutional barriers towards paying those with disabilities. However, there are lots of statistics to demonstrate financial barriers. I realize not many people would really understand the economics of living with disability. In reality, although people with disabilities are expected to make lower than average incomes, they require supports that cost money beyond what the average person experiences.

According to Statistics Canada, in 2012, there were more women than men reporting disability, women with disabilities are more like to be alone and even single parents than their male counterparts, and pain related disabilities are the highest for both genders. I learned that I am a member of the group of women with disabilities who have been single parents (11%) and to have lived alone (24.6%). And by the way, according to one of my classmates from my doctoral seminar course women, single parents in vulnerable sectors are most likely to wind up in abusive relationships. Only 5.8% of women with disabilities even have a child living with them versus the 16.1% of women without disabilities who have children living with them. Talk about scary. Even scarier, I have experienced these situations. There were also some fears that I always had confirmed. Like, I worried that being a woman with disabilities would be hard for a partner to handle. Turns out, men with disabilities were more likely to be married while women tend to be alone (14.5% of women versus 8.9% of men). In a nutshell, relationships are more complex and challenging.

One enlightening table as part of Statistics Canada's Participation and Activity Limitation Survey from 2006 is the one that shows that children with disabilities who live with their parents are more engaged with virtual peer networks than organized and non-organized sports activities (Statistics Canada, 2006). Age, sex, and place of residence all play a role. Age wise, the percentage goes from 60% in ages 5 to 9 up to 82% for ages 10 to 14 years old. I imagine this rate continuing to increase with age. Not surprisingly, more youth in urban areas participated in organized sports. However, the numbers for virtual were close to even (78% rural and 71% urban). For some reason, virtual participation and participation in non-organized sports was higher for girls (80 versus 69 for virtual and 61 versus 51 for sports). Very curious is that those who were more involved in virtual communities felt there were fewer societal and personal barriers to participation. Indeed, this virtual participation is where youth feel there are fewer societal and personal barriers to participation (Statistics

Canada, 2012). I can imagine that as of 2019, that number is high for almost age group and not just people with disabilities.

DISABILITY HISTORY

Going even further back, society has changed how it treats people with disabilities, especially over this last century. In the late 19th and early 20th century, people with impairments were actively segregated from the general population. I have wondered how they navigated the system in their day and age to become successes in their own rights. My follow-up question is, "how would they achieve the same in today's day and age?". So, how did a person a hundred years ago manage to feel included before technology? How did a person with disabilities participate in society? How did they navigate social situations, including dating without online dating? I know I always feel lucky as a person with disabilities to not have been shoved into an institution at their mercy because even 60 years ago, that is probably what would have happened, depending on my family's financial situation and government structures accessible at that time.

In the early 1900s, it was commonly accepted to be deaf and different communication styles were highly debated. In Gray's (2013) book on Bell, she describes the nineteenth century to be a place where "many people thought deaf was a perfectly good way to be – as good as hearing, perhaps better" (p. 283). Bell himself was shaped by his mother's and then his wife's hearing impairments and developed a "certainty that most hearing-impaired people could master lip-reading and mix easily with hearing people" and saw lip-reading as preferable over sign language (p. 282). That said, he had also confided to Helen Keller that he truly believed that disability should never prevent someone from living a full life, a full range of human experience (Gray, 2013).

The Eastern seaboard of the United States and Canada had very strong ties, going back centuries. Around the 1900s, it was common in the United States to find asylums, public houses, schools for the blind, schools for the deaf and other political and residential institutions. Eastern Canada was expanding its institutions at the time too. At home, in Moncton, New Brunswick, the Moncton hospital was an extension of an almshouse (housing built for poor people where if they did not pay rent, a poorhouse, which eventually turned into "NB Housing") in 1898 that became a large hospital structure by the 1950s (Mullally and MacDonald, 2017). Fear of going to the poorhouse was real enough in recent memories that it was still a saying I would here from time to time growing up. Unfortunately, I found out it was not necessarily said in jest but because it was a real possibility. Nowadays people have a lot more options to them to keep independent. Unfortunately, I do believe this physical proximity connection of the poorhouse and the hospital created a deeply held local perception of a distinct link between health and poverty.

The cusp of the 20th century was wild with innovation as the Boston Expo, Industrial revolutionists, philanthropists of old money and visionaries ruled the Eastern seaboard of the United States of America, or as Canadians call it, "The States". It is from this era you hear tell of people such as Alexander Graham Bell. He is most known for the invention of the telephone and lesser known for his work to improve the lives of those who suffered from deafness as his had seen his mother growing up with her deafness (while also being heavily influenced by his father's ingenuity). Bell is sometimes remembered for his misguided concern for inter-disabled marriages out of eugenic fear. That said, he successfully did open up dialogue and funded an incredible amount of people and programs alike. One of the people he "sponsored" was Helen Keller. Most 21st century people know the famous scene of her teacher, Anne Sullivan, at a water pump and spelling out each letter for “water” in the young girl’s hand before she finally understands and says out loud “water”. This moment of comprehension is incredible to witness even as an audience member of the infamous plays: that moment a deafblind girl learns to communicate with her teacher. Communication is the key here: Bell gave not just the world the ability to communicate by telegraph, but also the deaf to participate in society with hearing devices. Thanks to Bell and places like the Perkins Institute for the Blind, marginalized yet prosperous families had options for their disabled children. For the first time ever, the deaf and “dumb” were able to interact with others in society in unprecedented ways. Thus, began an accessibility revolution.

It is through philanthropic efforts around the turn of the 1900s by people such as Alexander Graham Bell, and the belief that those with disabilities are indeed members of society, that segregation has turned towards inclusion. It was in the early 20th century that Anne Sullivan taught Helen Keller, a deaf/blind person, to become one of the greatest disability inclusion advocates in government houses. Fast-forward to the late 20th and early 21st century, to where technology connects people in infinite ways to information that was difficult to obtain previously.

COMMUNICATIONS

Since the development of the telephone, individuals who are deaf/blind have increasingly maximized their potential in society. Until the advent of the telephone, the most common form of communication was in person and by way of writing letters through the postal system that was established before the turn of the 19th century. Even in the scientific and medical communities, letters make up for the majority of correspondences. Correspondences were formalized through journal publications. In fact, most medical journals still have a "correspondences" section. In the 21st century, we do still write letters but often our correspondences are through e-mail and the important documents are attachments and available to anyone who can access the internet. Chats happen online rather than at cafes. Interconnections now exist in clouds.

There has been an evolution of how society treats disability over time. The types of institutions, technology, champions, points of access, funding opportunities, and more have evolved since the early 1900s to New Brunswick in the 2000s. In this table, I outlined some of the distinct changes between society in around 1900 and around year 2000.

	~1900	~2000
Institutions for those with disabilities	Asylums (archives)	Horizon (annual reports) School system
Technology	Telegraph, telephone	Cellular, Computers, Internet
Champions	Philanthropists Government Officials Advocacy Groups	Patient advocacy Associations Third arm agencies Government Officials
Primary point of access (in order of priority sequence)	In person, by mail, by telephone	By internet, by telephone, in person, by mail
Funding organizations for education and devices	Philanthropists Charitable organizations	Government Private Charities
Agencies	Private and some Public	Public and some Private
Common Communication Methods	Mail Telegraph Telephone	Telephone E-mail Internet

What has changed is the technology and the avenues through which funding is accessed to improve health and development. It is a catch 22 situation – you need a computer with internet to access funding, but you need funding to obtain a computer with internet. The AGE-WELL NICE study brought another gap to light: public versus private agencies and funding. ICTs are only sometimes included as an assistive technology in programs (Schreiber et al., 2017). Mobile friendly websites are still a new thing and expensive to create, so most applications and information are only really accessible with a laptop or desktop computer. However, people with disabilities are often in low-income brackets, with less education, and struggle with obtaining assistive devices (Till, 2016). Especially given that most people access health and educational information via ICTs, such as connecting to the internet with a computer, it becomes doubly important for marginalized groups to gain access to the informed, neutral and inclusive environments found on the internet.

Crowley (2002) noted that at the time of his report, eighteen years ago now, that 80% of adult Canadian internet users accessed medical information online; namely reference materials and peer support found on federal, provincial, online vendors, private websites and others. Second most accessed resource was the educational variety, particularly by university students. It is no surprise that internet access increases with educational level as one need internet in order to pursue higher education these days. Crowley (2002) stated very eloquently that “the use of the internet as an information utility underscores the way in which IT skills are becoming ubiquitous skills and an extension of literacy and numeracy” (p. 478). So, how do we increase access, it is through the development of these ubiquitous skills or by infrastructure alone? What can we learn about the experience of navigating these systems and development of IT skills? A person with disabilities must increasingly rely on ICT to access required information to achieve life goals.

TECHNOLOGIES

Information and communication technologies (ICT) are said to be the key to Universal Design. In theory, Universal Design would allow everyone equal access regardless of disabilities. The Canadian government adopted this philosophy and invested in ICT infrastructure by way of creating Community Access Sites where members of the, often rural, community would have access to the internet that would otherwise be entirely inaccessible due to infrastructure and cost. The public access websites were specifically mandated to provide adaptive technologies so that even people with disabilities could access the CAP sites. ICT provides a bridge to people with disabilities to overcome both the medical and social models through virtual communities where Universal Design is achieved: each person is considered to be on the same level and same unknown face on the other side of a computer.

Information and Communication Technology (ICT) has long been identified by the Canadian government as a key element in achieving Universal Design for all. Back in 2001, education and public access sites were key elements designed by the government to bring broadband to every community by 2004 (Statistics Canada, 2003). The government was volunteered to take leadership to ensure affordable access by supporting public access sites (CAP site), to everyone, including individuals with disabilities and those with special needs. Indeed, the public access sites provided adaptive technologies that are in place to ensure that facilities are accessible for people with disabilities. In addition to technologies, support personnel were always available. It was beautiful, feasible, and meaningful to the communities.

Information and Communication Technology plays a major role of people with disabilities. I believe that the ways in which people with disabilities have used ICTs over history has changed how one develops self-culture. It seems to me that greater success in life has increased with the availability of ICTs. There are three conclusions I have reached over time:

1) Studies that assess assistive device programs do not address the access points, which I suspect is through an internet portal.
2) Internet as an assistive technology is a complex issue.
3) A person with disabilities must increasingly rely on ICT to access required information to achieve typical life goals.

People with disabilities use information and communication technology to further their education, obtain assistive devices for more effective communication experiences, obtain accommodations before going into and once in the workplace, access health information, and even prepare to travel the world. However, of 80% of those people with disabilities, 15 years old and older, 27% of them reported that they required more devices or assistance (Statistics Canada, 2012). Cost and training, of course, are common barriers to obtaining aids.

ASSISTIVE DEVICES

The AGE-WELL NICE study (Schreiber et al., 2017) classified assistive technologies as either: assistive, consumer or healthcare technologies. Canadian federal, provincial and territorial governments offer numerous programs. However, they drastically vary in criteria and availability; most of the programs are “the payer of last resort” variety where the applicant would have to exhaust all private and workers’ insurance avenues first. The AGE-WELL NICE report found that “from a consumer perspective, navigating through assistive technology programs to obtain what is needed can be confusing & time consuming, and can necessitate substantial knowledge and advocacy efforts" (Schreiber et al., 2017, p. 15).

I can tell you from personal experience, devices are very expensive and locating funding for them is a challenge unto itself. It requires a high level of self-advocacy, diligence, and patience. Oh, and a whole pile of luck. My mom asked why I did not have already an FM system and the hearing devices I do now. My response was that I got lucky. The difference is made by finding a champion at New Brunswick Deaf and Hard of Hearing (thanks Lynn!). It takes getting into the right program or employer that has a disability coordinator specifically to help people like me. I will forever send out a kudos to the local CBDC (Community Business Development Corporation) for hiring a coordinator dedicated to the program for those with disabilities, who set me back on track with support. It takes finding the right advocate to access appropriate services.

There is also a technology bias that occurs in medical treatment where practitioners are subject to their bias in technology and perceived capabilities. Lindsay (2010) found that some clinicians did not prescribe technology if they felt that the child could not effectively use the device. Both studies found that support need to be offered to clinicians as well as the users and their families. Everyone is equally affected with lack of time and resources to learn new technologies. Unless they are lucky to be granted that time as part of their paying job. Add in their own educational, cultural and personal assumptions, and therein lies more professional incongruencies in successfully adapting assistive devices.

Another issue with ATDs (Assistive Technological Device) is continued use, maintenance, and eventual replacement. Even when ATDs are used, they are often abandoned due to steep learning curves, buggy technology, or social pressure (Ranada & Lidstrom, 2017; Lindsay, 2010). Lindsay went further to providing training and support to teachers – the interveners with the most interactions with the child. Obtaining funding is also very difficult to navigate for everyone involved (Karlsson, Johnston, & Barker, 2017; Gordon et al., 2007; Ranada & Lidstrom, 2017; Lindsay, 2010). It is assumed that professionals have the training whereas they may not at all or may be outdated given how fast technology evolves.

On the technology side, I am a nerd and I give my audiologist a good workload with questions and troubleshooting. I honestly can see how others would struggle so much with adopting these fancy but super functional devices. Indeed, that frustrations cause a lot of device abandonment issues. Technology has come a long way in society in general, but especially for those with disabilities. Even better is that the crazy expensive devices that were once only available to the rich and lucky are now becoming everyday items for the masses (i.e. smart phones). Still, there are very limited ways to acquire such assistive devices. Technology wasn't always so advanced as it is today. Disability, however, existed long before many of the information communication technology advances of today. To look at life before smart phone, I present to you Helen Keller's teacher, Anne "Annie" Sullivan.

ANNE SULLIVAN (1866 –1936)

The following narratives have been assembled from several books (see reference list) on Anne Sullivan (14 April 1866-20 October 1936), Helen Keller (27 June 1880-1 June 1968), and Alexander Graham Bell (3 March 1847-2 August 1922). In this book, Anne's life has been assembled from an autobiography, several biographies and her academic writings. Anne Sullivan is known to most as the "miracle worker" from the infamous play where the deafblind girl, Helen Keller, is at the watering pump with her teacher and connects the dots between hand spelling and objects and for the first time she handspells the word water in teachers hand. The teacher is Anne Sullivan. I thought it important to look at the teacher, the person behind the scenes to see what led her to having that wonderful moment with Helen Keller. I discovered a person who rose up, above and beyond, a phoenix goddess in her own right.

Through Anne's own struggles in the early 1900s, she learned how to acquire information no matter the context, in order to survive and progress. Even though it has been 132 years since Anne addressed her class as valedictorian, her story is similar to that of a person with life-limiting conditions are still considered a highly vulnerable societal group that experience high rates of violence, poverty, and discrimination (Sullivan, 2009; Simcock & Manthrope, 2014). Her life tells of navigating medical care, education, earning income, and the legacy she left.

MEDICAL CARE

Health history is not as straightforward as clinical cases taught to medical students, rather health is longitudinal and complex. Take Anne Sullivan for example: according to the book, "Beyond the Miracle Worker" by Kim E. Nielsen (2009), Anne had lost her mother to tuberculosis three years after her eyesight began to fail due to trachoma, a contagious bacterial infection of the eye. After her mother's death, the family's situation worsened, and her abusive father left. She then went to Tewksbury Almshouse, which was as much an orphanage as an asylum, with her four-year-old brother who died a few months later. Her own impairments caused her a lot of pain and gradually got worse over her lifetime. Regardless, she found ways to overcome the pervasive disability label created by societal institutions and attitudes. Anne exerted great self-advocacy skills by tapping into the networks with champions that believed that people with disabilities have a place in society (ie. Alexander Graham Bell, Sanborn…) and who lobbied their efforts to public and to the government.

The only other mention of medical care in the books and journals that I thought important to note was rather Anne's professional affiliations in the cross between medical and education disciplines. I will talk more about the importance of these professional affiliations in a couple of pages on the interveners such the disabilities champions in the public and private sphere, the educators at Perkins, family, and oneself which all played a very important role in her life and those around her.

SCHOOLING

One day at the almshouse Anne saw an opportunity to talk directly to Sanborn, the General State Inspector of Charities who had come to the institute on a tour, to plea for the chance to further her education. Thus, she found herself enrolled at the Perkins Institution in 1880 where she developed her literacy and communication skills.

Anne is described to have shown up at the Perkins Institute "sans toothbrush, coat or hat, with a pair of clumsy boots that were much too small and with only a chemise and some stockings tied up in a bundle" (Brooks, 1956, p. 11). Anne went to the institute as her one and only chance she could foresee to get out of the house of death and horror at the almshouse by personally requesting to be educated. At that time, many schools for particular disabled groups were quite popular in the philanthropic circles. There were schools for the deaf and others for the blind in different cities in the United States. The schools had a network of their own to match students with teachers through people such as Alexander Graham Bell. Anne thrived at Perkins where she befriended the most isolated blind girl by communicating gossip and daily activities to her through hand spelling. At the school, they also performed surgeries on Anne's eyes which helped but she eventually lost all of her sight.

When Anne arrived all alone at the Perkins Institute, she had lost all of her family and had experienced many adverse childhood events. When Helen Keller was older, Anne did not beat around the bush about the realities of life and what she called the "dark knowledge" as "she had been surrounded from the age of ten with crazy old bedridden women, tubercular, cancerous, perverted, crippled, grotesque, and with ignorant unmarried girls whose babies were covered with sores and whose talk was all of seduction, starvation, and rape" (Brooks, 1956, p. 12). According to all books that spoke about Anne, she kept a distance from her life before Perkins and found it to be a "privilege to love and minister to such a rare spirit". I believe that she never wanted anyone to suffer from the loneliness she experienced. In every place she went, she was pulled towards those who were alone and helped bring joy. Madame Montessori called Anne the "creator of a soul" (Brooks, 1956, p. 12) because she knew how to connect to someone deep in loneliness. With Helen, she used the doll she brought with her as a gift from the Perkins' girls. Anne could see the intelligence behind the feral instincts and devoted her life to developing Helen.

Sullivan's ability to fit in at Perkins was challenged as her age as older yet unknown and she was bigger than the other kids. She had also learned how to socialize much differently growing up than her peers. She wished she could read to escape, but her vision impaired her. She felt awkward with resentment for her peers. She connected instead with the girl at Perkins who was the most isolated and decided to communicate the outside world to her. They created a bond, and the girl joined the rest of the girls once she gained the ability to communicate. This first interaction left an impression in the institute's mind.

On June 1st, 1886, Anne Sullivan graduated from Perkins School for the Blind as valedictorian. Her valedictorian address was a call to all of those who wish to progress in their lives. Anne spoke of the ability to self-culture as being a benefit to the individual as well as mankind; self-culture as the drive to improve oneself which ultimately improves society. It is the development of one's mind or capacities through one's own efforts (Merriam Webster, nd). Anne Sullivan said, "the search for knowledge, begun in school, must be continued through life in order to give symmetrical self-culture". She implored to her cohorts and those in the audience that, "all the wondrous physical, intellectual and moral endowments, with which man is blessed, will, by inevitable law, become useless, unless he uses and improves them". For Anne Sullivan, this included one's memory, understanding and judgment as well as the physical body's muscles. Her words still ring true in a timeless fashion that asks everyone to progress regardless of impairments.

Upon graduation, Anne became the first highly known person to be able share information with someone who could not gather information in the traditional senses as Hellen Keller could not acquire information through her vision nor hearing. Despite Helen's affluent family background, she was only able to express herself through tantrums until Anne arrived to educate the young girl. Anne transformed Helen's life by showing her how acquire information to interact with the world and develop a desire to learn. Negotiating communication of information was a very lengthy and intensive process.

Anne was extraordinarily resilient as she relentlessly sought out to have a good life for herself and, later on, for her student Hellen

Keller. She regularly secured her own and Helen Keller’s financial independence by learning to negotiate institutional and societal information through the development of her own education.

EARNINGS

Anne had to earn an income to live. Anne Sullivan was extraordinarily resilient as she relentlessly sought out to have a good life for herself and, later on, for her student Hellen Keller. She regularly secured her own and Helen Keller’s financial independence by learning to negotiate institutional and societal information through the development of her own education. Upon graduation from Perkins, Anne was assigned to a young lady named Helen Keller thanks to Alexander Graham Bell. However, self-sufficiency was still quite difficult even if you were educated, despite what school philosophized.

Her primary earnings were through publication writing and applying to benefactors who supported her educational cause. As the governess to Helen Keller, she attended all of Helen’s classes with her until she it became too tiresome for her elderly body and another educator, Sarah Fuller, was available to be hired. She attended luncheons, fundraisers, and any social event possible to move their cause into the eyes of those who would be willing to donate to Helen’s education and well-being. At one point during a financial drought, she enrolled both herself and Helen into the circus to earn income. She did well, by evidence of the many letters and books Helen went on to write and the causes she advanced. I believe Anne was proud of Helen, without a doubt.

Even in being the aide to a deafblind girl, she eventually hid her own blindness from the public as there were “unstated assumptions on the part of the general public that a blind woman could not teach a deaf-blind girl, and that blindness meant incompetence...” (Nielsen, 2009, p. 189). So, the publicist (for lack of better comparison) made light to the surgeries Anne had at Perkins to say that she had been healed so that she would appear able-bodied. Nielsen posited that Anne was uneasy about her disability and so she was fine with claiming able-bodiedness so she would appear to be the "nondisabled companion and aide of Helen Keller". It worked because a century later, no one sees Anne, as a teacher, had disabilities herself.

HER VILLAGE

Every person is part of a village. Family, neighbours, government, doctors, and so on make up a person's village. The village exerts great influence in one's life. Here is a glimpse of Anne's Village over her lifetime. Interveners such the disabilities champions in the public and private sphere, the educators at Perkins, family, and oneself play a very important role in the life of Anne and Helen.

Family Members & Caregivers

Anne grew up in a broken home with a sickly mother, alcoholic father, and a younger brother who died in the poorhouse. Over the years, she developed her own family and bonds. During Sullivan's time at Perkins', she befriended one mother hen type lady named Sophia Hopkins. It was there she found a home and extended family. Her greatest connection was with her student, Helen Keller. She was a part of, yet apart from, the Keller's household, as most governesses were in that era.

The particular challenges in communicating with family, friends, and peers are staggering. When a person does not have the ability to communicate, it is isolating, lonely, angering, and frustrating. In this way, having one champion that communicates makes a world of a difference. Whether that relationship is healthy or not, it reduces the loneliness. Eventually though, it becomes preferable to be alone rather than dealing with social and emotional pressures. Thankfully though, Helen Keller had Anne Sullivan and developed relationships with others as she grew older.

Doctors

One thing I found very curious is the minimalist role that doctors played in Anne's biography; doctors were only mentioned in regard to her surgeries. It was noted that she had surgery at the Perkins' institute. At the professional level, it was Dr. Julien John Chisholm (1847-1922) of Charleston, North Carolina who very bravely and humanely told Helen Keller's parents that their six-year-old daughter will never see nor hear but would have the opportunity to learn provided she went to see Alexander Graham Bell (Welch, 1999). Alexander Graham Bell was a well-known deaf educator in Boston when he met with Helen in 1887. After working with her for a year, he referred the child to the Perkins School for the Blind where the valedictorian graduate, Anne Sullivan was assigned to Helen's care.

Mentors

Anne herself was a mentor. She thrived learning and teaching. The two went hand in hand. She held many important philosophies of which that even Madame Montessori took note. Anne did not take to a particular person as a mentor, rather she had teachers who begrudgingly liked her throughout her studies. If I were to define a mentor for Anne, I would say it was life experiences.

Philanthropists

Anne Sullivan struck her deal with Franklin B. Sanborn, the 1881 Inspector for the Massachusetts Sate Board of Charities, "the bureaucracy that oversaw all state almshouses, asylums, and hospitals" (Nielsen, 2009, p. 31). He was connected with Samuel Gridley Howe, who founded the Perkins Institute and Massachusetts Asylum for the Blind. In Nielsen's (2009) book, Annie is described that "in an institution in which most children died, in which poverty and hopelessness overwhelmed many, and which traumas were piled one on top of another, the fourteen-year-old with limited vision demanded that the well-dressed leading philanthropists of Massachusetts live out their philanthropic ideals" (p. 33). Perkins held higher ambitions as it went from being an asylum for the blind to a school for the blind. Perkins' organizer, Anagnos, held higher ideals in that asylums were not the way to result in "economically self-sufficient adults" (Nielsen, 2009, p. 38).

IMPACT AND LEGACY

Anne Sullivan transformed Helen Keller's life by showing her how acquire and share information with the world and develop a desire to learn. Negotiating communication of information was a very lengthy and intensive process. Anne became the first person to be able share information with someone who could not gather information in the traditional senses as Hellen Keller could not acquire information through her vision nor hearing. Despite Helen's affluent family background, she was only able to express herself through tantrums until Anne arrived to educate the young girl. Anne Sullivan led a beautiful life regardless of the darkest roots she arose from in her endeavours to lead a life despite it all. To me, she is a prime example of resilient women with disabilities. Her legacy continued on through Helen Keller and beyond. All of her efforts are part of the history that leads me to my modern reflections.

MODERN REFLECTIONS (1984 – onward)

This is my attempt to show you what I know of Anne Sullivan's life, my own experiences, and from the mountain of literature bouncing around in my brain. These are legacies of disability that need to be told. I have been told that others are happy I am out there, to hopefully help build a better world for their own neurodiverse children. I have no idea how to accomplish that, but then again, I had no idea of how I would create this book and here it is in your hands. These paths are often akin to how Noah felt building the ark, he kept at it until it became clear an followed his instinct and the signs that guided him. There are many other stories such as these in practically every religion/path I have read about to date. I have been writing out my story ever since I could pick up a pen. Amazingly, I have even kept most of them, including poems. Each section is presented with a poem of my own followed by critical reflections from my point of view as a mother with multiple disabilities who followed academia as far as I could into doctoral interdisciplinary research. I may have reached for the moon in working towards my doctorate, but I will always be a librarian by vocation and disability will always be my life.

LIVED DISABILITY

Capacity[6]

I have the capacity to do great things
Arms open wide and embracing life
I have the capacity to accomplish anything
Steadily moving forward through dreams
However….
Underneath brews a batch of black muck
Dark and sinister, it can change everything
Filtered through are "what ifs" and more doubt
Gone unchecked for too long, it alights on fire
So then…
Acknowledge the darkness that brews inside

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[6] Monday, May 15, 2017, Thought Sketches (personal journal)

Nothing gained from hiding or ignoring it
Light befriends darkness, no longer alone
The voices become familiar faces, strangers gone
Evermore...
There's an internal love potion that takes over the pot
Stir and stir, slow and steady, low heat, it takes flavour
Surely steadily we dance in the rain without care
For it doesn't matter as your footing becomes more sure
Therefore...
The more you, you are you, the more solid the shield
The sneers and scorn turn into envy for they wish to be free
Ever humble, you become the poster child for xyz
Compassion keeps ego in check as you grow to outshine
Eternally...
I come to embody mother nature: rainy and sunny days alike
Negative associations are embraced with compassion and questions
Dissonance, a tool for recognizing the need for investigations
I claim to be wild and free like mother Gaia with love
After all...
Fear is a motivator and a tool to understand situations
Learning life, internally, externally and inbetween
Done with love, compassion and constructivism
I have the capacity to do great things

Living with disabilities is a complex phenomenon. So complex that only poetry can even give the barest idea of the emotion and energy that goes into everyday life. There are certain societal expectations we are expected to accomplish: get educated, get working, then get parenting. Well, it really is not that straight forward for anybody. For people with disabilities, the dynamics are even greater. Disability is complex. There is no real way about it. It connects many though. Be it disability through childhood trauma, be it the lose of senses, be it the lose of body parts, there are many forms of disability. All of these stories contain a grain of the same: desire to thrive despite the odds and to improve the lives for the next generation.

You are about to read modern reflections regarding devices and technology, role of transferable skills, education, and parenthood. I also brief on the economics of disability and modern village interveners. I also reflect on the roles of resilience and self-culture in disability identity. Finally, I explore how to define success diversely, followed by concluding remarks. At the very end, the last poem is a copy of Anne Sullivan's Valedictory Speech.

DEVICES & TECHNOLOGY

The way to thriving[7]

Wound up and wound down
I wait and wait and forget about waiting
Stirred around like a James Bond martini
Consider all the aspects on the inside and out
The results are the same to smile
Live in black and white
Everything is either a "fuck yes" or a "no"
No more room for grey in my life
Uncertainty is best avoided and unexplored
No more time for that in my life
I've learnt enough to have the confidence I need

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[7] Thursday, December 22, 2016, Thought Sketches (personal journal)

Enough trials that serve only as further evidence
Saturation has been reached
No more data to gather to prove points
Points have been proven, time to move on
Fully free and empowered by this knowledge
I give myself permission to take initiatives
I give myself permission to be empowered in my life
I am the best and most active player
There is also another element to add: my son
No longer is it just about me and the possibilities
Now it is about doing the best for my son
Which includes making the best decisions for my life
What I do in my life will impact him
Mama bear is my strength and best chance
I have the freedom to be me and to choose
Taking care of myself has become a higher responsibility
Bye bye to what does not bring positive to my life
Hello to the world of wonder and beautiful things
Smile upon smile, my breath is stolen away for a moment
All will be well, even in the clouds, smiles can be found
Take it all in, every moment, every detail
Grow before my eyes, you and I, in this together
This is thriving

I can tell you from personal experience and as mentioned earlier: devices are very expensive and locating funding for them is a challenge unto itself. It requires a high level of self-advocacy, diligence, and patience. Several information systems are involved with funding programs: banks, government, school, non-profit, and association. One must also account for Google these days as an important information source.

I grew up during a technology evolutionary time, watching ICT develop and improve. It was my Uncle who introduced me to computers and the internet. I was amazed at how his computer and connecting to the internet allowed him to live impossible social situations that he would other not experience due to social isolation and his disabilities. He grew up with epilepsy that left him with limited function on his left side, living with seizures and, later on, heavily medicated. He understood very well the social implications and (tried to) take initiative to guide me through bullying and learning important life skills, like card games and dart boards. I learned how to use computers, starting with his Vic 20, then Commodore 64, eventually Amiga. I still remember when he gave me an ASCII coding manual to learn before we had computer courses in school. Like him, and many others with disabilities, the internet has allowed me to achieve my life goals. I learned the structure of a computer system that, in many ways, makes more sense to me than most social structures.

Oh, and cannot forget the accommodations. ICTs have allowed me to join peer communities and to connect with agencies to advance my goals. This includes banking information, government programs (Service Canada, Canadian Revenue Agency, National Student Loan), scholarship applications, educational programs, and more. Increasingly, the only way to access information on programs to advance life goals is through internet access.

TRANSFERABLE SKILLS

Energy flow[8]

Sit back and relax, wind at your face
Streaming down on those lovely lips

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[8] Thursday, April 10, 2014, Thought Sketches (personal journal)

Eyes closed and lean back, soak it in
Lips turn up into a smile
Oh serenity
Let the water cascade over you
Peacefully enveloping your body
The mind calms down a moment
Lips turn into a grin
Oh simple joys

Take it all in once again
That's right.... laugh
Let it all out and grin
Happy this came to be

Open your eyes and see the world again
It takes on a brighter colour
This is what happiness is like
Let the energy flow freely
The heart turn up into a smile
Oh enjoyed

Spread your arms eagle spread
It has been a long time
Welcome, always welcome
Peaceful tranquility
The heart breaths relief
Oh wonderfulness

This is the results of hard work
I must remind myself
Look at what it took
Reap the rewards
You're allowed

I will go back to my social sciences years and tell you what I learned in my first year of university from the book by Brym (2001) about people with disabilities as a disadvantaged group in accessing employment and become trapped in “job ghettos”. In Chapter twelve they wrote:

> *“People with disabilities face barriers to good jobs because of inaccessibility of education and workplaces. Lack of financial resources to attend school, inflexible workplace schedules, and lack of employer’s commitment to hire disabled workers are some of the reasons people with disabilities have trouble getting jobs”. (p. 304)*

Much of this information was based off of studies from the 1990s but still held true. The government tried to take some of the load off by providing student loans. The future they did not tell you was that you would end up with higher loans due and have less chances of finding accessible jobs and thereby become over debt. I suspect most people with disabilities file for RAP (repayment assistance plan) regularly; it is available for darned good reasons.

I believe there are key skills can be learned to help a youth with disabilities achieve their life goals. However, learning these skills does not automatically occur. Independent organizations like the CCRW (Canadian Council on Rehabilitation and Work) have cropped up to support employers. There are becoming more programs available even for entrepreneurs. Times are changing for the better in terms of support agencies. The tricky part is whether you fall into their eligibility criteria at the right time, with the right people.

Skills learning through various methods is important. Skills are learned through observation, modeling, lecture, or serendipitously. To learn the necessary skills, I held an incredible amount of curiosity and I went to local Community Access Centre and local public and school libraries. The closest CAP to me was at the middle school, a good 15-20 minute drive into the village. During the days, it made all the difference in the world for developing self-culture. I was graced with opportunities to learn how to use computers from a very young age. It was wonderful learning how to interact with information without having to actually speak with someone. So, when I needed to become more self-sufficient, I required technological devices to assist in my learning.

Like my epileptic uncle, I grew up with a different interpretation of the world; one where my other senses make up for being blind in my right eye and moderate-severe hearing loss. So, other senses develop when the others diminish. Sensorial education can be self-directed or instructed. I believe that I developed another sense through computers. I was taught how to use computers from a very young age. It was wonderful learning how to interact with information. So, when I needed to become more self-sufficient, I required technological devices to assist in my learning. I relied on funding to obtain computers and assistive devices to accomplish my university study.

In addition to funding, I actively sought out workshops such as those offered through APSEA (Atlantic Provinces Special Education Authority) and then I attended transferable skills workshops (i.e. Library 101 at McMaster University) that I successfully transitioned into university from high school. As a girl I was very fortunate in that my Mom enrolled me in Brownies and then Girl Guides with her as a leader. Honestly, without her there, I would not have lasted as long as I did as it was very easy to attend by going with my mother. That said, I loved learning the badges. I went on to attend any First Aid, WHMIS, Workplace Standards, and so many workshops I had the opportunity to do so. I loved learning real life applicable skills that just made sense. These transferable skills were common sense to my neurodiverse brain.

In university, the long lectures were cumbersome and lengthy. I had the option of being 60% course load as a student, but I would lose too many benefits of being a complete full time university student plus would mean longer time spent in school, thus a greater potential debt load. No, I was a high achiever student. What better way to mask and hide but by doing so well you were pretty much left alone. I wanted enough of a future that I could not become delinquent if I wanted anything at all. So, I learned transferable skills to get me foundational jobs. I needed a trade to market. So, I got good at customer service then social sciences then librarianship. I theorized that what I lacked physically, I could make up mentally: turn my disadvantage into an advantage.

I took the kind of jobs that had a math quiz for their interviews and asked for demonstrations at hiring. I took the jobs that trained their new hires and had training programs to expand further. I did pretty darn good. I held steady employment for seventeen years, save for one semester in my undergraduate. Then I burnt out to in hopes to rebuild with the proper supports in play. The funny part is that the burn out impacted my ability to execute basic transferable skills like time management and budgeting. So, like calligraphy in grade 11 to reteach myself cursive, I set out to learn these skills again through teaching. I read an incredible amount of literature and attended many workshops that I needed to activate these important skills again. And it did get easier, and I did gain more confidence. I also hired help when I could afford. There’s truly always a way.

Leap of Faith[9]

Consider, consider, consider this
The world designed in your mind is your own
Beliefs tested, some tried and some untrue
Break them down for what they are and see
The truth lies underneath as truth knows truth
Black and white, "fuck yes" or no, all or none
Inside there's an everlasting knowing that tells all
Norms, standards, expectations changes it again
Strip them all away, Strip them down to the truth
Truth is both and neither negative or positive
You have to acknowledge the ugly to live the magical
Ignoring realities that does not help lead to truth
It's a leap of faith to take that holds such beauty
Step forward and remove the chains, heal from all that has been
Move forward from here as I am, as I will be
Split in half, quartered and drawn, I am awake
Take the best of what I know and make it better
The magic exists and is out there for me to grab
Lived too long in lives based on text books and nothing
Always remember how the wind feels on my face, freedom
Lead me no more, I am the wanderer who has learned to drive
Live with my heart and soul in all that I physically do and think

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[9] Sunday, December 25, 2016, Thought Sketches (personal journal)

Play reverse and catch up to get fully ahead in the moment
All those memories, pieces and more is my best bet
Piece by piece it all breaks own into something much bigger
Live in that beautiful, magical world full of love and wonder
Remember, acknowledge and empathise with all the ugly
I make the choice now to be able to choose which one I want
Take that leap of faith and keep it going, it will work
I will always make life work no matter what
That leap of faith of living positively and fully once again
I take a deep breath

Interestingly, Anne and I both found our higher education institutes and did not stop until we got there and beyond. She went to the Perkin’s Institute for the Blind and I attended university in social sciences, librarianship then interdisciplinary studies. We wanted to expand our minds to have gainful employment and to best contribute to society. Unfortunately, the real world of work then prevents meaningful engagement. However, creative thinking like Anne enrolling herself and Helen into the circus to make money is how one must go about keeping a roof over one’s head and food on the table. The world of work was harsh for women around 1900s. It got better a century later but still holds its limitations and glass ceilings. Add in disability and there goes the ability to work full-time, traditional jobs. Generating income as a person with disabilities requires a lot of hard work and resilience.

Teachers and parents thought the segregation into special education classrooms did the students a disservice. I disagree and posit instead that it could have been better handled so the kids were seen in their awesome rights instead of now being individually isolated in classes of 30 students. Would you rather be spending your days with 10 people who get you or 29 people who struggle to and may even be worse about it than you'd like without any skills to handle the trauma. Indeed, Lavalin put it aptly that that the "problems faced by [the parent's] children in school [are] a complex interplay of their children's impairments with the kinds of instruction they received, and with the school environment overall." (Lalvani, 2015, p. 386). Blending all the kids together allows for kids to hide until more educational assistants started working with specific kids who are then singled out for whatever disability they contend with on a daily basis.

Higher education is where I found some hope through government programs and being told wild tales of a beautiful life. Women with disabilities were half as likely to have obtained a bachelor's degree than those without. This is where I am most fortunate to have been accepted to a couple of programs, two with some financial assistance. That was thanks to the opportunity to attend as many workshops as possible. I am proud to be a part of the cohort of women with disabilities who enjoy the educational experience. Unfortunately, the academic faculty experience is not nearly as set up for people with disabilities as the academic education side of the institution. And… I did also feel like the 36% who felt like people avoided them or felt left out of school things. Thankfully, bullying in academia is fairly well dealt with, so of the ~25% who experienced bullying, it was not in my direct experience as a student. If/when these students with disabilities make it through university with these accommodations, they then enter the world of employment where the entire disability landscape changes once again.

Influencing histories[10]

Weaving together stories, one by one
Tales of history, experiences, successes, failures
Giving insight to worlds that once were
Influencing the person that now is

Here, I talk about the people involved in the lives of those with disabilities. There have been studies surrounding the role of interveners that I found on my travels that I found quite interesting. Interveners are doctors, special educators, parents, grandparents, other family, sometimes a knowledgeable friend. These interveners are often a hidden yet integral people in the village of the person with disabilities.

People with disabilities are often on our own, unintentionally, in our families and surrounded by other people who do not understand is due to communication and sensory barriers. This barrier is frustration for everyone on all sides. Thereby, there is a lot of abandonment or, the opposite, over protection out of fear. At the end of the day though, we people with disabilities must find our own ways that work for us. I believe this common social isolation experience is why often times this population become depressed and their health declines. Anne Sullivan (Hellen Keller's teacher) is an example of this whereas she got older her gusty attitude diminished along with her eyesight, which she kept hidden form the public eye.

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[10] Sunday, July 28, 2013, Thought Sketches (personal journal)

Ideally, interveners are able to develop shared symbols of understanding and meanings through the interaction and exchange of information (Lloyd et al., 2015), especially with children with complex health needs. Even though a doctor may not actively follow some children with disabilities once a sense no longer requires medical attention (i.e. the child is blind or deaf), every child with disabilities will need a doctor at one point in their life. I believe that fostering progress and developing positive coherence starts at the doctor's office by supporting information resilience and self-culture.

We also have a further divide of interveners with health offerings in the public and private sphere, which if communication is rare within each one of those spheres, it is even more rare for communication between the spheres. I am grateful that most of my appointments have been through the provincial healthcare system that extended its services to cover appointments and care in Halifax, with the IWK. Until recently, my primary ophthalmologist has been in Halifax where he has recently retired. Just now, June 2021, my files will be in New Brunswick for the first time ever. A person with multiple disabilities has multiple interveners that rarely coordinate.

Doctors

Today, doctors play a much larger role with citizens with overarching public health mandates. Thus, they have many opportunities to share information, teach, communicate, and accept people with impairments to work together to overcome disability barriers. Doctors need to be able to talk openly about how impairments affect quality of life while being respectful and knowing that person with disabilities wishes to be included in society (Goering, 2015). Campbell (2009) offers up the attitudes and self-assessed skill levels doctors express in understanding disabilities reveals "a coherent and gloomy picture" (p. 223).

Campbell argues that disability education for doctors must involve personal and clinical contact with people with impairments would have a positive effect on knowledge, attitudes, and self-awareness of medical students. Examples of training includes “disability awareness courses” (Minihan et al, 2011) and cultural training. The trouble with cultural training is not in understanding what barriers exist, but in understanding how a person accesses information based on their available senses and in positively influencing the availability of resources and support.

Therapists

The truth of it is that despite “like” wanting alike therapists, there is a barrier. Helen Keller was fortunate to have a teacher who experienced disability herself in a way. In a study by Cawthorn et al. (2017), they found in the literature that approximately 70% of deaf respondents preferred having a deaf or hard of hearing therapist. However, that is just as rare as finding a disability coordinator with disabilities of their own.

Family

I had my family and school to help develop my interactions skills. In literature, mentors and advocates are highly touted as being success factors. However, I also firmly believe that a person must be responsible for their own destiny and be their own advocate. I believe that advocacy can be learned in a way that bridges the gaps to neurotypicals.

Government

The Government of Canada has provided programs that were accessible to the few and lucky. If a program existed, the government required a mountain of paperwork that even paperwork wizards even balk at. So, unless you met the right person, you were on your own. This creates resilient beings because it becomes up to one person to gather it all up in hopes that their application is strong enough for another human being to say yes. That’s where support and navigation networks of today are of benefit. It is really thanks to the government for financing this type of work as support and education work was traditionally women's work and therefore largely went underpaid. It was wise of the government to provide funding so money could be aligned with value to have the helpers available to provide accommodations.

ECONOMICS

Figuring misconceptions[11]

Look at the numbers
Hang your head low in shame
Where did I go so wrong?
How can I come above again?

Look at the numbers
Think back to the past
All those misspent days
How can I come above again?

Youth and beauty and fun
All misconceptions that end
Sooner or later
You are faced with the fates

Youth and beauty and fun
Something I possess more

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[11] Friday, March 2, 2012, Thought Sketches (personal journal)

Only because I realize it
Not so much fun when you know

Something happens over the years
Responsabilities increase
Get better jobs, obtain more stuff
But the bottom line stays the same

Something happens over the years
You grow up and realize the misspent youth
You grow up and realize the misconceptions
You grow up and realize all these nothings

You sigh, you move on, and figure shit out

In this section, I reflect on the expense of disability in the lens of health insurance barriers that I have noted and come across over the years. Disability is expensive and seems to be largely misunderstood in terms of how a person manages to afford it all. I give you a hint: governments only help so much, and parents can only do so much. I do not go much into what happens when the bill cannot be covered, because that gets a little dire straits. So, I am keeping this section more informational than derogatory. Now, I will list my impairments for newcomers and as a refresher: prosthetic right eye, moderate-severe hearing loss, migraines, a mild s-curve to my spine, hip bursitis, GERD, IBS, depression, fibromyalgia, and complex post-traumatic stress disorder. There are no cures for any of these - only quality of life treatments and accommodations. This list will further expand over the years. For example, a couple years ago I added burnout to another aspect to heal. Healing is painful and expensive. Here is a list of what I should account for in my budget:

Migraines
- Magnesium
- Advil
- Specialized Glasses

Chronic Pain
- Medical Marijuana (MMJ)
- Hot water bottles and steam showers

Fibromyalgia
- Naturopathic therapies (i.e. acupuncture)
- Massage Therapy
- Prescriptions
- Yoga & other group exercises

IBS and GERD
- Ginger supplements

Depression & Complex Post-Traumatic Stress Disorder
- Counselling (i.e. EMDR therapy)

Spinal curvature
- Physiotherapy
- Chiropractor

Autism
- Sensory friendly clothing, tools, and lighting

Eye Care
- Eye Care Solution Kit
- Eye Drops
- Prosthetic Eye replacement & semi-annual cleanings

Hearing
- Hearing Devices (hearing aids, fm system, etc)
- Batteries

Insurance on personal appendages in case of loss or theft

If I actually got the treatments I need, it would be easily $1200 a month, plus dietary expenses. That is not affordable or possible for most people on disability do not even make that in a month. I have to consider all of the items as listed by disability, frequency of how often I usually have to purchase the item, total cost each time I have to purchase, how many months it takes me to accumulate that sum based on frequency, and then figure out how much it costs be per month. The average coverage is based on knowledge of most insurance company coverages, if you are lucky enough to have any, as most part time jobs do not come with any coverage. This is another area where it is no wonder that social assistance is a common route given that they at least have some coverage for most of these items. Or you can be a lucky one with an employer who connects with the right agencies. How else do you have your prostethic eye covered to the tune of nearly $2800? Luck! Do your research, do the math, and build the right team for your own health and wellbeing.

In middle and upper classes, there is a bias of health because of a lovely thing called medical insurance coverage. It often covers allied health up to 80% of appointments (usually up to a maximum of $1200–$1800), hearing aids $300–$500, usually only the first prosthetic at only 60%-80%, some orthotics and additional items. The Canadian Revenue Agency allows a person to claim the medical coverage cost and out of pocket expenses for items above and beyond. For both the CRA and private insurers, I advise you to pay attention as some require doctor’s notes and others don’t — its about as bad as figuring out which referrals require a doctor’s send off and which ones you can self-refer for insurance coverage. Also, many places that have coverage assume having some time off for such appointments. However… not all jobs have this kind of coverage if any at all. Not everyone has the ability to attend appointments due transportation, childcare and time. Only a fraction of working population hold full-time, benefit entitled jobs. So what happens to the rest of the people? It is out of pocket or paid by the government through a series of lucky loopholes. Either way, it is up to you, the patient, to advocate and attend the appointments.

Managing health with disabilities is often a full time, expense-ridden job unto itself. Keeping doctor's appointments and necessary medications is expensive and requires the ability to travel. I am fortunate to have my driver's license (requires both side mirrors). Anne Sullivan relied on public transport, employer paid transport, and mailing letters for getting around. She lived mostly in cities where basic need were more accessible. Whether in 1900 or 2000, how a person goes about taking care of themselves has not really change. The medical technology and assistive devices have evolved. In theory, this evolution has allowed more people with disabilities to enter education and the workforce. There are still great lengths to go to find the balance between working and managing one's health. Then add in other responsibilities like parenting.

PARENTHOOD

Little love, little smiles[12]

I look at you and smile
My heart swells with joy
You are so precious to me
You are loved forever and always

It was meant to be, you and I
Nothing in this world can tell me otherwise
You are a shining light in my heart
I break free from my cage and sing

I never knew my heart so raw and happy

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[12] Sunday, September 6, 2015, Thought Sketches (personal journal)

Wouldn't change anything for the world
You're my one and only
You are my child and love of my life

I sing to you every night and day
You hear me talking with you
I fill us with healing energy regularly
The possibilities are endless

Sweet dreams are ours to believe
Every night I wish you peace and kindness
Every morning I wake to see you smile
Every day I grow with you as you do

Night night, little boy
Night night, little love
Night night, little Reid
Sweet dreams, little dreamer

I believe that family plays an important role – whether they are absent or unable to communicate, a person with impairments needs someone who can teach them how to acquire information as they need information to progress in society. People with disabilities are often on our own, in families and surrounded by other people who do not understand is, become frustrated with communicating with us. Thereby, there is a lot of abandonment or, the opposite, over protection out of fear. Some children with disabilities are lucky and their parents support them best they can without taking on another damaging identity of the "woe is me" parent of a diverse child.

Neither Anne, Helen nor my Uncle were biological parents. I suppose this is where I add to the story of disability as an adult:

parenthood. To cope with parenting with disability, I wrote a little booklet called “Everyday Magic with Kids” that I sell on “The unLibrarian” website of mine. I have learned to be aware of when my disabilities are hampering my ability communicate with him, so I react kindly. I teach respect in ways that should be taught anyway like going to the room the person you wish to speak with instead of calling out from another room. I also show him my hearing devices and explain what they do, which has been easier my son gets older and more curious. He is a part of a new generation of kids who will be growing up normalizing disability without being ableist but rather by being kind and patient while affirming his own boundaries. That said, Anne did raise her brother mostly after her mother had passed to later watch him die at the almshouse. She certainly held a devotion to Helen’s learning before eventually retiring. Helen had parents who went to the lengths of the moon to help their daughter be able to thrive as they had heard other deafblind girls had found the opportunities at the specialized schools.

As a parent with disabilities, I am finding myself of being in a unique position of befriending parents of children with disabilities where I am asked honest questions. These parents are often quite grateful. As much as I *love* our health system, many professionals have not any disabilities themselves and yet become known as experts in the field that parents rely on for their children. Audiologists may not really recognize the benefits of being able to hear yourself, for example. Meanwhile I can do a 30 second to demonstrate the difference and how hearing aids help with unilateral hearing loss. Unless an audiologist has that lived experience, they would be none the wiser. My lived experiences matter and can help others live more fulfilled lives. It is beautiful.

It is still remarkable to me that of the figures with disability that I have included in this manuscript that I am the only one to be a full-time parent. I found that the “aunt” or “uncle” roles to be more prevalent in the literature. Adding parenthood to my plate required a lot of sacrifices which included working fulltime, thus nearly cancelling out my career, but thankfully I am darned stubborn. I have yet to meet other mothers with disabilities who successfully work full time and parent full time too. I sure they exist and are exhausted. I applaud them along with their support network. I would not change winding up as a full-time mom because I have a solid relationship with my son despite the difficulties. I am still sad because I was raised to be hard working and I was determined to be self-sufficient. That said, I know I will find another way because it has to exist, therefore I will make it exist. If neurotypicals can “crack the code” to a three- or four-day work week, then we can too!

RESILIENCE

Remember, Remember[13]

Remember, remember the history of who I am
Often forgotten out of fear or shame
The stories come to the surface to be shared
Only to realize there is of nothing to be scared
The stories of my youth, regaled with reflection
Are nothing more than youthful genuflection
That part of my story is key, I often forget
But really, it is just a result of neglect

Who I was and who I am are in fact the same
Now I am to realize how much I have to gain
These stories to be retold come out quite bold

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[13] Friday, December 16, 2016, Thought Sketches (personal journal)

New insights to remember the days of old

Now, I come to realize what has happened
I really was quite smart, compassionate and blackened
So much of me was hidden under the depression
As the years wore on, the outside became the expression

I was smart in school, volunteered and loved music
What I did was quite, for myself and others, therapeutic
I did so much more than for which I give myself credit
It is a shame I felt over the years to greatly self-edit

Memories fade away with a smile on my face
I have someone new with which to share my grace
Oddly enough, he understands it really quite well
This has given me new hope to break the old spell

Being misunderstood, hidden and confused were my norm
All of the sudden I feel understood seen and warm
Maybe that time of my life wasn't all so bad after all
I was bold, beautiful, and stood quite tall

I was also hurt, broken, bent and beaten in a cloud of pain
Only music could get through to me while the rest abstain
I knew not of another type of life I could live
The darkness I knew became my friend, to keep me alive

Oh, how many times that darkness nearly did me in
But I survived to live another day, I was allowed to begin
Each day anew it was an opportunity to change my dance

Always had to remember that music was my best chance

It was the best time that I felt alive, feeling the earth's pulse
Even though I surrounded myself in a haze in impulse
It kept me going and made me feel a part of something more
I really did need what it gave me to believe what is in store

In a world where I believed dreams could come true
I lived my life fully, even started each day anew
Along the way I forgot of how to live with my heart
It was my way out after my mind protecting from the start

Somehow my emotional being became disconnected
I was wrong; it has simply been neglected
When the world falls down around your ears
It is easy to revert back to old fears

Spirit and heart bright, my body and mind took flight
Only I didn't see it through the haze, especially at first light
My comfort zones were at night, hidden by the shadows
They absorbed my whole self in the foggy meadows

Come out into the sun, my child-self, to the warmth
Use your compass to find your due north
That little voice inside guides you along in trust
It's okay to know that some things do turn to dust

The girl you once were was very true but lost
She is you and you are her, it's time to cross

Remember, remember the truth of what was
Everything always happens, not just because

Let into the light the inside of who I was then
Take what I know and begin again
It all starts anew today, tomorrow and the next
I already have all the ingredients to be my best

Resilience is a common discussion that can actually increase ableist type treatment. For example, a common conception in the early 1990s is that children are naturally resilient and therefore unaffected by (medical) trauma and therefore grow up to be well adjusted adults. This idea has caused a great deal of harm. We are resilient but there is a price; the ferryman always exacts his price.

As per Sullivan, we can advance society by continuing our search for knowledge throughout life. So, how does one search for their knowledge - by being resilient. I ask, "what does it take to be resilient?". sensory and Parker (2016) said that, "…resiliency is supported and preserved, by having access to community resources such as telecommunication…" (p. 371). Resilience is shown when the need for adaptation rises. Protective factors (environmental) influence the need for resiliency. In reality. protective factors only exist in stressful environments.

A healthy social structure accounts for concerns such as resilience which includes assuring that the structure operates well under stress to be able to adapt and recover from a failure or disaster state (Windle, 2011). The ability to make sense of circumstances results in feeling more grounded in one's environment. The flipside of that is the necessity to feel relatively safe in one's environment. Manageability comes through in the confidence that one has in accessing resources and support. One must also imagine a desirable outcome to encourage meaningfulness. One must be able to pursue their needs even if their environment is unknown, unsafe, or unsupportive. In essence, the ability to understand circumstances makes a person feel more grounded in their environment, manageability is the confidence one has in accessing resources and support, and they must be able to imagine a desirable outcome to encourage meaningfulness. Those who experience a strong sense of coherence or independence will actively seek our resources to "overcome" their situation. This resilient type of human is also one who will hunt down every last human to make sure all the "i"s are dotted and "t"'s are crossed to get to where they need to be and the devices they need to get there. It is not handed to them by any stretch of the imagination — it is every bit earned.

An important step to resilience is figuring out how to communicate with the world. Often times, that requires learning Languages for Specific Purposes. Sometimes a person with disabilities has an advocate to help them communicate their needs while others are on their own to self-advocate with hope the message gets across properly. Interacting with other members of society is necessary to become engaged in communities of practice, to collectively assign value to phenomenon, and generate common symbolic knowledge.

Skills, such as resilience learnt by Anne Sullivan, were hard won through life experience until she saw an opportunity to learn skills that would give her tangible value in society: become a teacher for the blind. The school was unique in that it found girls suffering from the same conditions to be taught then trained to teach others who could pay for them as governesses, as special education teachers of that era. When she started to work with Helen Keller, the first skill she had to establish was even more foundational to achieve communication: trust or curiosity. It started with a teddy bear for Anne to become familiar to a girl who had been completely deaf and blind since 18 months old and had gone feral. The Kellers were at a loss of what to do with their little girl until Alexander Graham Bell suggested education. I find it remarkable that education was used as the treatment for a medical condition. Which brings me to question whether disability is a medical or an education issue? Either way, they were fortunate to have education as an option. I consider that the skills that Helen Keller went on to learn and embrace is simply amazing. She became a prominent disability advocate who contributed to significant constructive changes in government policy.

In my opinion though, when there is a language barrier especially, building external relationships complicates resilience. It is also human nature to satisfice and obtain enough information to make a decision quickly without considering options, often colliding with the Principle of Least Effort. This is human nature. People with disabilities must overcome that tendency regularly as more sensory information is often necessary to interact and to make decisions. Ultimately, we all want to make sense of the world and it takes more effort, energy for people with disabilities: more resilience than most. I share with you three steps that are repeated constantly along the way to build resilience:

Step 1: Gather information about the new normal
Step 2: Assume this is the new normal to work within
Step 3: Find constructive ways to work the new normal within your reality

This resilient type of human is also one who will hunt down every last human to make sure all the i’s are dotted, and t’s are crossed to get to where they need to be and the devices they need to get there. It is not handed to them by any stretch of the imagination — it is every bit earned. A culture of ones own is developed: a self-culture.

Story of a girl[14]

There was once a little girl who wanted to love the world so much that it hurt. She looked it from sideways, upside down, head on, and any other way she could imagine. She looked and looked for it everywhere. She even looked for it in books. She would read and read and read, trying to find that feeling of comfort and love. You see, what she did find in the world scared her. She couldn't understand what was happening nor the feelings she had. The world was a very confusing place; one she couldn't quite grasp. So, she lived through her books and imagination. Anything creative that came up, she would embrace with gusto. Make jewellery: bracelets, necklaces, rings, and earrings. She would get crafting gifts and embrace them with glee at the possibilities. One of her favourite things to do was watch her Mom create whatever out of nothing. This gave the little girl comfort knowing that she could do the same. They shared in those moments what they couldn't through words.

That little girl was me. How a person with disabilities views and accepts their own history of disability influences their self-culture too. I believe one solid way to ensure resilience is to have a strong self-culture. All the literature point to needing a supportive framework and culture is one of the biggest driving forces of community. So, what if you were a community of one and therefore your culture doesn’t connect with other people. Being able to find commonalities between cultures is a foundation of communication. Self-culture is a concept inspired by Anne

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[14] December 22, 2016, Thought Sketches (personal journal)

Sullivan's speech. Anne Sullivan learned how to be resilient, develop her own self-culture, and was her own greatest advocate. Anne persevered, kept her keen senses open to opportunities, and developed an understanding of societal and institutional structures. She sought out information at great lengths, relentlessly seeking a way out of the Almshouse by furthering her education. It is amazing how one day she saw an opportunity, and took it, to talk directly to Sanborn, the General State Inspector of Charities to plea for the chance to further her education. Thus, she found herself enrolled at the Perkins Institution in 1880 where she developed her literacy and communication skills. A century later, her legacy lives on because of her actions, her gumption.

I talk about self-culture as a mechanism for fitting in to balance when you do not actually fit in with other people. Some people like myself are not deaf, not blind, not disabled enough yet just disabled enough to be an outsider. So, one has to generate their own self-culture to feel welcome in society. Often times, the self-culture has many traits similar to sub-cultures. Self-culture is a term I discovered in Anne Sullivan's valedictorian speech that I am constantly exploring.

I am publishing this book in hopes that today's youth with disabilities will create their own self-culture to have solid resilience in this too-often harsh world while being supported by their village. I hope that they will grow up to flourish in life without the isolation and vulnerability experienced by many people who have disabilities, chronic health conditions, face the development of mental issues due to disabilities and so much more. A better quality of life for all, really. I believe it is those who experience a strong sense of self-culture will actively seek out supports to overcome their situation. However, there are systematic failures in information infrastructures and training for those with disability. Overcoming these barriers demonstrates resilience. One must be able to access information infrastructures to create their own self-culture.

Children with sensory disabilities develop self-culture through information resilience, physical literacy, and financial sufficiency. I believe that self-culture is a protection factor to overall resilience and overcoming vulnerable situations. Self-culture becomes a protection factor to overall resilience in overcoming vulnerable situations. I believe that having a solid self-culture enhances one’s assertiveness and comfort of being in their own skin. Online special interest groups assist with this but oftentimes, a person is missing another physically present human being to feel less alone in the world. I mean, no way Anne would have achieved what she did with Helen online: it had to involve physical touch. A nice thing that I have found over the years that there are way more out there of people who are like you than you think, though geographically spread out like dandelions in concrete jungles. Society has a lot of influence, but subcultures exist for a reason and are perfectly socially acceptable (as long as ye harm none).

A great way to promote self-culture is through the use of poetry and writing. It is also a common therapy for many people with disabilities, as you have read throughout this manuscript. Everyone finds their outlets, ways to cope, ways to adapt. Alone is often preferred because it means less commentaries, less judgement. The best opposite experience would to be fully trusted in that they know what they are doing. Commentaries disrupt that trust because they imply that the person with disabilities is wrong. Take the commentaries as simple signals of the speakers’ own internal bias, opinion, and insecurities. I am here to tell you ignore them: your creative outlets are beautiful and every bit worthwhile.

Self-culture is joining dance troupes that are perfectly fine with your awkward motor skills and plays music you can feel. It is losing yourself in books because the world makes little sense and learning skills and mores that way. It is believing that you need to water the garden once a week to keep the garden fairies happy. Bring in magic and never let anyone ever snuff out that magic. Every day magic is my way and it brings out the best every time.

DEFINING OF SUCCESS

Life obstructed[15]

Standing at the precipice, wondering
Deciding what to do from here
My heart simply starts fluttering
It lays open staring at fear
Nothing changes unless I want it to

The walls have been well constructed
Mazes without maps are rampant within
The view within well obstructed
The shadow inside sits there with a grin
It laughs at the efforts while I cry helpless

Wanting something different and something more
It starts with taking a step forward to change
The mourning is finally done furthermore
The sentiment shouldn't feel strange
Lessons of life only make me stronger

My chest burns with pride

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[15] Monday, December 2, 2013, Thought Sketches (personal journal)

My lips quirk up in a smirk
It's my time to ride
Gotta make it work
Only have one life to live and it's mine

What makes for a good quality of life? How does a person define success? Is it in the skills they have? Their education? Their parenting? Their career? I am sure there are aspects that I have not even covered in this book that others can think of right away. The truth is that success is highly subjective. How my mom defines my success is likely different than how I define my own success. Some successes are societally measured almost as common knowledge. It seems that what counts as a success for a person with disabilities could be something way simple and normal for a neurotypical person. We are in a world where for some, getting out of bed in the morning is considered a victory. We are also in a world where you cannot give up. I say this as a person who often required at least two solid attempts to achieve my goals: library school admission, several jobs, publications, and so much more. In my opinion, is true that a person with disabilities must work much harder to get what they want. Achieving goals and dreams despite many attempts and efforts is success. People with disabilities can be successful: it takes an incredible amount of determination regardless of support and barriers present. Anne Sullivan also proved how much a person with disabilities can succeed in life and teach others to do so. Despite all the history and the barriers, we find ways to live and even thrive. Successful people with disabilities often embrace stoicism without even realising.

CONCLUDING THOUGHTS

Leap of Faith[16]

Consider, consider, consider this
The world designed in your mind is your own
Beliefs tested, some tried and some untrue
Break them down for what they are and see
The truth lies underneath as truth knows truth
Black and white, "fuck yes" or no, all or none
Inside there's an everlasting knowing that tells all
Norms, standards, expectations changes it again
Strip them all away, Strip them down to the truth
Truth is both and neither negative or positive
You have to acknowledge the ugly to live the magical
Ignoring realities that does not help lead to truth
It's a leap of faith to take that holds such beauty
Step forward and remove the chains, heal from all that has been
Move forward from here as I am, as I will be
Split in half, quartered and drawn, I am awake
Take the best of what I know and make it better
The magic exists and is out there for me to grab
Lived too long in lives based on text books and nothing
Always remember how the wind feels on my face, freedom
Lead me no more, I am the wanderer who has learned to drive
Live with my heart and soul in all that I physically do and think

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[16] Sunday, December 25, 2016, Thought Sketches (personal journal)

Play reverse and catch up to get fully ahead in the moment
All those memories, pieces and more is my best bet
Piece by piece it all breaks own into something much bigger
Live in that beautiful, magical world full of love and wonder
Remember, acknowledge and empathise with all the ugly
I make the choice now to be able to choose which one I want
Take that leap of faith and keep it going, it will work
I will always make life work no matter what
That leap of faith of living positively and fully once again
I take a deep breath

As a person with disabilities, I see Sullivan's story as an important and telling narrative of how a person with impairments can overcome disability (resilience) while also being a productive member of society by teaching a person with multiple impairments through information sharing and teaching (literacy). These kinds of personal histories are important to understand but also know that health problems are often hidden and invisible. So, only few examples are readily available in history and presently. Granted, more people are speaking up since the shutdowns, so there is a change happening; an evolution, I think. People have individual experiences that add up to impact an entire society.

There is a history of disability too that needs to be better understood. Disability has been around from the beginning of timed and each society has handled in it in their own ways. Over history, the communication gap is narrowing thanks to technological innovations. Communication technology is more of a life necessity than luxury item. Assistive devices are becoming more intelligent and accessible. However, where there is a digital divide, people with disabilities risk being marginalized the most due to affordability and usability. We have gone from writing letters with hard to find paper and pen to typing emails on expensive computers that require certain senses to access without modifications. We have evolved as a whole society.

The Government of Canada started out the 2000s well with their broadband programs but, in my humble opinion, they cut them much too soon. Schools help even the playing field but only so much and only until 2-3pm, whereas a CAP site would be open until 7pm or later some evenings. Recently, when kids were unable to go to school, governments had a harsh wakeup call on the reality of the digital divide when they surveyed availability and found a lack of use of computers in households. Governments have also done things like abolishing the long form survey that gave policy makers much needed information to best support the Canadian population, as a whole. Now, it takes more independent, expensive surveys to avoid making shots in the dark that people have less time, income and energy to participate in fully. Each political party in charge of policies have their own take on the involvement of people with disabilities in education, employment and health. Thus, there is often a lack of longitudinal continuity and regular implementation of new hoops and barriers. This is frustrating for researchers, policy makers, and most importantly, people experiencing disability.

To be visibly gaining education, employment, income, and to be a parent with disability are all newly studied landscapes in the identities of people with disabilities. As long as there is a will, there is most definitely a way. It takes actively seeking out a better life in order to have the best hope of achieving a good quality of life. To paraphrase Anne Sullivan’s words - the search for knowledge must be continued to prevent a shriveling of the mind. Her philosophy included every man (and woman) of holding the responsibility to contribute to the advancement of society through one's own self-culture. One develops their own self-culture through sheer grit, curiousity and resilience. Even though I face disabilities due to my impairments and chronic pain, my objective is to always be a functional member of society. I have worked so damn hard to craft and thrive only to have been pushed back by visible and invisible barriers. Statistics Canada's surveys on disability proved to me the barriers are real just as much as they are perceived. Really though, I am as neurodiverse as I am an interdisciplinarian. I can weave all my worlds together beautifully, as can you.

The stigma of disability is evolving thanks to many individual and collective efforts, historically to present day, and I continuously meet folks who are are working today for better futures for everyone's tomorrow. Parents of children with disabilities feel the impact of the label just as much as a person with disabilities but in such different ways that often hampers independence; and that is changing. The stigma is maintained yet is changed through literacy dialogues, where real life experiences are brought into clinical consideration. I believe that proper disability literacy for health professionals, parents and those experiencing disability alike goes a long way because it creates a supportive network that is better protected from the stigma of disability. It is not just the folks with disabilities that ought to improve their disability literacy. If others know how to speak of us, then it is easier to interact with us, respectfully. The truth is that even the way doctors perceive and treat disability can make or break an experience (and the person).

So, whether or not a person with disabilities encounters support, they must be resilient in order to thrive. The key to being resilient even independently though is by having one's own self-culture that is constructively nurtured. This means special interests are greeted with a smile, no to mention that stims and odd expressions are joyously embraced. Being embraced in our how we are as a person with disabilities is way more important than being pressured into fitting in with neurotypical behaviours. I believe our neurotypical peers are capable of accepting us as we are as long as they do not insist their own behaviours and interpretations of the world being ours as well. It is okay if your Communities of Practice are small subculture type groups. There you can find your values aligned. With that understood value, stigma is reduced and the labels of disability are absolute validated and accepted as key element of your own self-culture.

It must be recognized that often times, an assistive device is just as helpful to a neurotypical but is considered a luxury item. Those luxury items such as iPads, teeth, eyes, supplements, hearings aids are our necessities. One day Universal Design will allow society to have communication infrastructure that caters to those with disabilities and therefore by proxy makes everyone’s life better. Listen carefully, for we have much to share about our world that will help everyone not just have a better-quality life but a better quality of society where people with disabilities are naturally accommodated. We can help out each other to create a beautifully accepting world. Welcome to the disability revolution.

Valedictorian Address[17]

Today we are standing face to face with the great problem of life.

We have spent years in the endeavor to acquire the moral and intellectual discipline, by which we are enabled to distinguish truth from falsehood, receive higher and broader views of duty, and apply general principles to the diversified details of life. And now we are going out into the busy world, to take our share in life's burdens, and do our little to make that world better, wiser and happier.

We shall be most likely to succeed in this, if we obey the great law of our being. God has placed us here to grow, to expand, to progress. To a certain extent our growth is unconscious. We receive impressions and arrive at conclusions without any effort on our part; but we also have the power of controlling the course of our lives. We can educate ourselves; we can, by thought and perseverance, develop all the powers and capacities entrusted to us, and build for ourselves true and noble characters. Because we can, we must. It is a duty we owe to ourselves, to our country and to God.

All the wondrous physical, intellectual and moral endowments, with which man is blessed, will, by inevitable law, become useless, unless he uses and

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[17] Sulllivan, Anne M. (1886 June 1). Perkins School for the Blind, https://www.perkins.org/valedictory-address/

improves them. The muscles must be used, or they become unserviceable. The memory, understanding and judgment must be used, or they become feeble and inactive. If a love for truth and beauty and goodness is not cultivated, the mind loses the strength which comes from truth, the refinement which comes from beauty, and the happiness which comes from goodness.

Self-culture is a benefit, not only to the individual, but also to mankind. Every man who improves himself is aiding the progress of society, and every one who stands still, holds it back. The advancement of society always has its commencement in the individual soul. It is by battling with the circumstances, temptations and failures of the world, that the individual reaches his highest possibilities.

The search for knowledge, begun in school, must be continued through life in order to give symmetrical self-culture.

For the abundant opportunities which have been afforded to us for broad self-improvement we are deeply grateful.

We thank His Excellency, the Governor, and the legislature of Massachusetts, and the governors and legislatures of the several New England states, for the most generous and efficient aid they have given our school.

We thank our trustees for the zeal and invariable interest which they have shown in all that concerns our well-being.

Directors, teachers and matrons: we enter life's battlefield determined to prove our gratitude to you, by lives devoted to duty, true in thought and deed to the noble principles you have taught us.

Schoolmates: though the dear happy years we have spent together are over, yet the ties of friendship, and an enduring love and reverence for our school, and the sacred memory of her whom God has called from her labor of love to be an unseen but constant inspiration to us through life, are bonds of union that time and a and absence will only strengthen.

Fellow-graduates: duty bids us go forth into active life. Let us go cheerfully, hopefully, and earnestly, and set ourselves to find our especial part. When we have found it, willingly and faithfully perform it; for every obstacle we overcome, every success we achieve tends to bring man closer to God and make life more as he would have it.

Miss Anne M. Sullivan

POSTSCRIPT: MANUSCRIPT WRITING METHODOLOGY

This writing was originally intended to be a doctoral project. The way I write and present myself was too relaxed for academia and yet too comprehensive for book publishers. Yet, I needed to share this manuscript with the world. Even though this story has become a book, I believe in process transparency, so I present to you the thoughts and reasoning behind the structure of this book. Who knows, maybe someone else can replicate it to see if it works and how it could be improved!

History has a lot of information to share through historical comparative research (H-C research). I first learn about H-C research in Neuman (2003), who described it is about learning the past to understand the present to inform the future by focusing on culture while also looking through the reconstructed eyes of particular groups or individuals. Historical Comparative Research has its purpose set on learning the past to understand the present to inform the future by focusing on culture while also looking through the reconstructed eyes of particular groups. Neuman (2003) compared social processes and concepts in different historical and cultural contexts. Evidence in H-C research is often reconstructed fragments and incomplete evidence, sees causes as influenced by conditions, and allows movement between "concrete specifics in a context and across contexts for more abstract comparisons" (p. 409). It is a contextual based style of researcher that compares old with new and different world views. Although a subject is approached as a whole, the layers are observed to see the surface appearances as well as the hidden structures and unseen mechanisms or causal processes (Neumam, 2003, p. 411).

Historical Comparative Research (HC-research) is useful to compare social processes and concepts from different historical and cultural contexts (Neuman, 2003). Using HC-research, concepts will be reconstructed in reference to achieving potential in the lives of the deaf/blind and the role of ICT. Here are three examples of the trifecta of resources that I used for my analysis: a historical account of Anne Sullivan and Helen Keller, my own personal experiences as a deaf/blind individual, and a demographics report of deaf/blind in Canada (Watters, Owens & Munroe, 2004). In this case:

> The first is a historical account that delves into the narratives that surrounded Anne Sullivan and her pupil, Helen Keller. Data included the researcher's personal narrative as one perspective and the story of Anne Sullivan and Helen Keller (around the 1900s) as presented in the book, "Beyond the Miracle Worker" and historical accounts.
>
> The second narrative is the researcher's perspective of the role of ICT in achieving potential as a deaf/blind individual. The demographics and services report that was prepared for the Canadian National Society of the Deaf-Blind, in which they report the findings from focus groups and individual interviews with the deaf/blind population. Other reports were also included along such as those from Statistics Canada.

When engaging in Historical Comparative research, quantitative data can supplement qualitative data. Also, the researcher's perspective is an integral part of the research process. The beauty of historical comparative research is in the blend of qualitative and quantitative information. This information does not have to be complete either; it is common with historical records to only access fragments and incomplete evidence. In this research, even the absence and the way existing evidence has been treated tells a story. Specific information found in the historical realm is compared against greater context and vice versa. It is a living process that has no true end or beginning, rather it is seen as a whole in hopes to identify hidden structures, unseen mechanisms and causal processes. It is useful in comparing social processes and concepts in different historical or cultural contexts (Neuman, 2003). That said, Neuman (2003), offered a guideline of steps. I do not see them so much as steps but as a list of the necessary processes needed in order to complete a proper historical comparative research project:

1. Conceptualizing the object of inquiry
    a. Who, what, when, where, why, and why is this important?
2. Locating Evidence
    a. Books, libraries, manuscripts, articles, narratives
3. Evaluating Quality of Evidence
    a. Providence
4. Organizing Evidence
    a. Identify themes and structure
5. Synthesizing
    a. Compare and contrast the themes and structures
6. Writing a Report

The Narrative Analysis coding that led to the section “Reflections on Disability” compared statistical data, historical narratives, and personal experiences in the realms of education, employment, quality of life, and communication. Given the type of literature, I felt it perfectly reasonable to include all literature with participant details from which to analyze data. However, I really struggled with deciding to focus on a particular group of people with disabilities and age ranges.

When it comes to identifying a particular group, as person with disabilities, I feel negligent and ignorant to assume that one group holds differing or even similar experiences to another. The librarian in me says that it is impossible to restrict by age because I truly believe anyone can learn new skills at any age to progress in their lives. Steinberg (2000) (as cited in Young et al., 2008) argued that “deafness serves as exceptional model for the study of adaptation and resilience, particularly in relation to the emergence of a sense of self” as they must rely on internal resources. Often times, information is difficult to establish and learning through language is less accessible (Young et al, 2008).

I decided to use the concept “people with disabilities” purposely broad in this book. Also, in following with Neuman, it was absolutely necessary to highlight my own biases and lived experience as a person with disabilities. Yes, I experience intense chronic pain and other maladies, but I decided to highlight the deafblind population as distinct subgroup. I started life partially blind and hearing loss was later discovered. Anne Sullivan has vision impairments and Helen Keller was fully deafblind at 18 months old. The deafblind population are great examples of how populations with comorbidities can thrive: comorbidities increase the chances of lower quality of life. The way the body and mind adapt to disability is incredible and there is always a way to adapt.

In theory, the data from this analysis will generate concepts to use in future empirical research. I hope that this opens the doors to gaining a better understanding of individuals who are deaf and/or blind interact with information and communication technology to achieve their maximum potential. In conjunction with the narratives is statistical data gathered from Canadian government organisations.

As a final contribution of how HC Research provides illustrations to best understand the evolution of a concept, here is a historical comparison table to visually demonstrate the changes over time and help identify what has remained the same:

Table: Historical comparison of education, employment, supports, information and communication technology, and funding.

	~1900s	**~2000s**
Education	Private special education schools State institutions	Informal education through mentor figures in life APSEA Public Education System Undergraduate Education Graduate Education
Employment	Publications Circus Fundraising	Restricted opportunities presented Regularly employed, even as a student University / Employer health insurance
Supports	Select Special Schools Philanthropy and Charity Letter writing and advocacy Books	Books Social isolation Mentorship Trial and error Schools transitioned to inclusive education Internet
ICT	Beginning of telegrams and telephones	Grew up through development of first basic computers
Funding	Philanthropists & Charity Agencies	Government & arms-length agencies - Federal monies - Provincial policies

Thank you very much for taking the time to read this manuscript. It has been many years in the making and I sincerely hope it opens up dialogue and generates greater understanding of disability in society. I hope it helps others experiencing disability embraces their identity through the various mechanisms, especially through self-culture.

Thank you,
Amanda “Rose” Horsman
The unLibrarian

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