Accessibility's Impact on the Information Literacy of the Deaf Community

by

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Submitted in partial fulfilment of the requirements
for the degree of Masters of Library and Information Studies

at

Dalhousie University
Halifax, Nova Scotia
April 2020

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Abstract

This Master's thesis explores access and accessibility and how they impact information literacy in the (d)eaf community. Information literacy is the ability to locate, evaluate, and effectively use the information the individual needs. Using Narrative Inquiry, participants from the Nova Scotia (d)eaf Community were interviewed about access, accessibility, and information literacy. Participants were asked to reflect on how they typically look for, use, and understand information throughout their daily, professional, and educational lives —as well as what role technology plays in those processes. Contrasts in the epistemological understanding of access and accessibility between the (d)eaf Community and the hearing world are highlighted. The results of this study give us a clearer picture of the current information literacy skills of the Nova Scotia (d)eaf Community, along with presenting overarching themes of mental health, accessibility, education, privacy, and the role of the (d)eaf community in information literacy development and practice.

List of Abbreviations Used

ADA: Americans with Disabilities Act

ASL: American Sign Language

ACRL: Association of College and Research Libraries

APSEA: Atlantic Provinces Special Education Authority

CAD: Canadian Association of the (D)eaf

CART: Communication Access Real-time Translation

CI: Cochlear Implant

CODA: Children of (D)eaf Adults

CP: Community of Practice

CRPD: Convention on the Rights of Persons with Disabilities

EMTs: Emergency Medical Technicians

FM System: Frequency Modulation System

HoH: Hard of Hearing

KM: Knowledge Management

RID: Registry of Interpreters for the (D)eaf

RIT: Rochester Institute of Technology

UN: United Nations

VRS: Video Relay Service

Glossary

Access: "*1) Approach or enter (a place) 2) Obtain, examine, or retrieve."* (Lexico, n.d.a) This is the common definition, but in the context of Information Management access involves: "[accessing] the desired information in an effective and efficient way; and assess[ing] information and information sources in a critical way and assimilate[ing] the selected information into his knowledge and values system" (Landøy, Popa, & Repanovici, 2020, p. 28). However, the information management definition is not very accurate because it does not clarify the difference between access and accessibility for me. To me, access does not include the ability to easily or even partially understand the information. For example, if the data you retrieved is in a language you are not completely fluent in, that means the information is not considered accessible to you, but you still can "access" the information.

Accessibility: A colloquial definition of accessibility is the following: "The quality of being easily reached, entered, or used by people who have a disability" (Lexico, n.d.b). When considering accessibility in the context of the (d)eaf community it is important to understand that (d)eaf individuals are not disabled but rather communicate in a different language. As such, accessibility is better understood in this context as: The actions of being easily understood, used as intended, and reached through digital and physical contexts. This also follows the information management perspective of accessibility, which suggests the: "Use the information for accomplishing a specific task, individually or within a group" (Landøy A., Popa D., & Repanovici A, 2020, p. 28).

Audism: "Audism occurs in all levels of government and society in the form of direct, indirect, and/or systemic discrimination and discriminatory behaviour or prejudice against (D)eaf people" (Canadian Association of the Deaf, 2019a para.1.)

Children of (D)eaf Adults (CODA): Hearing children born to (D)eaf adults are known as CODA.

Community of Practice (CP): "Communities of practice are formed by people who engage in a process of collective learning in a shared domain of human endeavour" (Wenger-Trayner & Wenger-Trayner, 2015).

(D)eaf: "A sociological term referring to those individuals who are medically (d)eaf or hard of hearing who identify with and participate in the culture, society, and language of (D)eaf people, which is based on Sign language. Their preferred mode of communication is Sign language" (Canadian Association of (D)eaf, n.d.). The capital 'D' identifies the sociological and cultural aspect of the (D)eaf community.

(d)eaf: "Lacking the power of hearing or having impaired hearing" (Lexico, n.d.c). The inclusion of the word 'power' implies that hearing is a *power*. That suggests that hearing people are more powerful than (d)eaf people. Unfortunately, history has shown that hearing people have oppressed (d)eaf people in multiple forms—education, cultural genocide, and social norms. To respond to this problematic aspect, I propose the following definition for (d)eaf: the medical definition of different levels of hearing loss in individuals. This distinguishes (d)eaf from (D)eaf in a more modest way without the negative label of lacking power or impairment. The inclusion of the colloquial definition of (d)eaf is included to highlight the differences in view between hearing and (d)eaf communities.

(D)eaf Community: "The (d)eaf community comprises those (d)eaf and hard of hearing individuals who share a common language, common experiences and values, and a common way of interacting with each other, and with hearing people" (Ladd, 2003, p. 41). When I refer to the (D)eaf community, I am only referring to the (d)eaf people who are culturally (D)eaf, but when I refer (d)eaf community, I am referring to all of the members of the (d)eaf community.

(D)eaf Culture: "Perpetuation of (D)eaf culture through a variety of traditions, including films, folklore, literature, athletics, poetry, celebrations, clubs, organizations, theatres, and school reunions. (D)eaf culture also includes some of its own "music" and poetry as well as dance." (Clerc Centre, 2019)

(D)eaf Standard Time (DST): "(D)eaf Standard Time (DST) refers to the cultural norms of (D)eaf people in regard to time usage: extended goodbyes, early arrival to certain events / late arrival to other events, length of time spent interacting, etc." (Vicars, 2018)

Hard of Hearing: "A person whose hearing loss ranges from mild to profound and whose usual means of communication is speech. It is both a medical and a sociological term" (Canadian Association of the (D)eaf, 2015, para.6.).

Information Literacy: "Information literacy is the set of integrated abilities encompassing the reflective discovery of information, the understanding of how information is produced and valued, and the use of information in creating new knowledge and participating ethically in communities of learning" (Association of College & Research Libraries, 2016).

Knowledge Management (KM): Knowledge management is the process of capturing, distributing, and effectively using knowledge (Grover & Davenport, 2001)

Oralism: "Oralism refers to the educational philosophy for the (d)eaf that insisted on the use of the oral method. The oral method, in its purest form, rejected any use of gestures, fingerspelling, or sign language in favour of teaching (d)eaf students' speech and lip reading" (Murgel, 2015).

Surdophobia: Phobia of (d)eaf people. "The hostility, intolerance or fear against (D)eaf people, (d)eaf culture and the (D)eaf Community. That includes resistance towards the sign languages used. It can consist of a range of negative attitudes towards Deafhood, the idea of (d)eaf-positive and (d)eaf rights. Definitions refer variably to antipathy, contempt, prejudice, aversion, and irrational fear. Surdophobia is observable in critical and hostile behaviour such as discrimination and violence on the basis of a perceived non-(d)eaf behaviours" (Shropshire (D)eaf and Hard of Hearing Forum, 2015).

Acknowledgements

I want to express my most sincere thanks and gratitude for the following people: Dr Sandra Toze, Jennifer Grek Martin, and Dr Teresa Burke Blankmeyer. Their dedication and willingness to help and teach me has helped me throughout the progress of thesis writing.

I am also very grateful for the participants who participated in my research. In essence, this would not have been possible without them. Thank you, and I also want to thank the Nova Scotia Deaf community for everything I learned from them growing up.

I also want to express my gratitude toward my fellow thesis students who had to encourage and cheer me on during the thesis progress.

I also want to thank the School of Information Management, as my graduate program for being a great teacher in it’s embody; including all of the professors who had taught me. I appreciate all of the anecdotes of knowledge and wisdom throughout the three years at the School of Information Management.

I also want to give my family sincere gratitude for supporting me so much throughout the last three years with love and encouragement.

Chapter One: Introduction

Introduction 1.0

In the following thesis I ask: What is the difference between access and accessibility for the (d)eaf community? How does it affect information literacy skill levels? Are the current accessibility technologies satisfactory for the (d)eaf Community? Or do technologies such as interpreters and Communication Access Real-time Translation (CART) require improvements to better facilitate access and accessibility? Technology is an important aspect to consider because it affects the (d)eaf individual and how they access information —including in an education context. Access, in turn, influences the information literacy skills of the (d)eaf individual. These questions are explored through the qualitative methodology of narrative inquiry, which involved interviews with five members of the Nova Scotia (d)eaf community. The interview questions allowed me to gather information about their experiences with information seeking in their educational and personal lives and information on their development of information literacy. The ultimate goal of the current research is to provide greater understanding of the barriers and issues facing the (d)eaf community regarding information literacy skills.

You are probably wondering: What is the (d)eaf community? What does (D)eaf culture mean? Why is this important? I will give you context on the historical, education, and general information about the (d)eaf community. Currently, there are no official statistics on the (D)eaf/(d)eaf community because there are two different types of deafness: 1) (D)eaf, meaning the individuals who identify as culturally (D)eaf; and 2) (d)eaf, meaning the individuals who identify that they have a type of medical hearing loss. This distinction is somewhat confusing because it is incredibly broad and does not include other identities such as hard of hearing (HoH) or child of (d)eaf adults (CODA) (see Keywords for definitions). For the sake of my research, I will continue to use (d)eaf for the general (d)eaf population who are either hard of hearing or who do not culturally identified themselves as (D)eaf on an individual basis. When I use (d)eaf with the word 'community,' I am taking into account every member of the community, including the (D)eaf members. The word (D)eaf will be used in conjunction with the words 'individual,' 'community,' and 'culture' depending on if I am only discussing the culturally identified (D)eaf individual and community.

The last official count for the Canadian (d)eaf community, completed by Statistics Canada, titled Health and Activities Limitations Survey (HALS), was in 1991 (Statistics Canada, 1991). The results of the survey show that one in 25 Canadians have some type of hearing loss. The total comes to slightly over a million people. However, that survey was done in 1991, meaning the data is nearly 20 years out of date. The Canadian Association of the Deaf (CAD) claims that there are no official statistics for Canada, but estimate numbers based on the assumption that Canada has 1/10th the population of the United States of America (USA) (2019b). Their estimate suggests that there may be around 350,000 Canadian culturally (D)eaf people and over three million Canadian people with hearing loss (Canadian Association of Deaf, 2019b). Taking the estimated numbers into consideration, it can be understood that the three million people with hearing loss make up the Canadian (d)eaf community. When considering the narrower population of the Canadian *culturally (D)eaf population* the numbers are significantly smaller. For instance, 6.2 million Canadians identified as a visible minority in the 2011 census (Statistics Canada, 2018). Culturally (D)eaf people do not identify as visible minority as there is nothing visible about being (D)eaf. Based on the current population of Canada, which is 37,589,262 million (Statistics Canada, 2019), the percentage of Canadian culturally (D)eaf people is likely less than one percent (0.9%) of the entire population. This number is based on the mathematical calculations of CAD’s suggestion that there are only an estimated 350,000 culturally (D)eaf Canadians (Canadian Association of (D)eaf, 2019). If you include (d)eaf people who do not identify as culturally (D)eaf, the number increases to 8%. The small percentage of (D)eaf people in Canada communicate using American sign language (ASL), Indigenous sign language (ISL), and Quebec sign language (LSQ). The differences in their way of communicating, along with the small population size, could make a case for considering (D)eaf individuals as part of a linguistic minority.

Considering the (D)eaf community as, arguably, a linguistic cultural minority makes the topic of accessibility to information very relevant. Accessibility encourages us to ask: How do we ensure that the (d)eaf community has access to mainstream society? The (d)eaf community is different from other linguistic minorities —like Gaelic speakers— because we use a different mode of communication. We use signing, while mainstream society uses spoken words to communicate. Both use written communication as well. For signed communication, we use our hands, arms, body positions, and face to communicate in a complex language that vocal language cannot express. To communicate with the broader hearing society, we primarily use resources like closed captions, transcripts, CART, Frequency Modulation (FM) system, hearing aids, cochlear implants, and most importantly, interpreters. In the following sections, I will show you a clear image of the current meaning of “access” and “accessibility” and the potential for more specific definitions in the context of their relationship to information literacy in the (d)eaf community.

To present a clear picture of the different positions on the best methods to be used in education to develop information literacy for the (d)eaf, I will identify the different positions presented by the academic hearing and (d)eaf communities, through research articles and books written by both the hearing and (d)eaf community. As you will see in the History of the (D)eaf Community (Section 1.1), the different positions primarily rest on the sign language versus oralism argument.

History of Deaf Community 1.1

The historical context of the (d)eaf community is measured in centuries, but I will focus on the last 200 years because that is when the (d)eaf community began blossoming into the strong community that exists today in North America. This blossoming was as a result of the development of sign language and formal education. The (d)eaf community gained access to formal education through Abbé Charles-Michel de l'Épée, who created the first state-run school for the (d)eaf, the National Institute for (D)eaf-Mutes, in France in the 18th century (Murray, 2019). Prior to this, (d)eaf children were only home-schooled. The most well-known examples are the attempts by European religious orders in Spain in the 1500s to teach prominent (d)eaf heirs to Spanish families how to speak. They did this because the laws of Spain at the time would have disinherited the (d)eaf individuals based on their being mute (Shea, 2017). Several hundred years later l'Épée's school —now known as the National Institute for (D)eaf Children of Paris— had a (d)eaf teacher named Laurent Clerc in the 1800s. The rise of School for the (D)eaf in North America and the beginning of American Sign Language (ASL) began by following Clerc's decision to go to America with an educational philanthropist called Thomas Gallaudet. Together they created another school for the (D)eaf (Murray, 2019). The first university for the (D)eaf — The Columbia Institution for the Instruction of the (D)eaf and Dumb and the Blind— was founded in Washington D.C. in 1857. Later, the name changed to Gallaudet University, after its founder Thomas Gallaudet in 1894 (Gallaudet, 2019). The history of education and the (d)eaf community is further discussed in-depth in the Education of (D)eaf Community (Section 1.3).

When l'Épée first established the school for (D)eaf, various theories of education for the (d)eaf came into play. The two major theories regarding the best methods of instruction are the usage of only sign language in education and the method of oralism, which is teaching students how to speak and lip read. The tension between these theories caused in-fighting in (D)eaf education circles about which method is the best to use. The history of education in the (d)eaf community spanning the last two centuries can be loosely summarized in a few words: oralism versus sign language. Those four words are very simple but have loaded meaning, including oppression, hearing power, audism, abuse of power, and a great deal of struggle within the (d)eaf community. Samuel Heinicke was responsible for setting up an oralism school in Germany in 1778, with the goal of teaching (d)eaf students how to speak and articulate in their national language. L'Épée and Heinicke each argued for their own methods of communication and teaching by entering into a long correspondence in the 1780s. This, however, was not the end of the debate. L'Épée's argument for sign language and Heinicke's argument for oralism developed into the two major theories of (d)eaf education of the last 200 years, from the Enlightenment Age to the 21st century (Murray, 2019).

In 1880, the Milan Conference — officially known as the Second International Congress on Education of the (D)eaf — worsened the in-fighting. During the conference several resolutions were passed, one of which banned sign language in education. Deaf teachers with the exception of one, were not invited to the conference, therefore, the conerence was not reflecting the education of the Deaf community proportionally. Banning sign language caused an increase in oralism in (D)eaf schools and a suppression of sign language, both of which had lasting effects on education for (d)eaf individuals (Johnson, Liddell, & Erting 1989). The largest problem with the oralists of the last two centuries is the belief that sign language is inferior to spoken languages and is not a real language. This belief had the potential to cause people to look at the (d)eaf community as inferior and dumb over time. This view turns up in many old names for schools for the (D)eaf, for example, 'School for the (D)eaf and Mute' or 'Dumb and Mute' were common official and unofficial names. 'Dumb' has two meanings: speechless or mute, or stupid and dazed (Online Etymology Dictionary, n.d.), both of which are demeaning to the (d)eaf community.

These beliefs continued until the late 1900s when one of the most important events for the (D)eaf community occurred: the establishing of American Sign Language (ASL) as its own language. In the 1960s, a Gallaudet professor called William Stokoe completed linguistic research that established ASL as its own language and changed the view of ASL by the (d)eaf and hearing communities (Stokoe, 2001). It can be argued that this is when the linguistic aspect of the (D)eaf community was beginning to be formally recognized by the general population. Stokoe's work proved that the sign languages the (d)eaf community used are actual languages, not gibberish. Since language is one of the main requirements for a culture to be considered valid, this work was especially important. Once Stokoe's work showed proof that American sign language is an actual language, it started the ball rolling to show that the (D)eaf community is a part of a linguistic minority distinct from the general disabled population. The work done by Stoke was furthered by Padden and Humphries (1988) whose book *(D)eaf in America: Voices from a Culture*, shared anecdotes, tales, experiences, every-day life, and stories that came directly from (D)eaf people. Their work along with Stokoe's paved the road to better recognition of (D)eaf culture and language by mainstream society.

Education of Deaf Community 1.2

> "In response to new parents of a (d)eaf infant who ask you if you felt cheated by your deafness, you say no, but the oral education you received cheated you."
>
> (Holcomb, Holcomb, & Holcomb, 1994, p.15)

I am an insider in the (d)eaf community who is one of the 10-20% who have beyond grade 4-9 reading level skill (Hrastinski & Wilbur, 2016). Though I have a higher reading level, I ask: How can the (d)eaf community access and understand information if the information is presented in languages other than sign language? Information literacy is when an individual has the ability to locate, evaluate, and effectively use the information the individual needed (American Library Association, 2007). To unravel the problem of how the (d)eaf community, with an average fourth grade reading level, can be information literate, issues of access and accessibility and the different needs of the (d)eaf community need to be examined and understood. First, the most probable reason the general (d)eaf community's reading level is at grade four is because sign language and the written version of the spoken language used in mainstream society are different languages. They have completely different syntax, grammar, usage, and expressions. This distinction has serious consequences on how education works for the (d)eaf student. In this thesis, I will primarily discuss American Sign Language (ASL), since it is the predominant sign language in North America. Most people have a misconception that ASL is based on English. This is not the case, but that misconception affects how teachers perceive (d)eaf children. Liddell (2003) argued that the misconception could affect how teachers teach, including the help they provide and their expectations of (d)eaf children in learning how to read English.

The (d)eaf community nowadays has two main options for their educational needs: mainstream or (D)eaf schools. Mainstream is the practice of sending (d)eaf individuals to their local hearing schools, either with interpreters and/or assistive technologies. (D)eaf schools include (D)eaf and (d)eaf students and teachers who only communicate in sign language while teaching, and where students learn the national written language. However, some existing oral (d)eaf schools only teach the spoken and written national language. The three choices, mainstream, (d)eaf schools with exclusively sign language, and (d)eaf schools with spoken language, have not always been available. Prior to the set-up of mainstream institutions and classes, fewer choices existed for (d)eaf individuals, for example, home schooling or boarding at the school for the (D)eaf. Some of the participants in this research lived through some of this more recent history.

As mentioned in the previous section, the Milan Conference of September, 1880, gathered a large group of hearing teachers of the (D)eaf. Though, at least one (d)eaf teacher, James Denison, participated in the conference (Gallaudet, 1910, p. 281). The underlying goal of the oralist hearing teachers was to ensure that the (d)eaf teachers, or teachers who supported the signer method, were unable to change the votes (Gallaudet, E. 1881). The hearing teachers of the (D)eaf, known as Oralists and who taught students to speak and lip read, passed a resolution banning the usage of sign language in education for the (D)eaf. In total, eight resolutions were passed at the conference, but this one was the most serious (Gallaudet, 1881). Gallaudet (1881) discussed the conference thoroughly and claimed that the participants in the conference wanted the focus in schools for the (D)eaf to be on oralism. It was thought to be important that the (d)eaf students could pass for hearing people in society. The reason this occurred was that the Pereire Society, who organized the Milan Conference, were strong supporters of oralism (Gallaudet, 1881). They ensured that the outcome of banning sign language happened by carefully selecting who was invited and encouraging negative reactions to those who supported sign language at the conference. According to Gallaudet:

> We believe that the sober second thought of many, even, who were carried away by the enthusiasm of the hour at Milan and were led to vote for impracticable and even impossible things, will deter them from attempting manifest absurdities. (1881, p.16)

Gallaudet discussed how the majority of the conference were members of the Pereire Society, and Oralists in general. With insufficient proportional representation from sign language supporters, the eight resolutions were passed. Gallaudet included quotes from several members of the conference, which were intriguing and disturbing for me to read. The accounts of the conference included how members of the Pereire Society derided and heckled the supporters for the sign language method. Pereire Society also tried their hardest to ensure that oralism measures passed rather than sign language measures. To me, it means they saw (d)eaf people as lesser, and the only way they become ‘better’ is to learn how to speak. Gallaudet also pointed out the shortcomings of the eight resolutions based on several factors. For instance, the Oralists claimed that the (d)eaf can learn how to lip read and speak without any sign language. Gallaudet (1881) argued that claim is impossible because some of the Oralists contradicted themselves by mentioning that some of their (d)eaf students learn how to lip read via sign language or gestures.

Over the centuries after the Milan Conference, oralism gathered momentum and was at its strongest in the 1900s. All secondary schools supposedly had to follow the Milan Accord at this time, even if it was not a binding resolution in terms of law or policy. However, sign language still grew in secret. Due to Edward M. Gallaudet's efforts after attending and protesting the conference, Gallaudet University and other schools in the United States were resistant to this resolution and continued to teach (d)eaf students sign language. However, Canadian schools for the (D)eaf followed the Milan Conference's resolutions. People told stories of abuse and attempts to stop (d)eaf children and teenagers from using sign language in public or in education settings. Fast-forward to the mid-late 1900s in Nova Scotia. There was a single (D)eaf School in Amherst, which previously was the Halifax School for the (D)eaf and Dumb that moved to Amherst in 1960 (Atlantic Provinces Special Education Authority, 2019). The Amherst School for the (D)eaf focused on oralism because of the following reasons well known in the (d)eaf community: the resolution from 1880 had not been removed, there was no proven research on sign language's impacts on education, and the thought that sign language was not a real language. Based on the viewpoint that (d)eaf people are inferior to hearing people, oralism was determined to 'save' (d)eaf people and rehabilitate them to pass as hearing people. This view is well known in the (d)eaf community.

In the 1980s, increasing research showed that oralism was not a superior method and that it lead to questions of the influence of accessibility on the (d)eaf community's educational pursuits. Johnson, Liddell, and Erting (1989) wrote an important text, *Unlocking the curriculum,* discussing how to create a better model for the education of (d)eaf children after evidence had shown that (d)eaf children and teenagers are constantly falling behind their hearing peers. They suggested that the results of their research "represent a failure of the system that is responsible for educating (d)eaf children" (p.1). They argued that the reasons for their falling behind stem from the failure to ensure that (d)eaf children acquire their natural language (in the form of ASL) early on. They describe the education system in the late 1980s as not giving enough support or education to the (d)eaf children based on the fact that the linguistic nature of the curricular content is inaccessible to (d)eaf children (Johnson, Liddell, & Erting, 1989). It was clear to see in their research that when (d)eaf children came to kindergarten, if they did not have the benefit of using their natural language (ASL), they would nearly always be very behind in their language development in comparison to other hearing peers.

This informs my viewpoint of the oralism vs. sign language discussion, which is influenced by the fact that I myself am also a (D)eaf individual. I am aware that growing up using sign language has enabled me to become successful in my academic career. However, usage of sign language is not the single factor that caused my success. To reflect my point of view, oralism and sign language will be discussed in-depth within the Literature Review and in the Discussion and Findings (Chapter Four), particularly how both methods reflect the meaning of access and accessibility. However, it is important to keep in mind that the concepts of accessibility and access have both positive and negative viewpoints for the (d)eaf community. Positive viewpoints include keywords such as: success, understanding, learning, and knowledge. Negative viewpoints include terms such as unsuccessful, not understood, not learning, violence of human rights, abuse, power, and oppression.

The Literature Review places my argument in a contemporary context by presenting articles from the academic community that describe the different educational experiences and norms for (d)eaf individuals in the (D)eaf community. Following the Literature Review, I identified common themes based on the information provided by five (d)eaf research participants through a content analysis of their interviews, with the goal of understanding what has influenced their information literacy skills. The common themes included: mental health, privacy, the difference between access and accessibility for each participant, and methods of education.

The (D)eaf community has a deeply rooted cultural way of life, which is exhibited by the relatively strong empathic feelings that are pervasive throughout the community. My personal experience has shown that the connection can be described as similar to what one would see in close clans, in groups under the same banner, or in teams. The (D)eaf community uses a different mode of communication, otherwise known as sign language, which is a far more physical language than vocal languages. Because of these differences in communication the (D)eaf community's members become isolated from the 'hearing world.' The technology boom, however, has affected the (d)eaf community positively and significantly throughout the last 50 years. Technology such as text messaging, emails, video phones, computers, and others have enhanced the (d)eaf community's experience in and with the hearing world.

For my data collection, I am using the method of narrative inquiry to gather life stories of five (d)eaf participants located in Nova Scotia. The Methodology chapter includes a short review of the literature about narrative inquiry methodology. The results of the research are discussed in the Results and Discussion chapter. Here, I present overall themes identified from the participants' data and include summarized transcripts based on my coding, which occurred using a seven-phase process (as described in section 4.3 and 3.6.2 respectively). The goal of this research is to provide a clear picture of how language deprivation, accessibility versus access, mental health, and isolation affects the participants' lives and how their information literacy skills have grown throughout their lives.

The benefit of this research is to increase knowledge of the epistemology of the current (D)eaf community and the methods of gathering knowledge of (D)eaf community practices. Epistemology is commonly known as philosophical theories of knowledge, however, in my thesis, epistemology is seen through Holcomb's (2010) framework, with a (d)eaf-centric approach. (D)eaf epistemology is the 'standard' of knowledge used by the (D)eaf community and some of the (d)eaf community. Knowledge in the (D)eaf community is gathered through the actions of listening to or gathering testimonies, experiences, and stories by other (d)eaf people. This form of knowledge gathering is very close to the narrative inquiry method I used to interview the participants in my research.

Additionally, my research could potentially increase awareness of accessibility of information and how to gain information literacy within the (d)eaf community when they exist in a world that mostly shares information only in a tongue 'non-native' to the (d)eaf community. With this research, I hope to provide a better idea of the current state of accessibility in the topics of technology, communication, and education. Along with that, I hope to provide recommendations regarding better technologies or media to support the development of information literacy within the (d)eaf community. The next section will introduce the general history and education contexts of the (d)eaf community, which will give an idea of the current climate of the (d)eaf community, and how it has been affected by the history and education decisions that occurred in the past.

Chapter Two: Literature Review

Introduction 2.0

Current research on the topic of information literacy in the (D)eaf community is scarce. The lack of research may be caused by the dominance of the two main types of teaching methods being used in (d)eaf children's secondary education: oralism and sign language. A primary focus of this thesis is to establish possible ways to develop information literacy skills in the (d)eaf community. Along with that, it is my responsibility to raise awareness of (D)eaf culture and community in my research because I am a (D)eaf person myself. In my role as researcher and as a (D)eaf person, my goal is to show the reader the (D)eaf community and to respect and challenge the oppression that (d)eaf people have experienced with researchers.

In the following Literature Review, I will introduce you to various aspects of the (d)eaf community by sharing information about the (D)eaf community and culture's norms and typicality. These aspects are well known in the (d)eaf community but may not be familiar to the hearing community, whether academic or non-academic. Norms are similar to unwritten rules while typicality refers to what is considered normal in situations, culture, and language. Typicality is something that happens when you become immersed in the culture and learn what is considered normal in said culture (Davidson, 2017). Similar to other minority cultures and communities, the (d)eaf community is not often discussed by mainstream society. I examine this in the section entitled Epistemology of (D)eaf Culture followed by the Cultural lens of the (d)eaf community.

More research is being done on different topics, such as mainstream education and the (d)eaf community, the history of the (d)eaf community, amplification technology (cochlear implants, hearing aids), and oralism versus sign language education. This research has been increasing thanks to the work conducted at Gallaudet University and is being published through several journals related to the (D)eaf community, e.g., *(D)eaf Studies Journal*, *American Annuals for the (D)eaf*, and *Journal of (D)eaf Studies and Education*. Additionally, the hearing medical profession is increasing research in the benefits of hearing aids.

To find out how members of the (D)eaf community typically gather, understand, and distribute information, I scanned the current literature on the topic of (D)eaf community and Education. I selected research based on the following criteria: topics of the publication included knowledge of the (d)eaf community; secondary education of the (d)eaf community; and applicability toward the best types of education for (d)eaf children and adults. Additional criteria included publication dates within the last 20 years.

Epistemology of Deaf Culture 2.1

"Deaf individuals are said to be approximately 15 to 26% of the world population, with severe or profound deafness prior to acquiring language effects an estimated 7 per 10,000 individuals" (Agrawal, Platz, & Niparko, 2008; Bubbico, Rosano, & Spagnolo, 2007; Fellinger, Holzinger, & Pollard, 2012; Mitchell, 2005)" (VanOrmer, Rossetti, & Zlomke, 2019, pg. 179). Since the epistemology of (d)eaf culture is to provide knowledge via the members of the community through stories, how (d)eaf children learn about their culture is influenced by learning from their community. When (d)eaf children are able to learn from materials created within the (D)eaf community, they interact with an expression of "a cultural, not a pathological, view of (D)eaf people" (Von Bitter & Turley, 2016, p.82).

If the members of a marginalized culture or community lack access to their culture materials, it negatively affects their future access even if there are increased resources. Currently, (D)eaf children lack full access to education, relevant information, the sign language of their country, and access to digital resources. Therefore children —from early childhood to teen years— have insufficient support to help them achieve success in society (Pfister, 2017; Bat-Chava, 1994; Johnson, Liddell, & Erting, 1989). Factors that influence success in education include family support, accessibility resources, language deprivation, isolation, and mental health resources (De Freitas, Guimaraes, Antunes, Garcia, Lopes, & Fernandes, 2012; Holcomb, 2010; Moroe, 2019; McGlew, 2013).

Cultural Lens vs Disabled Lens and Deaf Community 2.2

> Together, these personally interpreted experiences, along with the visually oriented linguistic and social culture of the (D)eaf community, come to make up a (D)eaf Worldview—an epistemology of (D)eaf people and their culture—which is then interpreted by others to be the lens through which they view the (D)eaf World.
> (Miller, 2010, p. 484)

Miller (2010) looked into the views of people in the (d)eaf community, including hearing children of (d)eaf adults and (d)eaf children of hearing parents. In a similar way, I strive to look at my research and data through a cultural lens to reflect the (d)eaf community's worldview. Historically, communities that share linguistic and social culture support the development of a strong understanding of others in the same culture. Czubek and Greenwald's (2005) research further supports the development and application of a cultural lens in their work examining J.K. Rowling's *Harry Potter* book series. Their work provides insight into the nature of the (D)eaf community that gave rise to the strong and beautiful culture currently existing today. Czubek and Greenwald's approach influences my application of a '(D)eaf lens' to the current thesis.

> As with every sociological field of study, (D)eaf Studies intends to further our understanding of the human condition. Using a "(D)eaf Lens," we can gain greater insight into social arrangements in the same way that fields like Women's Studies and Black Studies have brought gender and race issues to a level of awareness we never imagined years ago. (Czubek & Greenwald, 2005, p. 442)

(D)eaf perspectives provide researchers the chance to look at the (d)eaf community and individuals from the viewpoint of how being (D)eaf make them the person and community they are today. Czubek and Greenwald devised a template they called the (D)eaf Lens and it changed how they view the *Harry Potter* series because the parallels between the *Harry Potter* storyline and the (d)eaf experience are very similar. Choosing to examine the (D)eaf community with a cultural (D)eaf Lens is appropriate to explore the (d)eaf community because they are a linguistic minority culture. In contrast, when the hearing community has looked at the (d)eaf community with a disability lens, the (d)eaf community has experienced oppression. The lens of the disabled implies that the (d)eaf community is not able-bodied enough for mainstream society and this lens denies the culture and language of the (d)eaf community. Using a disability lens is oppressive and not effective for research with the (D)eaf community. Therefore, a cultural lens is the best way for me as a researcher and a (D)eaf individual to look at my data and coding analysis.

DEAF EPISTEMOLOGY 2.2.1

Epistemology is a way of knowledge gathering. Different communities or groups often have ways of knowing that are specific to their own experiences. Holcomb (2010) concluded that the standards of epistemology within the (d)eaf population are considerably different than those for the general hearing population. In the hearing population, the standard of knowledge that appears to be prevalent comes from the scientific method, which is defined by hard evidence and systematic process, such as hypothesis, observations, and proven theories. However, in the (d)eaf community, knowledge is gained and shared through personal testimonies, experience, and accounts (Holcomb, 2010). I am using Holcomb's framework to describe the "standard of knowledge" in the (d)eaf community because it is both applicable toward the narrative inquiry method, which is used in this research, and the common way of trading information and knowledge I have experienced in the (d)eaf community. Holcomb's approach to (d)eaf epistemology refers broadly to a (d)eaf person's view of theories of knowledge rather than a specific area of knowledge.

The discipline of philosophy has shown that epistemological approaches are often in conflict with each other, even amongst individuals who share the same general epistemological approaches but differ in the interpretation of specific theories. For example, (d)eaf schools have only recently begun to subscribe to the epistemological values of personal stories and testimonies of the (d)eaf community, instead of the general hearing-centric epistemology standard of the scientific method.

Holcomb comments that "the data on graduates of a school whose policies have been shaped by (D)eaf epistemology are showing that these students are performing at a higher level than their (d)eaf peers elsewhere" (2010). This statement suggests that the hearing-centric approach to educating (d)eaf children is not better than the (d)eaf-centric approach. The epistemological standard of the hearing population presents significant barriers to the (d)eaf community and could be a primary reason for the poor standards and success rates of education for (d)eaf children. (D)eaf children are shown to learn better with sign language and visual learning, but that approach is not widely taken for all (d)eaf children. Instead, the standard mainstream education is often used with the (d)eaf children despite the evidence to the contrary (Johnson, Liddell, & Erting, 1989). The hearing-centric approach does not allow full accessibility for (d)eaf individuals as it suggests that hearing is normal and (d)eaf is not.

DEAF-CENTRIC APPROACH 2.2.2

Hearing people construct the social environment to reflect their specifications, not to (d)eaf people's specifications. For example, using audio announcements instead of captioned announcements at airports demonstrates the emphasis on hearing. Learning about how these hearing-centric environments and experiences impact (d)eaf individuals can be done by taking a (d)eaf-centric approach. The (d)eaf-centric approach can be shaped by knowledge sharing from (d)eaf individuals through personal testimonies, experiences, and accounts of (d)eaf individuals. Anecdotes from the (D)eaf community written in *(D)eaf Culture: Our way* by Holcomb, Holcomb, and Holcomb (1994) show this in a relatable way and it remains a valid approach to this day.

> You pull up to a self-service gas station. You proceed to pump gas in your car, unaware that the cashier had asked you over the loudspeaker to wait. You wonder why you get a dirty look when you approach the window.
>
> (Holcomb, Holcomb, & Holcomb, 1994, p. 31)

These types of experiences are so common for (d)eaf individuals, who often encounter severe derision from hearing individuals just because they cannot hear what was said. This is also why (d)eaf people seek out other (d)eaf individuals who they can relate to; especially if information accessibility is an issue in a particular situation. (D)eaf individuals are able to offer each other sound advice, further help, and additional resources.

KNOWLEDGE MANAGEMENT AND COMMUNITIES OF PRACTICE 2.2.3

Considering a (d)eaf-centric approach, which considers the cultural and linguistic perspective of (d)eaf individuals, I ask: How does knowledge management work for the (D)eaf community? Are there particular ways the (D)eaf community manages and organizes knowledge? The research conducted by De Freitas, Cuimaraes, Antunes, Garcia, Lopes, and Fernandes (2012) analysed how knowledge management (KM) influences community of practice (CP) and knowledge creation in the (d)eaf community. KM refers to how to distribute, retrieve, and process knowledge, and provide access to the public consumers. Community of practice, as defined by De Freitas et al., is the process of people gathering around a certain subject or topic they are interested in (2012). For example, vlogging about make-up by a (d)eaf make-up artist attracts other (d)eaf individuals to gather around that subject. CP has always been an important method of gathering knowledge for the (d)eaf community.

Web-based CP has the benefit of being a virtual network, which allows for frequent interactions without the need to meeting in-person in order to pass on knowledge. In their qualitative study, De Freitas et al., observed the interactions within a Brazilian (d)eaf community on the web platform of LIBRAS (Brazilian Sign Language). The results from their observations concluded that CP is an important learning tool and it also provides insight into potential problems of the web-based platform.

The research provided insights to the community's need for the identification of their members, additional computer tools for the application of the (d)eaf community's CP, and the standardization of sign language for the Brazilian (d)eaf community. These insights are also applicable to other (D)eaf communities. For example, the United States' (d)eaf community may be more advanced in respect to their technological development regarding the usage of technology, but that does not mean all members are as advanced in additional computer tools such as coding. The virtual community is one of the best resources the (d)eaf community has to perform CP.

DEAF TEACHING 2.2.4

A survey conducted by Marlatt (2004) compared the practical knowledge storage of (D)eaf and hearing teachers of students who are (D)eaf or hard of hearing (HoH). Marlatt (2004) surveyed a limited population of students or alumni from the graduate and professional teaching program in Gallaudet University, Washington, DC. The purpose of the survey was to find out if there are differences between (d)eaf and hearing teachers. The results of the study showed a marked difference between the teachers in their custodianship of the classroom, practical knowledge, and how they manage the classroom (Marlatt, 2004). They conducted the Survey of Practical Knowledge (SPK) on three separated groups: graduating education students, experienced teachers, and students at the beginning of their education. Marlatt showed that (d)eaf teachers scored higher on custodianship of the classroom and practical knowledge. Custodianship is essentially the caretaker or keeper of the classroom which includes (d)eaf children. Marlatt (2004) suggests that the reason for the higher score may be because of the (d)eaf teachers' feeling social pressure to ensure that they remain a role model for the students. I agree with their comments because the (d)eaf community is small and isolated: where if even one role model—such as a (d)eaf teacher— fails, it is significant. In light of this study, knowledge management for the (d)eaf community can be influenced heavily by (d)eaf teachers.

Knowledge management is similar to custodianship in the sense of taking care of information and keeping it organized in particular ways. In a classroom scenario, the (d)eaf children are fonts of information that the teachers have to take care of, but the teachers must also make sure the children are learning the information they need and want to learn. Knowledge management with children needs to be organic because children's brains cannot be managed like MS Excel spreadsheets. In conjunction with community of practice, the children see the teacher as a foundation of knowledge and if the teachers enact their roles responsibly, they will be able to influence the children to see everyone around them as foundations of knowledge as well.

Subcultures of Deaf Community 2.3

To create a more in-depth picture of the members of the community that may benefit from a (d)eaf-centric approach, I want to explain more about the subcultures of the (d)eaf communities including the Hard of Hearing (HoH), and the (D)eaf. If we have a better understanding of all members of the community, it may result in more resources offered to (d)eaf children, which would increase their information literacy skills.

In addition to the main subcultures in the (d)eaf community, as mentioned above, there are less well known subcultures: interpreters, DeafBlind, LGBTQ, Black (D)eaf, (d)eaf families, and children of (d)eaf adults (CODA). 90% of children of (d)eaf adults are born hearing, and, in turn, 90% of (d)eaf children are born to hearing adults (Mitchell & Karchmer, 2004). This statistic is well known to the (d)eaf community but not as much to the hearing community.

CHILDREN OF DEAF ADULTS (CODA) 2.3.1

The issues discussed in Preston's work (1995) focus on how the hearing children of (d)eaf adults view (D)eaf culture. As the children grew up, they realized that they were different from their parents simply because they can hear. According to Preston, (D)eaf parents might say to their hearing children, "*Hearing people cannot be trusted*" (Preston, 1995, p. 1463). This statement may confuse the hearing children of (D)eaf parents on a profound level. The parents may claim that their children are not like the hearing people they know, simply because they were raised in the (D)eaf culture. Yet, the hearing children born of (d)eaf parents and having grown up in the (d)eaf community are sometimes still set apart from (D)eaf children because they are hearing. In Blankmeyer Burke's chapter in *(D)eaf Gain: Raising the Stakes for Human Diversity* (2014), they argued that there must be a distinction between auditory hearing and cultural-sociological hearing, in the same way (d)eaf can be distinguished by the lower or uppercase 'd' in (d)eaf. Thus, (h)earing refers to the auditory function, while (H)earing indicates those who identify with the cultural-sociological aspect. In the CODA's case, they arguably are (h)earing (auditory) and (D)eaf (cultural and sociological) at the same time, which is a fascinating thing. This situation resonates with the term '(D)eaf Heart', which is used to describe being part of the (d)eaf community because you can empathize and understand the actual (d)eaf community. (D)eaf Heart can be shown by becoming interpreters, going to (d)eaf events, or by becoming involved in the (d)eaf community in any capacity.

From my personal observations and knowledge of the (d)eaf community, CODA struggle to be accepted as interpreters and teachers at interpreters' programs. This lack of acceptance may be because they do not hold a linguistic mastery of sign language. However, total mastery of a sign language is not expressly necessary to teach or to interpret.

Moroe's research (2019) on the psychology of the children of (d)eaf adults is intriguing because it brings up the question of how (d)eaf culture can have a strong influence on the hearing CODA who are exposed to (d)eaf culture. They may grow up feeling like they are (D)eaf at heart despite having working ears. In this case, it shows that a person does not have to be born (d)eaf or develop hearing loss as you age to be a card-carrying member of the (d)eaf community. The same is true for some interpreters who become immersed in and become important members of the (d)eaf community. However, Pearson's (1995) research presents a counter argument by showing that underlying fears of hearing and audist people are unfortunately common for (d)eaf individuals (1995). These fears have developed because the (d)eaf community has been oppressed by a hearing-centred society. Additionally, the mistrust of the hearing community can adversely impact the mental health of (D)eaf parents of hearing children.

My research focuses on a specific section of the (d)eaf community: the hard of hearing (HOH) and (d)eaf people who are fluent in American Sign Language (ASL). This criteria places children of (d)eaf adults, hearing interpreters, and (d)eaf people who do not know ASL outside the scope of my research. However, it is important to take these subcultures in account during the coding process and analysis because they may have influenced the participants' information literacy skill levels (Dreyzehner & Goldberg, 2019).

Language Deprivation and Deaf Community 2.4

In her article *Forbidden signs,* Anne E. Pfister (2017) discusses the differences between hearing babies and (d)eaf babies born into hearing families. From the moment of birth, (d)eaf children are denied access to communication in the same way their hearing family has. Children generally learn social norms, manners, and socialization with other people through listening to their family's and other people's conversations (Pfister, 2017). In most cases, (d)eaf children are denied access to that socialization because most hearing families do not learn or teach sign language to communicate with their (d)eaf child. Pfister argues that language is a necessary component to any person's life in a society or culture. Once (d)eaf children enter the world with deafness, they become a part of the (d)eaf community. However, the fullness of their access is influenced by many factors: lack of socialization, language access, and access to education. Pfister's research was conducted in Mexico and with the spoken Spanish language, however, this research can be applied more broadly to other (d)eaf children in any setting born to hearing parents. Language deprivation refers to people who are blocked from language development, including fluency, understanding, and communication skills. The concept of language deprivation stemmed from a study of hearing feral children. This study (Davis, 1940) introduced research into the effects of deprivation of human contact, socializing, and language on children and how it impacts them for the rest of their lives (Shattuck, 1980; Davis, 1940; Pines, 1981). (D)eaf children in effect have been experiencing language deprivation before it was identified as such. Pfister (2017), Hall (2017), and Mayberry, Chen, Witcher, and Klein, (2011) all found that if (d)eaf children did not receive access to sign language or learn sign language at an early age (0-2 years old), it impacted how they process and learn language later in life. Mayberry, Chen, Witcher, and Klein showed that if the children did not learn sign language early on it impacted the way their brains processed language. My thesis focuses on how language deprivation affects (d)eaf children in adulthood. Through the narrative inquiry method, I examine how the lack of sign language or lack of national spoken and written language affects their access to education and knowledge to be either *partial* or *full* accessibility.

Existing research shows that at the beginning of a (d)eaf child’s life, they automatically start out with barriers to access in comparison to hearing children — especially if they are born to hearing families where there is less access to socialization, communication, information, language, and education.

> Because of their biological need to access information visually, (d)eaf people often felt alienated from oral information and hearing-based knowledge circulating around them. In this narrative, Ana María depicts how “words” and “vocabulary,” components of spoken

> (and written) Spanish, were central to understanding in mainstream hearing environments, in this case, university settings. (Pfister, 2017, p.150)

Language socialization, speech therapy, the forbidding of sign language – both in the sense of outright blocking access to sign language or a lack of awareness of sign language – all impact on how (d)eaf children grow up and acquire language. In his book *Language of light* (2017) Shea describes that during the height of oralism education (d)eaf children were, in a sense, like monkeys, copying the teachers who were trying to teach them how to speak. The children did not understand the signifier of what they were saying. A signifier in this case means the sound of the word, where the signified refers to the meaning of the word. When children do not understand the signifier, they lack the connection or sign between the signifier (word) and the signified (concept) (Barthes, 1968). Preventing children from learning sign language deprives the children of a great deal of language socialization and natural language development, which could have further impact on information literacy.

ORALISM VERSUS SIGN LANGUAGE 2.4.1

As I briefly presented in the Introduction (Section 1.0), one of the main influences on language deprivation is the infighting about the best method to teach (d)eaf children, specifically, oralism versus sign language and how these methods affect (d)eaf children throughout history and in their education.

Education and language deprivation may be entwined, causing a dangerous precedent for (d)eaf children and adults. When language deprivation occurs, it causes changes in the brain's processing system and mental health (Mayberry, Chen, Witcher, & Klein, 2011). Glickman and Hall (2018) researched the impacts of language deprivation on the mental health of (d)eaf individuals. Mental health, which is discussed further in section 2.6 below, is connected to the chemicals in the brain, along with and individual's social and emotional experiences.

> Mental health includes our emotional, psychological, and social well-being.
> It affects how we think, feel, and act. It also helps determine how we handle
> stress relate to others and make choices. Mental health is important at every
> stage of life, from childhood and adolescence through adulthood.
> (U.S. Department of Health & Human Services, 2019, para.1)

The general findings of the research by Glickman and Hall were that language deprivation has a severe impact on the mental health of the (d)eaf individual if the individuals were unable to learn their natural language from an early age. Their mental health can be impacted by failure to gain access to their natural language or to develop a good grasp of the spoken language early enough for it to become fluent. Hall, Hall, and Caselli's (2019) research reinforced Glickman and Hall by arguing:

> Deaf epistemology, demonstrated benefits of access to sign language, and the simple fact that there is no harm in being exposed to any natural language lead us to believe that the most effective way to reduce language deprivation of DHH children is to provide them with immersive access to a natural sign language as early as possible in their development. (Hall, Hall, & Caselli, 2019, p. 389)

Language deprivation occurs when the children fail to gain *full* access to the language surrounding them from birth to five years old. The wording of *full* access leads me to think about the difference between access and accessibility. (D)eaf children may have access to the language around them by seeing people moving their mouths, seeing their body language, and seeing it occurring everywhere. But that does not mean they have been provided access to the full understanding of the language, including linguistic nuances and function. Thus, language deprivation occurs when people fail to provide children *full accessibility* to language development.

Education and Deaf Community 2.5

ENGLISH AS A SECOND LANGUAGE AFTER SIGN LANGUAGE 2.5.1

One of the issues impacting the education of (d)eaf students is that they learn differently from hearing students. The “native” language of (d)eaf students is sign language, not the typical spoken language of the community in which they were raised. I speculate that not having access to their ‘native’ language potentially impacts the literacy skills of (d)eaf students, making it lower than that of hearing students. My intuitions are supported by Johnson, Liddell, and Erting (1989). Furthermore, Napier and Kidd’s (2013) dissection of literacy in the (D)eaf community suggests that literacy levels are influenced by the fact that sign language, as opposed to English, is their preferred method of communication. Literacy levels in the (D)eaf community have influence beyond an educational setting. For example, how does the (D)eaf community deal with health care information and emergency situations, especially when they lack strong literacy skills in English and/or lack a medical interpreter due to the inattention of the general staff they are attempting to communicate with?

LEGAL ISSUES 2.5.2

In Canada, we have federal and provincial laws, policies, and bills to contend with. It is complicated because, on the federal level, they have proposed the Accessible Canada Act (ACA), waiting on Royal Assent since June 21, 2019 (Parliament of Canada, 2019). However, on the provincal level as previously mentioned, only three provinces have an accessibility act. Canada also joined the United Nations (UN) Convention on the Rights of Persons with

Disabilities in 2010. Additionally, Canada also joined the Optional Protocol to the Convention in December 2018, which allows individuals and organizations to send in a complaint to the UN if they believe their rights have been violated (Social Development Canada, 2020). Canada has passed previous laws regarding the rights of disabled people on both provincial level and federal levels in the human rights section. However, in the past twenty years, three provinces have passed accessibility laws: Ontario, Manitoba, and Nova Scotia. All other provinces and territories have human rights acts to protect their disabled populations.

In the United States, the Americans with Disabilities Act (ADA) functions on a federal level and was originally passed in 1991 with multiple amendments since that time (ADA.gov, n.d.) Looking at each of the 50 states to establish if they have accessibility laws is beyond the scope of this thesis, thus, I am only comparing Canada's laws to the US federal level. The difference between the ACA and the ADA is that the ACA is recent in comparison to ADA, and yet to be officially passed. Also, differences in wording exist and in what exactly the laws encompass. For example, the ACA also recognizes ASL, Indigenous Sign Language (ISL), and Quebec Sign Language (LSQ) as sign languages of Canada. However, this recognition is not in an official capacity, because that would require every government worker to know all three of the sign languages.

McGlew (2013) discusses two different United States legal suits brought against two different educational institutions due to discrimination of (d)eaf and hard of hearing students. In one case, the student was forced to pay over $100,000 to ensure that he would have access to a device called Communication Access Real-time Translation (CART). CART is a captioning machine with a person typing on a screen so that the student can read what the teacher says in real time. In the other case, the student was denied access to CART.

Another recent situation in general (D)eaf news shows the inaccessibility of the hearing world to (d)eaf individuals in medical contexts. In 2013, the hearing adult child of (D)eaf parents passed away in a Minnesota hospital and the parents sued the hospital for not providing a continuous interpreter. The couple was unaware of how serious the situation was with their child nor did they know that he was passing away. The couple decided to sue the hospital for neglecting to communicate with them and for violating the ADA. The situation was particularly contentious because the court hired an interpreter to act as an expert witness, who provided testimony claiming that the (d)eaf parents would not be able to understand the situation even if interpreters were provided to them. (United States Court District of Minnesota, 2017). The witness's testimony took direct aim at the (d)eaf adults' English literacy and information literacy skills. Interpreters should have been able to interpret the information in easily understandable terms for the parents and, according the ADA, it is the responsibility of the hospital to provide that assistance. The example of the child dying in the hospital shows how inaccessibility to information can cause heartbreak and tragic situations. In 2016, the Affordable Care Act added that: "Hospitals, health plans, clinics, nursing homes, physicians and other providers must offer qualified interpreters to Limited English Proficient patients" (Hunt, 2016). This amendment changed the language around how access is worded and made it beneficial to the (d)eaf community.

In Nova Scotia, a lawsuit against Halifax School for the (D)eaf and Amherst School for the (D)eaf in particular is ongoing. The defendants are the province of Nova Scotia and the Atlantic Provinces Special Education Authority (APSEA), and the lawsuit is against both Nova Scotia Schools for the (D)eaf regarding systemic negligence and breach of fiduciary duty from 1913 to 1995 (Willick, 2020). The reason I am discussing this case is because it is currently in the community that I am researching. I want to draw attention towards the discussion around the trauma experienced by (d)eaf children who attended either of these schools. This is one of the most devastating blows to the current (d)eaf adults of the Nova Scotia (d)eaf community. One of the previous students, now a representative for the lawsuit, commented: “That school destroyed my life” (Willick, 2020, para.115). This comment is echoed by many of the previous students, words like “childhood lost,” or “I’m scarred by the experiences.” The treatment of the (d)eaf children from 1913 to 1995 in these schools may be caused by ignorance: “…Deaf Canadians experience prejudice and discrimination because of their differences from the non-Deaf majority. Much of this discrimination arises from ignorance or thoughtlessness. Much of it is institutional, systemic, and/or attitudinal.” (Canadian Association of Deaf, n.d. para.2.). The belief is that (d)eaf people are lesser and do not deserve the same treatment hearing people do.

GOVERNMENT INFORMATION 2.5.3

Shaheen and Lazar (2017) discuss the messages from US federal and state governments on the standards or requirements of accessibility technology in K-12 education. Using the method of content analysis, Shaheen and Lazar examined documents regarding technological accessibility. The criteria they used to assess the documents are as follows: the document must come from one of the US states; it must include discussion or implementation of instruction technology; it must include the procurement, development, and/or maintenance of accessible technology; it must be either a state statue or a strategic plan by the state department of education; and it must be a type of common document across states (Shaheen & Lazar, 2017).

The legality of technology accessibility is different than physical accessibility. When you are building a school environment, the engineers and builders will ensure that the buildings follow the accessibility law regarding the physical environment. However, building the virtual or technology environment is stickier because of factors such as federal, provincial, and state laws, differing perspectives of federal and state government, and funding availability.

ACCESSIBILITY LEGISLATION 2.5.4

Lack of explicit direction and requirements in statutes and laws are common problems regarding accessibility technology standards. Web Content Accessibility guidelines discussed by Shaheen and Lazar (2017) identify four overarching concepts: perceivable, operable, understandable, and robust. The problem is that these concepts of accessibility are not written into law. The content analysis of the documents of state governments' messages to K-12 on policies of technology accessibility show that only 38% of the states have technology accessibility statutes. In the states that have accessibility statutes, only 47% mentioned educational standards and only 10.5% explicitly mentioned K-12. It is not known if these statutes refer to (d)eaf children specifically. Accessibility technology should be standardized, passed as law, and actively enforced. Though laws on accessibility standards exist, they are not currently being actively enforced. The lack of enforcement may be a combination of unconscious messaging of the government that accessibility is not a priority and that in turn the general population does not advocate or demand implementing the statutes.

EMERGENCY SITUATIONS 2.5.5

Accessibility in emergency situations can be a dangerous barrier when the ability to hear is vital, for example, hearing sounds of danger or communicating quickly with people. In a qualitative study, Tannenbaum-Baruchi, Feder-Budis, Adini, and Aharonson-Daniel (2014) focused on 15 (d)eaf people in Israel to see what is necessary to help (d)eaf people in emergency situations without hindering their privacy, ensuring they understand the situation, and keeping them safe. They provide a series of suggestions, including having various means of communicating with the general (d)eaf population through news channels and accounting for the different sign languages in an area. The authors also suggested text messages via cell phone in emergency situations and the use of professional interpreters whenever possible. Also, people who may have direct contact with the (d)eaf people in emergency situations should be familiar with some aspects of the culture of (d)eaf community, along with some basic sign language.

The solutions they offer are not practical in the face of an actual emergency situation and they acknowledge that. They agree that it may not be practical, but do not make an effort to discuss why. When one is in an emergency situation as a (d)eaf person, one is up against the barrier of using secondary methods to communicate. One may be scared or in shock and have to work extra hard to use these secondary methods the authors suggest.

I have personally experienced such a situation. Initially, I had to find and communicate with someone to call 911, then I had to communicate to the Emergency Medical Technicians (EMTs) by using paper and pen, as well as dealing with the trauma unit at the hospital immediately without an interpreter. Finally, the hospital assigned an interpreter to allow better and necessary communication with the medical staff. My situation was actually one of the best possible situations for a (d)eaf person. In most cases, no interpreters would be available, and using paper and pen is a frustrating and somewhat inexact exercise for both the (d)eaf and hearing person to use, so the situation may worsen. As seen in my personal example, multiple barriers to accessibility are present throughout the experience. Though the suggestions provided by the article would be helpful, it is unlikely they would benefit the (d)eaf individual in the immediate emergency situation. Through examples such as these everyday life situations I hope to show how accessibility affects a (d)eaf individual.

Mental Health and Deaf Community 2.6

Mental health is very important, and discussion surrounding the issue is increasing because people are dealing with many things like stress, anxiety, depression, and/or mental health disorders. Literature on mental health and the (d)eaf community is examined in various disciplines like behavioural psychology, while the experience of mental health is influenced by factors including age. I chose to look primarily at adult or young teen (d)eaf participants in my research, because I wanted to see if there are any similarities, differences, or parallels between the experiences with mental health throughout their lives. Leigh and Pollard's (2003) chapter on mental health in the *Oxford Handbook of (D)eaf Studies* discusses the fact that current psychological evaluations continue to be an issue because of the need for accessible language and fluency for (d)eaf clients. If (d)eaf clients are not provided accessible services, it may cause challenges in arriving at accurate diagnoses. Though it is positive that treatment approaches are focusing on respecting cultural needs, research on best practices remains insufficient. For instance, the scarcity of literature on information literacy in the (d)eaf community shows a lack of research on best practices for understanding information literacy in the (d)eaf community.

DEPRESSION AMONG DEAF YOUTH 2.6.1

Dreyzehner and Goldberg's (2019) work also discussed how depression is occurring more among (d)eaf youth in comparison to hearing youth. This increase could be influenced by the type of language used during screening. It is highly possible that the high rate of depression is due to the vulnerability of (d)eaf youths because of their increased isolation and communication barriers (Leigh & Pollard, 2003). In my experience existing in a hearing world as a (d)eaf youth is not easy; you are not quite an adult yet, so you cannot just go and see your fellow (d)eaf peers anytime you want to. (D)eaf youth may also experience increased stigma and discrimination. Dreyzehner and Goldberg (2019) conclude that additional attention, research, and resources are needed to support (d)eaf individuals and their families as early as possible to lessen the impacts of audism and surdophobia (the fear of (d)eaf people).

LANGUAGE DEPRIVATION AND MENTAL HEALTH 2.6.2

Language deprivation or delays in language acquisition may also play a role in the mental health of (d)eaf individuals. If a (d)eaf child or youth suffers from delays or deprivation associated with language, it can negatively impact various brain processes, such as working memory, inhibition, and attention (Pisoni et al., 2007). VanOrmer, Rossetti, and Zlomke's (2019) work in researching the development of behavioural difficulties in hard of hearing and (d)eaf youth also discusses the dangers of language delays in causing potential behavioural difficulties.

VanOrmer, Rossetti, and Zlomke also argue that family support is one of the biggest factors in behavioural difficulties.

> Therefore, it would appear that parental support provides role models that enable families to discover effective ways to parent and live with a hard-of-hearing child. Since very few hearing parents have regular contact with adults who are (d)eaf/hard of hearing, this lack of a model for effective parenting strategies/behaviours is a potential risk factor to the development of behaviour difficulties.
>
> (VanOrmer, Rossetti, & Zlomke, 2019, pp. 188-189)

Family support can come in many forms: providing mental health resources, facilitating adequate language development, supporting the (d)eaf individual, involvement in the (d)eaf community, and perhaps developing a better understanding of how Deafness affects children.

Contemporary Technology and Deaf Community 2.7

Modern technology has become a big part of the (d)eaf community because of how some devices can facilitate easier access to information and communication methods between the (d)eaf and hearing. Shoham and Heber's (2012) research investigates how the (d)eaf community exists in virtual environments and how that impacts them in the virtual and real world. Their research asks: Does the virtual community further support the (d)eaf community and enhance their communications and knowledge? To answer this question the researchers looked at 2,050 messages on a forum by the Israeli (D)eaf community. Shoham and Heber's work offers a view of more isolated (d)eaf communities than those in North America and how they struggle to gain access to education and communication. This information is based on my personal knowledge and understanding of the availability of technology and interpreters' resources for Israeli (D)eaf people. My knowledge was gained through various discussions with my (d)eaf friends at Gallaudet and in the Nova Scotia community who are from various Middle Eastern countries: Syria, Iraq, Israel, and Saudi Arabia. Shoham and Heber (2012) noticed a trend among the messages that the most frequent questions included: education, rights of the (d)eaf people, and how to move in the world of the hearing. This research shows the technological and virtual side of the epistemology of the (D)eaf community.

The impact of technology and virtual communities is further supported by Schreuer, Keter and Sachs' (2014) research in accessibility of information and communications technology in youth with disabilities. The research shows that youth with disabilities have a strong desire to feel supported and connected, not isolated or lonely: a desire similar to (d)eaf youths and any youth on the planet. The study found that learning and using technologies was better done via one-on-one tutoring, however, the participants indicated that they preferred group sessions for the socialization factor (Schreuer, Keters, & Sachs, 2014).

Shoham and Heber (2012) identified a high percentage of the comments they collected on the forum as providing social support for (d)eaf individuals in daily life. This observation is interesting and shows that the (d)eaf community reaches out to help someone in the community regardless of where they are in the world. Comments from some members of the forum crossed into real life by revealing that the members had already met in person. These interactions show that the (d)eaf community is more than a virtual community "… communities play an important role in providing social support for their members and in transmitting and evaluating information" (Shoham & Heber, 2012). Social support also has the additional benefit of providing, showing, transmitting, or suggesting information included in the interactions.

E-INCLUSION 2.7.1

Schruer's (2014) research into the merits of E-Inclusion, i.e., inclusion in the virtual world, further supports Shoham and Heber's work. Using a mixed methodology of quantitative and qualitative approaches, Schruer assesses computer performance, skills, and social participation in individuals with disabilities ranging from severe to mild and from physical, to intellectual, and to emotional. Participants included 65 individuals aged eight to twenty years old who were invited to participate in this study with the consent of their guardians. Ten of these individuals were chosen through purposeful sampling for in-depth interviews to see the differences in social participation of the ten individuals after one year.

The research included an assessment of the individuals' performances, skills, and usage of the internet over a one-year period. Schruer found that the individuals' skills increased, but only slightly, unless they had either group tutoring or one-on-one tutoring. I feel that it makes sense that their skills would significantly increase if they had some type of tutoring to show them how to use the computer more efficiently. For example, despite my digital native status, I am still learning how to use my laptop efficiently by downloading apps and programs, and I am on my toes about updates that may change the apps or programs I download.

E-inclusion is an important topic as current society is not entirely welcoming to people who may look different, act different, or need more help than other people. It was a lonely time for me during my secondary education years because I struggled to communicate with other students. Students do not like to work hard at making friends with people who require more or different effort to develop and foster friendships. Computers were my refugee for leisure reading, virtual chatting, and playing games. The interviews by Schruer (2014) show that the individuals appreciated the virtual inclusion and social participation; however, participating socially face-to-face was preferred.

ASSISTIVE HEARING DEVICES 2.7.2

Modern technology provides access for (d)eaf individuals through non-invasive virtual environments and online forums, but it also provides access through invasive medical devices. The immense field of assistive hearing devices contains numerous examples of technology pitfalls. Cochlear implants are invasive because they require surgery. Do not get me wrong, I understand why this procedure exists and the technology does help some HoH and (d)eaf people who truly want to hear and communicate in the same way as a typical hearing person. However, the use of invasive surgery to make HoH or (d)eaf people hear brings up the topic of ethnocide and how to keep (d)eaf culture strong despite attempts by the medical field and *unaware* hearing parents.

In their work, Marschark, Rhoten, and Fabich (2007) bring to light the literacy skills of children who have cochlear implants through a critical analysis of empirical studies that assessed literacy skills. The assumption of the researchers was that children who had implants earlier in life would show increased literacy skills over children who had implants later in life. The reviews of the studies revealed clear benefits, but the empirical results vary. Additionally, the findings showed that reading levels between young children with or without implants were not significantly different. The difference only became more obvious when the children became adults and teenagers. The authors suggest that the difference may be due to a lack of enforced reading by the educational system after grade 4. Marschark and colleagues reviewed work by Geers (2002), who argued that earlier implants may be connected with better speech communication exposure. Geers (2002) concluded that the best ‘method’ is to constantly expose children to speech and to ensure that they do everything auditorily. As previously mentioned, however, the exposure or ‘better’ speech communication may be due to the socialized nature of the children’s language development, which includes more emphasis on reading that could lead to increased enjoyment of reading and higher reading levels. This argument is further supported by Pfister’s research on the language development of (d)eaf children when they are blocked from sign language and national spoken language (2017). Conversely, Spencer, Tomblin, and Gantz’s (1997) study concludes that the literacy skills of children with implants are improved because of their increased competence in English, which is made possible by the implants. However, I question if their competence in English was indeed associated with their implant? English competency is not necessarily made possible by their implant, but rather by the environment the child grows up in. For example, if parents foster healthy reading skills in a child, it will cause the child to have better literacy skills later on in life whether the child has implants or not (Pfister, 2017). The cochlear implant is merely a tool that can be used by (d)eaf individuals based on how efficient and effective the environment and supports around them are.

QUALITY OF LIFE STUDY 2.7.3

Schorr, Roth, and Fox (2009) discuss how to ascertain the 'quality of life' for children with cochlear implants. They gathered children's self-reported quality of life through surveys and examined their perception of speech and emotional information conveyed by sounds. The sample included 37 children aged 5-14 who used spoken language with cochlear implants and who were congenitally (d)eaf. The article mentioned that these children surpassed any results provided by children who have hearing aids or children who did not understand particular items or scale responses. This result caused me to question the study. The so-called outliers are more average than the non-outliers if you take into consideration the average reading level of the (d)eaf community, which is at the grade four level (Johnson, Liddell, & Erting,1989). Schorr, Roth, and Fox (2009) tried to figure out if children with implants have the ability to enjoy "normal" life activities, which gives a justification for the financial costs of implants, along with the parents' perception of life after implants. This study seems to be focused on consumer satisfaction and is supported by organizations that support oralism in funding. In the (d)eaf community, this article would not be taken seriously nor listened to due to its oralist nature and because of the history of ethnocide oralism has undersigned.

VALUE OF COCHLEAR IMPLANTS 2.7.4

Parents and members of the medical community make the decision about cochlear implants for (d)eaf children. The decision involves considering the risks of the surgery and whether the child will still be 'classified' hard of hearing or (d)eaf by the medical and hearing community after the surgery. Cochlear implants are not a 'cure' for deafness.

The oralism movement is the main reason modern technology in hearing aids and cochlear implants have developed as far as it has. Alexander Graham Bell was one of the most famous oralism supporters and he contributed to the development of the research on hearing aids to ‘cure’ (d)eaf people through the invention and patent of his telephone in 1876 (Howe, 1947; PBS, 2007). That research eventually progressed into the new devices known as Cochlear implants. The implants are a type of prosthetic hearing technology that can cause short- or long-term pain. The initial surgery implants a magnet onto the skull with a wire from the magnet into the cochlea shell inside the ear. The surgery and recovery – and for years afterward – can involve pain. After recovery, the person must re-learn how to hear and how to translate the sounds in the brain. Similar to re-programming your computer, this task can be long and arduous. Though the side effects are considered rare, they can involve debilitating migraines or other headaches, dizziness, vertigo, and facial numbness. These effects can happen for years after the surgery or in the short-term after the surgery (Stanford Health Care, n.d; Food and Drug Administration, 2018).

For me, personally, after the surgery at eight years old, I suffered from debilitating vertigo migraines, tinnitus, and nausea, as well as severe fatigue from learning how to hear and speak. Prior to the surgery I existed as a profoundly (d)eaf individual who had a hearing aid but was amused by it because it was just a toy to me. After the surgery and recovery, I understood my status as a profoundly (d)eaf person more intimately and it was very difficult for me to re-wire my brain to ‘hear’ from the cochlear implant. It was not successful for me, so I choose to stop using it and I got it surgically removed at 20 years old. Removing the implant caused the vertigo migraines that used to happen at least five times per year to downgrade to one or two massive vertigo migraines per year, which I am thankful for.

Many articles and research will claim that cochlear implants are ‘successful’, however, we must ask ourselves what does successful mean to the researchers? Does ‘successful’ mean being able to pass for a hearing person? Does success mean wonderful academic performance? Does it mean the cochlear implant is successfully implanted without any serious effects? Due to the complexity of the cochlear implant technology, its medical and emotional impacts are considered outside the scope of this study.

LANGUAGE DEVELOPMENT, LIBRARIES, AND EDUCATION 2.7.5

Eisner (2012) discussed how to engage (D)eaf and Hard of Hearing (HoH) youths and adults in school libraries. This study is important because the US statistics show that 70% of (D)eaf or HoH youth are in public or mainstream schools. In Eisner’s research, they sought to create step-by-step procedures for teacher-librarians to help (d)eaf children increase their literacy levels. Eisner (2012) argued that teacher-librarians can improve their instruction if they improve their understanding of (D)eaf and HoH students.

Eisner (2012) suggests that there are phases of language development, with specific focus on phonological awareness and spoken and/or sign to written language. It is one of the hardest phases for (d)eaf individuals to transition to: sign to written and written to sign. The difficulty could be related to language understanding. I have observed that American Sign Language literacy is an issue in the community right now because communication appears to be lost in translation. There seems to be a disconnection between English and ASL, which could impact the language development of (d)eaf children. Eisner suggests that a “Coordinating, Cooperating, and Collaboration” approach used by the teacher-librarian would be helpful because (D)eaf individuals learn differently and are reluctant readers due to past traumatic experiences. The approach involves: coordinating with the teachers of the classroom; cooperating on what topics will be taught; then collaborating to ensure that the classes will be taught efficiently for the students and the teacher (Eisner, 2012). Traumatic experiences can range from being forced to read 'out loud' books they do not understand and being constantly told that they will never fully understand the books.

In light of this research, Convertino, Marschark, Sapere, Sarchet, and Zupan (2009) discuss the possibility of predicting academic success of (d)eaf individuals in post-secondary education. Completing a study on (D)eaf and HoH in post-secondary education is difficult because of expenses, time-consuming surveys, and of the etiology of the hearing loss. Additionally, other issues include accessibility, preferred mode of communication, and educational background including placement in mainstream or (D)eaf schools. The article draws information from previous studies to examine potential predictors of achievement in high school including course intensity, overall number of courses taken, and type of courses. Data collected by the Rochester Institute of Technology (RIT) (Cuculick & Kelly, 2003) show that 92% of the (D)eaf and HoH students with Bachelor of Science, and 65% with Bachelor of Arts are at reading levels between grade nine and twelve. In Convertino et al.'s study, family support is shown to be a strong predictor of being ready for Post-Secondary attendance, but not academic achievement. However, it is unclear if these results are affected by their earlier education experiences.

Convertino et al.'s (2009) research show that a family's support has a strong impact on (d)eaf individual's general ability to succeed in general life —but not an impact specifically on their academic success. Eisner's research suggests best practices for providing literacy instruction (coordinating, cooperating and collaborating) by teacher-librarians to (D)eaf individuals. Schorr, Roth, and Fox's (2009) research in the quality of life for (d)eaf children with cochlear implants are found to be biased toward the oralism community. Schreuer's (2014) results show that the disabled students' skills increased in both one-on-one tutoring and group learning activities, but it increases slightly more with one-on-one tutoring. Finally, Shoham and Heber's (2012) research into the (d)eaf community in the virtual environment shows the nature of (D)eaf epistemology appearing strongly in the virtual community through social support.

There are many conflicting opinions on how technology can be used to increase access and accessibility for the (D)eaf community. Technology is such a broad word and it can mean many things ranging from computers to cochlear implant technology, from non-invasive to highly invasive methods respectively.

Literature Conclusion 2.8

The literature review covered many aspects of the (d)eaf community that affect access, accessibility, and information literacy: history, epistemology, use of a cultural lens, subcultures of the (d)eaf community, language deprivation, education, mental health, and contemporary technology. The goal of the literature review is to pave the way to better understanding of what accessibility really means to the (d)eaf and (D)eaf community. How does accessibility inform or influence information literacy? Are there ways of creating procedures and techniques to help the overall (d)eaf community increase their information literacy skills? We know for certain that language deprivation is a serious issue with (d)eaf children because sign language is acknowledged as natural language for the (d)eaf community and not all (d)eaf children have access to this language (Pfister, 2017; Mayberry, Chen, Witcher, & Klein, 2011). We know that a wide range of different education types occurs in a (d)eaf children's life including mainstream school, (d)eaf school, (d)eaf class, or oralism school (Murray, 2019). We know that cochlear implants and hearing aids are not cures for (d)eaf people (Pisoni, Conway, Kronenberger, Horn, Karpicke, & Henning, 2007). We also discussed how sign language, education, family support, isolation, and accessibility impact the mental health and well-being of (d)eaf children and adults. It is evident that when a (d)eaf child or adult lacks one or more of the following: family support, knowledge of their natural language (sign language), socialization, accessible education, and any accessible resources necessary for their well-being, it can have a diminishing effect on their emotional and mental well-being (Pfister, 2017; Mayberry, Chen, Witcher, & Klein, 2011; Bat-Chava, 1994; Glickman & Hall, 2018; Leigh & Pollard, 2003). All of this knowledge helped greatly with my analysis of the data from the five participants and with identifying the main over-arching themes affecting the outcomes of accessibility and information literacy. Are there acceptable levels of accessibility at the expense of mental health, for instance? Does isolation have a factor in affecting the participants' decision-making about education? Did any of the participants know ASL early on and did that impact how they were educated and how they made decisions later in adulthood? Do they identify as (D)eaf, Hard of Hearing, or (d)eaf? What time in their life did they self-identify? These questions, prompted by the literature review, will be answered in the Discussion and Findings (Chapter Four).

Chapter Three: Methodology

Narrative inquiry is a qualitative research method that explores lived experiences (Leedy & Ormrod, 2016). The method of narrative inquiry and epistemology of the (d)eaf community have a common link in the way that both emphasize the importance of personal experience in sharing information and knowledge. In the (d)eaf community, knowledge is shared through personal experience, testimonies, stories, and emotional expressions of the (d)eaf person; narrative inquiry uses interviews to gain insight to peoples' lived experiences (Holocomb, 2010). The interviews completed as part of this research were designed to discuss the (d)eaf individual's personal experiences and thoughts. I identified interviews as the best method to gather data for the research in order to conduct thematic analysis and qualitative coding phases while respecting the (D)eaf community's epistemological standard.

As a (d)eaf researcher, the narrative inquiry method works well for me because I am familiar with —and follow— the standard of (d)eaf epistemology. The (d)eaf community and culture are considered a linguistic-cultural minority. Based on my personal experience and knowledge of the (d)eaf community and culture I am also looking at the data through a cultural —not a disability— lens. Along with that, I am taking into account other (d)eaf people's personal experiences in (D)eaf culture. This chapter will discuss the following: research objectives, narrative inquiry and how it is intertwined with the (d)eaf community, data collection, and coding. The Methodology chapter is followed by Discussion and Findings.

Research Objectives 3.0

To identify the appropriate methodology for this research, I must first establish research objectives and questions. In the Introduction Chapter, I discussed how accessibility and access potentially impact information literacy skills in the (d)eaf community. To ascertain information literacy levels, understanding how (D)eaf culture and community work is crucial. This includes understanding the nature of (D)eaf epistemology and how people gather their knowledge through personal testimonies, stories, and life experience (Holocomb, 2010). The research questions for this thesis are as follows:

1) How does (D)eaf epistemology affect the (d)eaf individuals' education?

2) Does the difference between access and accessibility impact the (d)eaf individual in good and bad ways?

3) Are there any common threads among the (d)eaf participants that may give answers to the above questions?

What is Narrative Inquiry 3.1

The methodology I chose to use for my research is narrative inquiry. Narrative inquiry is the methodology of evoking life stories, experiences, and testimonies told to the researcher by the participants (Polkinghorne, 2010). The data was collected using the method of interviews. According to Clanndinn and Connelly (2000): "Experience happens narratively, so educational experience should be narrated" (p. 19). The interviews aimed to gain answers regarding: How does a particular experience affect the individual later on? Does it affect their information literacy skills, or do experiences of barriers to access cause issues in gaining literacy skills? The answers to those questions supplemented my original research questions.

There are many different ways of conducting narrative inquiry, but the standard method involves interviewing the participants, then analyzing the data from the interview sessions (Clandinin & Connelly, 2000). Interviews can take many forms including audio recording, videos, and taking notes down. I chose to record the interviews through video due to the physical nature of sign language. You cannot audio-record hands moving around. After the data collection and transcription for all participants was completed, I conducted coding.

Narrative Inquiry and the Deaf Community 3.2

The methodology of narrative inquiry is appropriate to engage with the (D)eaf community because the two are based on the same foundation of sharing information through life stories, experiences, and testimonies. Narrative inquiry is a research method that provides researchers with an opportunity to learn from and gain understanding of individuals, communities, or cultures. In the current research, I am trying to understand the effects of accessibility and access on individuals who come from a linguistic minority, community, and culture. Narrative inquiry has been used in a variety of settings, including diverse and international contexts. For example, teacher development and tensions between Western and Chinese viewpoints on education (Xu & Connelly, 2009). Their research showed that teacher development and educational reforms need to begin with local cultural knowledge. The narrative inquiry in Xu and Connelly's (2009) work was able to capture the participants ways of thinking about life and conceptions of world.

Other research that examined personal narrative or other cultural heritage through a cultural lens was completed by Ta (2014). Ta's master thesis explored K-12 educational experiences of "successful" Vietnamese American students from strength-based perspective.

Narrative inquiry allowed Ta to analyse how the students' experiences influenced their academic and general success (2014). Ta devised profiles which included backgrounds for each of the participants. In Ta's analysis he looked for themes, similarities, and differences in the experience shared in the interviews. As is important in qualitative research, Ta also discussed the trustworthiness and integrity of the research. According to Lincoln and Guba (1985), reliability can be developed through the usage of prolonged engagements, research log, member checking, negative case analysis, and bracketing. Ta and Xu and Connelly's research studies show the benefit of taking personal narrative and cultural history into account.

Similarly, Adler's (2011) research using narrative inquiry examined teachers' opportunities to learn about diverse cultures in America and shows the importance of lived experience. Learning about the personal experiences of diverse people is important so that teachers are able to acknowledge the students' diversity and cultural heritage without diminishing the students' confidence and identity.

De Frites et al.'s (2011) article shows the connection between (D)eaf epistemology and narrative inquiry in their discussion that the (D)eaf community gathers around topics of shared interest. This gathering happens through various means such as virtual forums, community events, and reunions. Individuals in the (D)eaf community have a strong tendency to pass on information when they meet each other. The capacity to gather is particularly important in the (D)eaf community as they have experienced being isolated from other (d)eaf people and have a history of poor access and accessibility to resources.

The development of a distinct epistemology within the (d)eaf community and its influence on the identity and cultural heritage is important to understand. Davidson's (2017) thesis on (D)eaf culture uses the methodology of personal experience narrative (PEN) to expose similarities amongst groups of people. The goal of the research was to explore the ‘typicality’ embedded within the narrative. Typicality, again, refers to characteristics of what is “normal” within a class, a community, or a culture. Davidson focuses on distinct qualities of the (D)eaf community through narratives, which are products of individuals’ everyday life experience. In his research, Davidson explored how (d)eaf experiences are embedded in signed personal narrative. He examined what these experiences reveal about the typicality of the (D)eaf community. The PEN method collected data about functions of typicality as shared through lived experience and signed poetry. Davidson found that typicality of (D)eaf is not mainstream knowledge —something that I think is well known in the (D)eaf community. Davidson (2017) used Gee’s framework to structure the narrative into chronicled and segmented texts. ‘Chronicled’ refers to personal narratives set in a straightforward timeline and ‘segmented’ breaks the structured narrative down into pauses and prosodic features such as intonation (Gee, 1986, 2011). Gee found that when people tell stories, their narratives generally have an underlying event structure. Collecting narratives from (D)eaf individuals through written formats restricts (D)eaf people’s expression of their stories. Written English cannot express the same exact emotion, words, or event as sign language can. (D)eaf signers can articulate language to larger extent than hearing through the combined use of body and expressions.

Davidson used the procedure developed by Maxwell (2005) —Interactive Model of Research Question— to shed light on otherwise unnoticed patterns in the personal experiences. The model provides a set of procedures for data collection, analysis, and validating the analysis. There are five directions presented by Maxwell’s interactive model: goals, conceptual framework, methods, validity, and research objectives (Maxwell, 2005). Davidson’s research was structured as follows: establishing a set of criteria for participant selection, purposeful sampling, compiled corpus data from shared narratives, applied stratified approach to British Sign Language (BSL) corpus data and data reduction as recommended by Darlington and Scott (2000). The criteria that Davidson applied to selecting participants was British Sign Language user, (D)eaf, and willing to share personal experience. The data was collected through interviews at (D)eaf Clubs, which are like second home to (d)eaf people. Davidson then prepared the data, developed familiarity, interpreted, verified, and represented the personal narratives (Maxwell, 2005: Davidson, 2017). He then applied linguistic and content analysis frameworks and applied 'analysis of narrative' rather than 'narrative analysis' (Wilson, 1996: Davidson, 2017). Analysis of narrative is when researchers collect stories as data and look at them through lens of examples (Wilson, 1996: Davidson, 2017). Narrative analysis is when researchers collect descriptions of events and configure them into a story or multiple stories (Polkinghorne, 1995). In order to analyse the high volume of data and identify how experiences crossed over between events, Davidson applied analysis of narrative to identify themes (Davidson, 2017).

Hole's (2004) thesis examining three (d)eaf women's life stories also discusses the methodology of narrative. In their work, Hole suggests that from a 'post structural' viewpoint knowledge is not fixed, open to questions, and always temporary (Hole, 2004). Post structural approaches question the relationship between human beings, their culture, and the natural world. It occurs by studying words, the meaning of words, literacy theories, culture theories, and questioning how traditional structures work (Belsey, 2002). Hole references the idea that "language is self" —originally presented by sociologist George Herbert Mead (1934)— which suggests that language is how we express our *self* and estimate our identity (2004, p.36). This resonates with my own cultural lens. Hole used collaborative narrative method which was completed using several stages: meeting the participants and get to know them, multi hour interviews, followed by transcription of the interviews. The transcription process included having the participants checking the transcript to make sure the translations are up to their standards. The final stage of the analysis included a "4-D" interpretative reading of transcript as outlined by Arvay's (1999, 2002, 2003) method of 4-D interpretative reading. This approach involves the researcher re-reading of the transcripts for the specific aspects of content, self, research question, and relation of power and culture (Arvay, 1999, 2002, 2003). I had been puzzling over how to avoid missing things while re-reading transcripts collected in my own research and Hole's approach informed how I completed my work.

Validity and Reliability of Narrative Inquiry 3.3

Considering that the (D)eaf community is a linguistic minority with a strong culture, employing narrative inquiry, which facilitates collecting data about personal experiences, is the best method for conducting qualitative research. It supports accessibility as it collects data face-to-face and facilitates the researcher's aim to create comfortable research environment for anyone.

However, when completing research within the (D)eaf community I needed to take in account how the (D)eaf community has been taken advantage of by researchers, governments, and industry for profit, research purposes, knowledge, and power. That is based on documented proof and my personal experience as a (D)eaf individual. My positionality affected my goals for this research. I wanted to ensure the comfort of the participants during the interviews since my questions could evoke traumatic or emotional memories. Using narrative inquiry, is a way to work towards ensuring that the participants feel more comfortable that that the conversation between researcher and participant will be more organic. Along with that, I agreed to pay honorariums to each participant to show that I am not taking advantage of their time and their desire to help fellow (D)eaf community members.

Bias and snap judgements are a common issue in broader society and as a researcher, I needed to be able to either rise above or acknowledge the possible bias in my opinions. The reason this is important was to show the validity and integrity of my research. Phillion (2002) emphasizes the importance of considering bias when becoming a narrative inquirer in a multicultural landscape. In their research, Phillion completed a 20-month study of teaching and learning in a diverse classroom in downtown Toronto. The purpose was to describe details of teacher and learner in a multi-cultural classroom, and to develop successful strategies with immigrants and minority students. The research suggested schools and teachers use narrative multicultural teaching, which is the process of understanding multi-cultural teacher and learners using personal experience as a starting point (Phillion, 2002). Phillion (2002) said their research experience was a passionate, intensive, and involved up-close participation over a long period of time, during which they developed relationships with the participants. This turned out to be true for myself while conducting my interview sessions. I noticed myself becoming emotional when the participants told their stories and felt closer to them as well; I saw them as they saw me.

Narrative inquiry methods, as described by Phillion, is also influenced by John Dewey’s (1938) notion of the four directions of interaction: 1) inward, which refers to internal conditions, feelings, emotions; 2) outward, regarding existential conditions, environments; 3) backward and forward; and 4) temporality including the past, present, and future (Phillion, 2002). Dewey (1938) suggests using these four directions to frame how researchers can interact with data in different ways, which can be particularly useful when analysing qualitative data. Phillion applied the direction outlined by Dewey to their own reflexivity and to position themselves to their research environment. As a researcher, Phillion was constantly listening and observing, taking field notes, and living in the midst of the participants lives. From their specific positionality, Phillion considered how her own biases could impact her conclusion and shows the importance of positionality and reflexivity statements. In the following, I include my own reflexivity statement to encourage understanding that as a researcher I aim to be flexible, gentle, adaptable, and open to the different points of view from the participants in my research.

Reflexivity Statement 3.4

I bring to my role of researcher a personal bias regarding the topics of access and accessibility through my experience as a (D)eaf individual. My insider status as a member of the (D)eaf community also contributes to my bias. In the field of Anthropology, I would be considered an 'emic', rather than an 'etic' researcher. An emic researcher is an insider to the participants while an etic researcher is examining from outsider perspective (Stark & Trinidad, 2017.) My emic outlook will be beneficial to the research process as I have knowledge of the (d)eaf community and culture. I have a strong understanding of how to conduct an interview to ensure the (d)eaf individual's comfort, along with how to explain the research objectives and how to draw information from the (d)eaf participant.

To confront these biases, I conducted reflexivity journaling throughout the research and data collection process to keep myself in check. I also constantly reexamined my thoughts on a daily basis. (Leedy & Ormrod, 2016, p. 260). The re-examination of my thoughts was done by reading saved transcripts of online chats with my research committee and the personal reflections during the coding process. Typical reflexivity journaling or logging are not the best methods for me because I am unable to think clearly if I write or vlog. I found that I was able to think about things better if I conduct them in discussion format. I asked myself the following questions during conversations with my research committee and personal reflections:

1. What am I doing during the interview? What am I trying to accomplish?
2. Did the answers surprise me? How so?
3. What is new during this interview process?
4. How do I feel about the (d)eaf members' understanding of the questions?
5. What assumptions am I making? What could I improve for the next interview process?
6. What do I see going on here (patterns)? What did I learn from the interview?

Data Collection 3.5

This research received ethics approval from Dalhousie's Social Sciences & Humanities Research Ethics Board in 2019 and was continued through to 2021. The phases of the methodology occurred as follows: recruitment, interview, transcription, member-check, and data analysis/code processes.

The recruitment period was limited to two months of finding five people willing to commit their time to my research. My sample came initially through convenience and then also through snowball sampling methods (Leedy & Ormod, 2016). Convenience sampling method was used for the majority of my participants because I advertised my research through Facebook groups called 'Stayed Connected' and Society of (D)eaf and Hard of Hearing Nova Scotia (SDHHNS). Stayed Connected is a group on Facebook with membership including (D)eaf, hard of hearing (HOH), child of (D)eaf adults (CODA), and interpreters. The goal of Stayed Connect is to update the members on events and news in the (D)eaf community. I advertised through

SDHHNS the official page rather than my personal Facebook account. I began the interview process with three participants before recruiting the final two through the snowball sampling method. Snowball is a probability sampling method and can be used to recruit hard-to-reach individuals or populations through contacting one person and they contact other people. (Leedy & Ormrod, 2016). One of the participants of my research contacted other (d)eaf individuals and invited them to participate.

During the recruitment process, participants had to commit to interviews conducted in two sessions. The goal of the second interview was to refine the data via feedback. Prior to the first interview, the participants signed a consent form in English, and I provide them with an American Sign Language (ASL) interpretation of the consent form on request (Appendix 2) allowing the following:

1) Answering yes or no to allowing direct quotes to be published.
2) Agreeing to the time commitment.
3) Acknowledging potential emotional outbursts or impacts.

The 10 interview questions, shown in Appendix 1, were used as a starting point for all of the interviews, however, they were not followed to the letter. Narrative inquiry is a flexible method that allows for organic conversation and with the aim to ensure that the participants felt comfortable (Polkinghorne, 2010: Fellinger, Holzinger, and Pollard, 2012). Since the interviews were conducted in sign language they were filmed using a video recorder at Dalhousie School of Management offices. Reviewing of the data involved transcription of the interviews and member-check process.

The most interesting thing about conducting the interviews was how much my ideas and thoughts changed as I found different things to focus on for each participant over the five interview sessions. Each participant had their own personal stories and lives with varied influences. During data interpretation, I saw common threads that I would never have thought of during or before the interviews. This inevitability caused me to wish I had conducted more interviews with the participants. In hindsight, I should have conducted three sessions with the participants; two main interview sessions and the last session designed for member-check. This does not impact the integrity of the data, rather it is a suggestion for future research.

Before I conducted the second interviews, I transcribed the initial interviews. It is well known in the (d)eaf community that written formats restrict (D)eaf people's expression of their stories. English cannot convey the exact same emotion as sign language to express a particular word or event. (D)eaf signers can articulate language to larger extent than hearing. For example, a (D)eaf signer can use one sign and a facial expression that means almost the same thing that hearing people would use one or two full verbal sentences to express. This complexity of sign language expression caused me to take a deeper look at the transcription process to ensure that the transcription was faithful to what the participants meant in their answers and stories. I chose to add expression of emotion (e.g., **Smiles**) in bold fonts, and actions in italics (e.g., *Rolls Eyes*). I did that because the hardest part about transcription is balancing accuracy and interpretation. Scripts and narrative interviews are different styles of writing and scripts are the better option for ensuring that there are complete translations. Since transcripts are uncompleted, partial, selection adding the emotions and actions of the participant and myself as the researcher helped greatly with ensuring faithful transcription (Riessman, 1993). Checking with the original participants for feedback on the transcripts increases validity of the researcher's translation of sign language to English.

The second interviews were performed following analysis of the first interview transcript to gain clarification and to refine and refocus the transcription as required. The second interview was, in effect, a member-check process, with the participants looking over their transcript from the first interview and correcting any necessary mistakes in the translations of the sign language to English. Along with this, the participants had the right to remove any personal information they prefer to not be public. This is regular practice in narrative inquiry. For example, Hole (2004) conducted member-checks, similar to my second interview, to check with the participants to validate the transcriptions.

As an insider in the (D)eaf community, I had to complete further analysis of the information to eliminate or mitigate any potential biases about the (D)eaf community and (d)eaf culture. I chose reflexivity as the tool to help me to create a strong personal framework of my positionality as a researcher. The aim of this practice was to ensure a constant awareness of potential bias and to prevent corruption of the data results by biased translations and interpretations. As mentioned in Validity and Reliability of Narrative Inquiry 3.3, reflexivity was done through constant conversations with my thesis supervisors and keeping track of personal thoughts. The Reflexivity statement (see Section 3.4) shows how I aim to make sure my potential and actual bias did not skew the results of my research.

The analysis of the data was completed using thematic qualitative coding. Using inductive-driven analysis method, the data collection was not put into any type of preconceived theoretical framework (Braun & Clarke, 2016). Putting personal experiences, stories, and testimonies in a pre-set framework may not give clear answers. I am interested in giving voice to members of the (D)eaf community, so I wanted interviewees to speak in their own words. I wanted to provide the opportunity for interviewees to talk about themes surrounding the hearing world versus the (D)eaf community.

> Theoretical knowledge is made up of selected components from examined participants neglecting the effect of participants' unique history, social environment and aims on the meaning of that component in the participants' lives. (Polkinghorne, 2010, p. 394)

Researchers develop theories from observation and analysis of participants. However, it is important to ensure that the theories are not formed while neglecting to acknowledge the participant's unique history and how that affects the participant as an individual. I turned to discourse analysis for further coding and analysis. Discourse analysis involves questioning the context of the information gathered. The analysis includes deconstruction, which is the process of acknowledging power relations, authority, and strives to understand the underlying assumptions of the information. I had titled it thematic analysis—in section THEMATIC ANALYSIS 3.6.1, but it includes both thematic analysis and discourse analysis. The data analysis involved two distinct but interwoven processes: coding and identification of themes through thematic and discourse analysis. The coding process describes how the analysis was done, specifically the breaking down and identifying concepts within the data. The thematic analysis process involves describing the approach taken to illuminate themes within the data

The knowledge standard of the (D)eaf community, otherwise known as (D)eaf epistemology, is shared through relating experiences, testimonies, stories, poems, songs, and conversations. Generally, (d)eaf individuals prefer learning through storytelling and knowledge sharing from their peers and other community members (Holocomb, 2010; Shober & Heber, 2016). Therefore, inductive method is a good way to draw out the (d)eaf participants' thoughts, personal stories, and experiences. Inductive-driven thematic analysis helped greatly with the thick description of the data collection, especially when completing the narrative summaries. This type of thematic analysis also facilitates identifying clear patterns without the need for specific frameworks.

As the researcher, I needed to follow an established process for collecting the data through interviews and followed with a specific coding process to ensure that in each interview the data was collected and analyzed in a similar manner. The description of the coding process in the following section shows changes and deconstruction over time. Along with that, you can see my thematic analysis changing throughout phases of coding process.

Data Analysis Process 3.6

Following the completion of transcription, I began the coding during which I followed an inductive thematic analytic and discourse analysis model. To be clear, I employed two processes to look at the data that was collected through the interviews. The coding occurred over seven phases, beginning with converting data and ending with narratives summaries. The thematic analysis also included seven steps with the goal of illuminating themes present within the data. I will describe each of these processes in turn.

CODING PROCESS 3.6.0

The coding process was adapted from the six phase process proposed by Leedy and Ormrod (2016): 1) converting the data into one or more forms that is easier to organized or analyze; 2) organize the data in a preliminary way to enable easy locating; 3) identify preliminary categories likely to help in coding the data; 4) divide the data in meaningful units that can be individually coded; 5) apply the initial coding scheme to a subset of the data; and 6) construct a final list of codes and sub codes and define each code and sub code specifically and concretely as possible (p. 292-293). My coding process included an additional seventh phase, which involved crafting two-pages narrative summaries of each participant's interview as a life summary. The coding phases I followed are: 1) highlighting aspects of interest from within the transcripts 2); in-depth comments on the highlights; 3) changing comments to general themes; 4) developing general themes and comments; 5) setting up chronological timeline; 6) identifying similarities and differences; and 7) narrative summaries. Please see Coding Phases (Section 3.6.2) for an in-depth explanation of the different coding phases.

The coding process is organic and not fixed. The reason for this is because I do not want to place my research at a fixed point. A fixed point may affect my potential bias to come out stronger and influence my coding process toward a certain point.

Throughout the coding process I considered the thematic analysis and iterated what steps should be taken to analyze the data more effectively.

THEMATIC ANALYSIS 3.6.1

1) **Record reflexivity journal entries:** This ensured that I was able to sort my thoughts out first before looking over the transcripts of the interviews. This was done through chat transcripts of conversations with my supervisor and self-reflection.
2) **Look over the interview transcripts (videos and notes):** This included looking for and commenting on sections of the interviews to see if I could see any patterns emerging.

3) **Decide on preliminary patterns coding:** The goal here iswas to decide on major themes that emerged from the interviews, which could include access, technology, or culture, with certain words under each category that match the meaning of the theme.
4) **Re-examine reflexivity journal entries:** Re-evaluate to ensure that the pattern coding and themes matched up with what the researcher had been expecting in the interviews and modify if required. This practice is also beneficial to the project as it may give further support to the interpretations of the findings.
5) **Member-check the interview transcripts:** Before beginning indepth thematic analysis I met up with the participants to check over their respective transcripts to ensure that it follow their meanings and wordings.
6) **Repeat step 1 to 4 and decide if the patterns are well justified or need to be tweaked**
7) **Re-enter the changes in the reflexivity journals:** If there were any type of changes in the pattern codes decided upon on, they were shown in the coding phases to show the process of changes the research went through as the project developed and was analysed.

The distinct processes of coding and thematic analysis did not go in a straight line and informed each other throughout the process. I used several methods during the coding process including visualizing, compounding, and splitting. Visualizing is the process of preparing the data to be seen in different formats. In my case, I created clusters along timelines in a chart. Compounding is the format of connecting data. For instance, in when looking over the interview transcripts I connected highlighted sections of the transcript with researcher comments. Splitting is the process of breaking down information to their basic meaning, in the sense of breaking down complex ideas into simple ideas (Leedy & Ormrod, 2016): for instance, breaking down data to contain the participant numbers, theme names, and timeline label.

I conducted the process of thematic analysis and the coding process simultaneously. The thematic analysis was completed iteratively to ensure a strong definition for each themes and subthemes found in the coding process. The thematic analysis process was incredibly helpful while moving between the different phases of coding because I was able to objectively apply the (d)eaf lens to the thematic and discourse analysis at each part of the process.

Through the coding phases I used Word and Excel documents. My reflexivity journaling was completed throughout each phase of the coding and analysis.

Narrative inquiry typically begins with the raw data from the life stories and progresses organically and holistically to specific themes. Leedy and Ormrod (2016) call this ‘the constant comparative method’. As the researcher I strove to establish my own process to enable myself see the how the different parts of the data work together to tell a bigger story. The standard narrative process, as presented by Leedy and Ormrod (2016) is reflected in the coding phases I developed: 1) converting the data so that it is easily organized and analyzed through highlighting; 2) organize the data to make it easily locatable by adding in-depth comments to highlighted parts of the transcription; 3) identify preliminary categories by adding comments to general themes; and 4) divide data into meaningful united by developing general themes and comments. (Leedy & Ormrod, 2016, p. 292-293). I further adapted Leedy and Ormord’s work in phases 5 and 6. They suggest: 5) applied the initial coding to a subset of data where I set up a chronological timeline; and 6) rather than construct a final list of codes I worked to identify similarities and differences between the codes. I further added a seventh phase where I constructed narrative summaries. Though these alterations to the general process could be considered as my personal preferences influencing the process, I am confident that by stating my possible biases and the ways I attempted to reduce their influences, my research remains valid. As can be seen in the analysis, each participant clearly had different important themes identified in their transcripts. It is impossible to remove all bias from research, however, I had tried my best to remove any bias from the coding phases process and thematic analysis process.

In the coding phases and analysis process I provided fictional names for each of the participants: One-Molly, Two-Josie, Three-Alexander, Four-Hermes, and Five-Ronald. This was to show that the participants are real, living human beings and not mere numbers in a research study.

CODING PHASES 3.6.2

Coding Phase One: Highlighting

As part of the initial phase of the coding processes I highlighted what “caught” my eye and made me think or feel something. Each participant had between 10 and 15 pages of transcript generated from the one, to one and a half hours of interview. In total, there are 62 single-spaced pages of transcript to look through and analyze. My highlighting was done manually with a physical yellow highlighter on the printed participant transcripts. Then I added the yellow highlighting to the electronic copy of the participant’s transcripts. During this process, I started to notice different themes in the participants’ transcript. For example, with Molly, I started to think about the effects mental health may have on (d)eaf individuals — especially if the individuals experienced abuse or oppression in educational institutions. What impact could that have on their “love” of learning? If an individual was hurt or suffered from trauma in education setting, they may start to associate pain with education. This psychological association is known as “emotional memory” (Lerner & Keltner, 2000; Lewis, 2008).

Each participant had a specific theme that I took an interest in. In Molly's interview the themes included mental health, responsibility, and (d)eaf community came forth. Josie's interview illuminated the themes of privacy, travelling, family, and lack of (d)eaf role models. The theme of locations, family, mental health, and language access came out in the interview with Alexander. Hermes discussion shared the theme of "inferior" education, family, and (d)eaf community. Ronald's interview had the theme of abuse in education, oppression, mental health, and (d)eaf community. These are the overarching themes in individual participants I identified in my initial coding phase. This is different from overarching themes *across* participants. To find the themes that connect across all participants further coding was required.

Coding Phase Two: In-Depth Comments on Highlighted

After I completed my highlighting, I added comments to establish the reason why they caught my eye. The reasons ranged from how some of them confirmed my thoughts, surprised me or provided additional information on why some of the things are important to note. I wanted to add comments regarding exiting themes, as well as further themes that I may not initially have thought of. The comments ranged from a few words to a paragraph for nearly each highlighted section. I also avoided typing the same comments and treated each highlighted section as its own entity. I undertook this approach as an attempt to avoid bias or skewed results. During this second phase of coding I identified possible in-depth names of categories to be applied in phase three of the coding process. For instance, I added the wording "accessible" and "access" to show the differences between the comments I applied the thematic term to. The criteria I used for distinguishing access and accessible was based on what kind of technology medium or situation the participant was referring. For example, 'accessible' was applied if the situation was referring to assistive technology. In turn the category access was used the situation being described by the participant did not involve technology, assistive technology, or interpreters. According to my keyword section, ‘accessibility’ refers to the actions taken to make information easily understood, used as intended, and reached in cases where access to information is partial. In order to draw this out from the transcripts, I had to take a look at the different factors affecting how accessibility and access work for the (d)eaf participants. I chose to create flexible criteria for looking at how technologies, or mediums of communication and knowledge sharing is presented in the situation shared by the (d)eaf participant. This involved considering how sign language compares to spoken language in the situation.

The process of commenting on the highlighted sections influenced how I identified themes. For example, when I was initially coding the data from the participant named Josie, one of the overarching themes I identified was ‘privacy’. From Josie’s perspective, they were unable to conceal that they are hard of hearing because of their cumbersome hearing aid technology. I recognized that this may impact mental health and how people look at learning/education. I took another look at all other participants and noticed aspects of privacy in their transcript. That caused Privacy as well as Mental Health to be included in the overarching themes across the five participants.

Coding Phase Three: Comments changed to general theme

In phase three, the goal was to name the categories for the comments I created during phase two. I chose to remove all parts of the transcripts that were not highlighted so I could see all of my comments. This action helped me greatly with fixing any vague comments. It also made it easier for me to identify possible theme names quicker as I saw words popping out at me in my comments of the transcript. The names ranged from Mental Health to Accessible Education. Please see Appendix E for the comments. I re-read my comments and made edits for clarification. Along with that, I added keywords from the general theme to each comment to identify which themes came up most for each participant. This is the compounding section of my coding process as I started to make official connections between participants and possible themes. As is common in iterative coding, the themes can be confusing since the connections being made are preliminary and still subject to change. Similar to phase two, I chose to focus on the unique themes for each participant based on their stories.

Some participants used terminology differently, which impacted the coding of the theme. For example, both Molly and Josie used '(D)eaf epistemology' in different ways and in reference to different time periods in their lives. This caused me to take another look at how I could code effectively, which cause the creation of phase six in the coding process, which focused on identifying similarities and differences between themes. By including this phase, I strove to make changes to themes for consistency but also to showcase the unique instances where they differed for each participant. During coding of the themes, I also choose to compound themes because a few sections have multiple themes. Education and (D)eaf Community, Accessibility and Technology, Privacy and Mental Health are a few of the themes I compounded. One of the most common compounds included Education. This is particularly important when taking into consideration how my research has a strong focus on information literacy. I chose to take Education as one of the overarching themes *across* participants.

Coding Phase Four: General themes and comments

In the fourth phase of coding, I moved only the comments and identified themes onto a new document in order to establish how much I had written under each theme. I read the comments and general themes to see if I still agreed with what it said without the benefit of the transcripts as a reference. I found this phase very interesting because it helped me with my personal bias greatly. I was able to note which comments were written with my expectations prior to this research. I noted that Molly and Hermes grew up with (d)eaf members in their family which affect how they perceive education in different ways. Molly's education is mainly mainstream while Hermes's education is mainly in a (d)eaf school. Molly had a few arguments with their parent on how Molly wanted to go to (D)eaf school because they wanted to experience the socialization however their parents refuse to let them go due to abusive allegations. Hermes mentioned that socialization is the only good thing about the (D)eaf School. Both participants have the same desire for socialization but have different perspective of their childhood education. Nowadays, they have the same thought that the (D)eaf school's education is inferior in comparison to hearing school. According to Ronald and Hermes, the reason they consider (D)eaf schools to be inferior is based on the government and province's stance on (d)eaf people. This was mentioned in my Introduction (Section 1.1 and 1.2), in reference to the government's stance on banning sign language and their perspective that (d)eaf students are not able to succeed at the same fields hearing students subsequently impacted what (d)eaf education looks like. It is not the fault of the teachers who may have wanted to teach the (d)eaf people on the same level as their hearing peers.

When considering the similarities and differences of the participants' experiences regarding their first interactions with the (D)eaf community I realized that (D)eaf Community could be considered a separate theme. For example, Josie, Alexander, and Ronald had similar emotional experiences including shock or surprise — though the initial interactions took place in different settings for each of the participants. An additional aspect of the theme (D)eaf community included sign language and its' affects on participants' lives, as well as whether or not they grew up in (d)eaf or hearing families. That led me to include (D)eaf Community as one of the overarching themes across participants. The (D)eaf Community theme was also intertwined with (D)eaf Culture, (D)eaf Epistemology, and (D)eaf in general, so it's the best theme word that is still broad enough for me to discuss fully.

Coding Phase Five: Set up chronical timeline

The goal of this phase was to set up a highly visualized clustered chronical timeline to see if there are common threads of a particular time in the participant's lives that have the same themes. The sections I set up are as follows: childhood, teen years, adulthood, as well as secondary education, and post-secondary education. I created specific time period points for education in conjunction with their three major stages of growing up. The results of this phase illuminated patterns and differences in the participants' experiences. Sometimes these patterns presented themselves in unexpected places. For instance, Josie demonstrated the need for privacy in their childhood, while Molly shared the importance of privacy in adulthood and post-secondary education. The difference could be due to multiple factors: age of involvement with the (d)eaf community which occurred at early age for Molly, and late age for Josie, usage of hearing aid technology etc. Molly said they prefer to have the ability to be independent without depending on anyone for information, while Josie said they preferred not having the obvious: "Look at me, I'm (d)eaf!". Ronald shared a similar sentiment. They made a comment that they dislike being forced to sit in the front of the classroom just because they’re (d)eaf. During the coding process, I also noticed the theme of participants having to work extra hard to normalize. This theme appeared across all participants and it began early in their education and ranging from elementary to middle school. Molly, Josie, and Alexander, who attended mainstream schools identified this theme in particular. This shows an insidious concept that (d)eaf individuals have to think about the amount of work required to establish what is “normal”. I realized I had personal experience with this. I attended three different English classes in middle school to make sure I can be as good as a hearing person in English. Working extra hard to normalize occurred across all themes as it is intertwined with mental health, (d)eaf community, education, and privacy.

Coding Phase Six: Differences and Similarities

Phase six was completed using Excel with the goal of estimating the differences and similarities among the participants. Quantitative analysis of the themes can be helpful in qualitative research is because it helped me as the researcher to see the forest rather than the trees. It helped me see patterns and groupings in each participant and how they cross-over with other participants. I did that by combining all participant in a single list with columns for themes, number, and time period. I sorted by themes so I could see similarities and differences in the theme name coding. If the themes were similar and only need minimum changes to match, I did so. I highlighted instances where a change had occurred. I notice that the main changes I made were to streamline the themes. For example, the themes ‘accessibility education’, ‘accessible education’ mean the same thing, so I changed all instances of either to Accessible Education (Please see Appendix E). The final data set had 242 entries, and I was able to identify that the most significant themes as: Accessibility/Access, Mental Health, Family, Education, and Privacy. This confirmed my overarching themes are correct and identified that the theme of (D)eaf Community was ‘intertwined’ with themes.

Coding Phase Seven: *Life Stages and Narratives*

Following the thematic coding, I completed phase seven, for which I wrote out each participant’s life stories in two-page narratives, putting the stories in a consistent format. It helped to see the participant’s stories in life stages and in flowing points. The narrative summaries were the final phase of the coding process and provided me with the opportunity to look at each participant’s transcript and life as a whole. It helped me as a researcher because the last few coding phases focus on the small details of each participant’s transcript and comments. I wrote the life summaries by looking at each participant’s original transcripts and seeing the major points of their life in a chronical timeline. I also added direct quotes to show all participants’ direct thoughts. I kept the summaries short and further elaboration of the analysis is presented in the following chapter, Discussion and Findings (section 4.5), which includes analyses of the themes influencing the participants’ individually and overall.

Chapter Four: Results and Findings

Introduction 4.0

The current research was done using the narrative inquiry method through the cultural lens of the (D)eaf community. I chose to look at the stories of the (d)eaf participants through a cultural lens because the (d)eaf community has a beautiful culture and language that deserves to be recognized. The importance of examining lived experience from members of the (D)eaf community was front of mind as I looked over and interpreted the stories shared by participants. My focus was to draw out experiences of accessibility and access and how this impacted the participants information literacy.

To show you my process of analysis, the seven code phases will be discussed in order, with the in-depth analysis of the participants' stories. The participants have been given alias: One - Molly, Two - Josie, Three - Alexander, Four - Hermes, and Five - Ronald. See Appendix D for tables depicting the various phases of the coding process and approach to thematic analysis. All of the tables are only showing partial aspects of the particular phase in the coding. Before discussing the analysis and the overall findings, I begin by positioning myself with a summary of my own life story.

I feel that for you as the reader, and for me as the researcher, I need to show you what made me, me. Specifically, how being (D)eaf affected me growing up in the scope of socializing, education, and family settings. This is also to show you the road I took over my life, bringing me to this moment. This summary works in conjunction with the Reflexivity statement in Chapter 3 (Section 3.4). I wrote this summary after I conducted all five interviews.

Researcher Life Summary 4.1

My experiences throughout life resemble many familiar narratives of the (d)eaf community. When I was five, I attended an insular (d)eaf class, which was separated from the hearing classes, but coexisted in the same school. This experience exposed me to the concept of separateness at a young age: Us and Them. All I knew at the time was that my classmates understood me, and I understood them. The “outsiders” mostly did not understand me. I befriended a student from the hearing class and —to this day— she is one of my lifelong best friends. She attempted to learn the sign language instead of depending on interpreters to communicate with me. She was one of the rare ones. During my early education years (5 to 18 years old), I went through periods of high and lows. The most prominent influences on my highs and lows are English and the (D)eaf Community. When I learned about information literacy, I finally understood what I had been struggling with in my early education. I remember having a total disconnect or disassociation from information that is really important to me. I wonder how the disconnect from important information has impacted other (d)eaf people, especially because I have more access in comparison to others. My family knows ASL, I had interpreters in school, and despite that I still struggled with information literacy early in my education. For instance, I didn’t understand why sex education was important or what it has to do with me when the teacher taught it until I got my period. That was mortifying for me to finally understand what it means to me as a human being. That was with an interpreter in the class. I understood the topic further when I managed to discuss it with my fellow (d)eaf peers; when I saw them, they were able to explain to me about the topic more in-depth. This was the beginning of (D)eaf epistemology — sharing stories and experiences— having a large presence in my life.

At that young age, the separateness was simply divided between the inner —those within my (d)eaf classroom— and outer —those from the hearing classes. I had my life inside the school, in several particular rooms, with my classmates my age or older. We had recess with the hearing students, but they did not come up to us often —except to gawk or harass us. Now at 25 years old, thinking back to that moment in my life, it had a significant impact on how I reacted to subsequent experiences. After three years of (d)eaf classes, the (d)eaf classroom closed for good. The closure was the last gasping breath of a (d)eaf community that once held up the (d)eaf school as their centre of (D)eaf culture.

I was immediately put into mainstream school. They held me back one year, but I did not understand at the time that it was something "bad" because my parents decided to simply not mention that I was "held" back. All I knew was that I was still in grade three and the oldest student in my class. I was awkward and had to get used to having an interpreter full-time in my classes, not having the teacher signing to me, or having any classmates who could use sign language fluently with me. I felt like I was a fish out of water, trying to gasp for air in the different environment.

I struggled with making good friends because I had different ideas of what friendship represented. In the small insular (d)eaf classroom, with classmates who were just like me, we had a pack mentality. Fast forward to the fifth grade, I was more open, more stubborn, and closer to the original personality I had in preschool to grade three. In grade five, my little sister was transferred to my school from her French immersion school and I learned that I was held back one year because I had to share the same classroom with my sister, who is 14 months younger than me.

That moment is not something I care to remember; I felt shamed —like I'm stupid, and dumb. I asked my mother about it and she remarked that the mainstream school did not feel that I was "ready" for grade four. I understood this to be code words for: "You're did not get the education you were 'supposed' to in (d)eaf class." In that moment, I felt strong hatred for the fact I was (D)eaf. I was asking myself —and the whole world— one question: WHY? Why do I have to suffer while not fully understanding what is wrong with the system? Why do I have to go through all of this? Why do I have to be (D)eaf if it's not something to be prized? Why do I have to be (D)eaf if it's not something to be welcomed? I recall sitting down with my Atlantic Provinces Special Education Authority (APSEA) teacher and asking her, "Why did I have to be held back? Can I move to my rightful grade?" I argued with her that I'm smart enough, good enough, and I do not need anyone to hold me back. I recall her expression: she looked unsure but at the same time in agreement with me. She proceeded to have discussions with the school that I was not privy to but in the end, one month into the school year, I was moved to grade 6. I was, once again, exposed to an alien environment, with new classmates that I hadn't spent the last two years with. I stubbornly carried on even though I struggled with the math quite a bit since I was skipping the entire grade 5 math classes. I made new friends and taught them some signs. The familiarity was short lived as I was exposed to the dreaded transition into junior high school. I recall I was so excited because I felt like I was finally growing up, becoming a teen, and in the process of maturing. From grade seven to high school of mainstream, I went through a lot of high and lows. The highs have a lot in common: I was hanging out with people like me. I felt exuberant, happy, comfortable in my skin — despite my horrible puberty— and genuinely open with my real self. The lows include sitting on the bed wondering: Why do I have to be (D)eaf? Why can't I be like my family or the students at the school I have to go to? Why do I have to deal with all of this? I have pride in being (D)eaf but even I have my moments of crying tears of bitterness, frustration, pain, annoyance, and defeat.

The reason I know English very well is because I learned to love reading. In the sudden transition from grade 5 to grade 6, I was going through a lot of terror, nervousness, experiencing the true start of my puberty and feeling just plain unsure. I started reading the series *Madison Finn* by author Laura Dower and fell in love with the character. I constantly begged for more of her books and I felt a bond with the character. From there, I started reading more and more until it become something I did on a daily basis. I took in books with different stories, different genres, to find my preferences. In the seventh grade, I also travelled through the lands of poems and fell in love with the freestyle poems because they're something I can write myself. I recall one project required us to create several poems in specific styles. Some of the poems needed to rhyme so I piped up and ask the teacher if I could simply switch the rhymed poems out for freestyle. With this request I experienced the first resistance between myself as a student and a teacher. My teacher insisted that I can write the poems myself. I argued that I cannot hear the rhyme of the words: How can I write the poems if I do not hear the rhyme? In the end, I was forced to write the poem with the teacher pushing me along with words she knows rhyme with the words I suggested. It was not a fun time for me.

This experience made me shy away from English after so voraciously taking it in through various books and poems. I was forced to take three different classes from grade seven to nine in English. Normal English, English Plus, and the English class provided by APSEA. Normal English was the regular class with other students; English Plus was a literature class; and the APSEA English class involved going over all the work I did in English and English Plus. It was hell. I had to constantly learn how to use verbs, tenses, adjectives, nouns, pronouns, how to check grammar, etc., until I felt like I no longer can learn more. I felt my brain bending under the strain of getting my English as perfect as I could get it to be.

After years of the constant ups and downs, in the summer before grade 12, I went on a summer camp trip that changed my life. The summer trip was to Gallaudet University —the only (d)eaf university in the world— and completely shifted the paradigm of my mindset of how I can exist in the world. The trip was one week of complete ASL, short tastes of college classes, hanging out and eating with (d)eaf people—all on one beautiful campus in Washington, DC. Unlike the (D)eaf camp I went to each year in August, Gallaudet University functions all year round. It is deeply rooted in all of the heart of the (d)eaf people who go there, and it held up a torch of hope for me. My eyes had been shielded for so long while I coexisted with the hearing people with the only occasional (d)eaf events and annual (d)eaf camp. The trip to Gallaudet University opened my eyes to a new way of being. I did not have barriers during that one week. I did not have to struggle to communicate with anyone. I did not have to hold back tears of frustrations while attempting to articulate my ideas that my interpreter can understand without re-asking me what I mean. The experience at Gallaudet University exposed me to the idea that it is definitely possible to have no barriers for the (d)eaf community, and for me as a (D)eaf individual. I insisted that my mother send me to a (D)eaf school. I believe that I would be happier there than mainstream. I did a lot of research and end up at Ernest Drury School for the (D)eaf (ECD). In the one semester I spent there, I made a lot of friends, joined the swim team, did three plays with leading roles, went on field trips, walked around Toronto with my friends and finally felt like a teenager. The school was not perfect, however, because I was forced to go back to my hearing school because of problems with credits. I would have to remain one more year at ECD to complete all of the credits for Ontario, or I could leave and do the last semester of grade 12 at my old mainstream school. After returning to the mainstream school, the last semester was difficult for me. I had to come back from the vivid smiles, jokes, no barriers, and lots of friends at ECD. I returned back to a life that felt less colourful, with plenty of barriers, tight smiles, raised eyebrows, and pitying looks.

The effect that had on me was profound, my mother became worried that I would not be able to graduate on time because I was skipping quite a lot of classes. I had no desire to go to school with hearing students, but I did all of my homework at home and passed it in on time. My mother was frustrated with me and did not understand why I did not feel like going to school. I was frustrated with her too; I did not understand why she could not see how I was suffering. I was going through a labyrinth of suffering, constantly going in the wrong direction and getting hurt because of it. I was struggling to find my way out of the labyrinth, and I had no idea what to do. I had been exposed to an amazing life at ECD and Gallaudet University but it was not something easily reached and I felt that it was just beyond my grasp.

Once I entered my university years, I choose to attend Gallaudet and I am better for it. I attended for two years until I was unable to continue under the strain and stress of student loans. Gallaudet is located in United States of America (U.S.), so I was considered an international student. That meant the tuition was higher for me. After two years, I became too stressed about my tuition and how I would be able to pay back that. Similarly, to my experience at ECD, I had to make a choice. Is it worth doing two more years under that strain? Or, should I choose to attend a hearing university in my hometown for an affordable education? As an international student, I have to pay $40,000 per year for an education at Gallaudet, while American students pay around $25,000. My province did not give support for Gallaudet until I convinced them that they would be paying for interpreters for me anyway if I stayed in my province. They reallocated that money to me as grant funds for Gallaudet —but it was not as much as I needed. Other provinces, like Ontario and British Columbia, give better support from what I hear among my Ontarian and British Columbian (d)eaf friends. I ended up choosing to move back to my hometown and I do not regret it. The reason for this is because I'm grown up and I have the ability to see any (d)eaf friends I want in my city. I feel less isolated for that reason. As a child and teen, you depend on your parents for permission, transportation and such. As an adult, you can grant yourself permission. Since returning to my hometown and attending a hearing university, I had graduated with a Bachelor of Art in Philosophy and am currently working on my Master's in Library and Information Studies (MLIS).

Self-Reflection 4.2

The reason why I have gone in-depth with my life summary is because I feel, in a sense, guilty about my research into the (D)eaf community. I have relationships with all five participants and now I have to use the information they provided me to serve my research. I was able to be very responsive and empathize with my participants during our interview sessions. However, for the purpose of this thesis, I now have to take this information and showcase it. Because I am a (d)eaf individual too, I chose to be transparent and share of myself as well. In this sense, I am a participant of this research, even as the researcher. The degree the participants agree or disagree with some, parts, and/or all of my interpretations is unknown. I ensured that my participants are aware of what I will do with their information through consent forms, discussions, and in-depth descriptions of my research.

Participants’ Life Story Narrative 4.3

The two-page narrative summaries for each of the participants is the final phase of the coding processes (please see Chapter 3, Section 3.6.2 for a more detailed explanation). I chose to use plural terms instead of gender terms to achieve two goals: 1) to anonymize as much as possible; and 2) it is the general sign used in sign language. To be clear, when (d)eaf people refer to a person, we rarely use she or he in our signs. For instance, where in English one might say “She will do the work”, in sign language we use our hand to gesture by either pointing or presenting a flat hand toward the person followed by sign for “…Will do the work.” That shows how we use ‘they’ and ‘them’ more often in sign language.

PARTICIPANT ONE: MOLLY 4.3.1

Molly grew up in Nova Scotia within a (D)eaf family, as their grandfather is (D)eaf. Their mother used sign language to communicate with Molly. Molly went to (d)eaf school at first, then switched to mainstream. Molly switched because of what their mother found out about the (d)eaf school from their grandfather’s experiences and the shared experiences other people who worked and attended there during Molly’s childhood. Molly commented that they were very upset that they were unable to go to a (d)eaf school until they found out from their mother that there was abuse occurring there. Molly was upset about not going to (d)eaf school because at the mainstream school there was a lack of interpreters, socializing, and she felt isolated. Molly is able to lip read and do oralism, but it fatigues them. They experienced this particularly as they transitioned from elementary to middle school/high school. *“In the past, there is not much information. I have to ask people, struggle, I ask people to tell me things, but they do not tell me everything”* (Molly). That was due to how the different classes caused Molly to tire out faster because of looking at different people’s lips and trying to memorize them.

Molly graduated from a mainstream high school at 18 then was hired to the job that they are still working now decades later. They love their current job very much. Molly said that one of the definitive things about their education is that they had to work very hard on it because they have no interpreters. *"The short sentences were fine, but it lacks context for me" (*Molly). Molly was speaking about how the notetakers always took notes in shorthand which end up vexing them because the notes lacked context. This created more work for Molly, who was already focusing to on the teachers lips during classes. They had to ask people for extra help or teachers for more time to do work. At the time, it seemed normal to them that they had to put in extra work and time. Molly also has to deal with helping her fellow (d)eaf friends and family: *"I need to work to lower my level to their level. I just thought about my grandfather and my ex-partner and my current partner, how they're all from Amherst school and Halifax school*" (Molly). In Bat-Chava's (1994) article they examine self-esteem in "smarter" than average (d)eaf individuals, who have to navigate feelings of resentment when they feel like they have been put on a pedestal or heavily relied on to provide extra help.

PARTICIPANT TWO: JOSIE 4.3.2

Josie was born (D)eaf into a hearing family. They grew up using oralism with their family who do not use sign language. Josie used hearing aids and FM system growing up. One of the most noticeable aspects of about Josie shared experience is their genuine lack of awareness regarding which resources were available to them as a hard of hearing individual growing up. Nowadays, they identify as (D)eaf community member. Back then, they identified as hard of hearing (HOH), they lacked (D)eaf role models and were not "aware" that the label (D)eaf could be applied to them. For example, when they were in high school, they witnessed a (d)eaf student using an interpreter but never thought that particular resource was for them to use because they do not know sign language at the time. They were also used to working extra hard in school where they used lip reading, depended on others to take notes for them, and stayed after school to ask for extra help. All of this caused Josie to feel fatigued, but they did not realize how tiring it was until they attended university and received interpreters after they learnt sign language. They provided interesting input on how privacy is a large issue for them, and how they had a strong desire to be seen as just a normal child: "*Also, they can see my chest system. I was adverting that I was (D)eaf by just the FM System*" (Josie). It's not just Josie, many other (d)eaf people complain that they try their hardest to hide their cochlear implant (CI) or hearing aids or FM system etc., because they want to be "normal" in the general hearing world without being point out to be (D)eaf. I know that from personal experience and hearing from other (d)eaf people. That does not mean they are ashamed to be (D)eaf.

Molly's teachers compared them to their hearing peers. Despite this, Josie graduated from university with high marks, which was a change from their low marks in secondary education. They had access to resources, such as interpreters and advanced technologies, which influenced their academic work. Josie's favourite thing is to travel the world, but travelling comes with its own perils. In one instance, Josie missed their flight because they could not hear the airport announcing that their flight had changed gates. At the time, there were no TVs showing gate numbers and times. Josie had to deal with communicating with the airport and getting a new flight. Her experience in airports is a further example of "normalizing extra work" since Josie has to be hyper-vigilant. This vigilance can be exhausting if you're supposed to be on vacation and excited about travelling to a new place. Nowadays, transportation has better accessible technology but there is still need for improvement.

PARTICIPANT THREE: ALEXANDER 4.3.3

Alexander was born (D)eaf into a hearing family. One of the key differences that set Alexander apart from the four other participants is their experience as an immigrant. Alexander can clearly remember growing up abroad and moving to Canada when they were in their teens. That caused them to have an interesting concept of what locality meant to them: *"I have different experiences based on location. It feels like a UFO took me to a different planet*" (Alexander). The feeling of being overwhelmed by a new environment can be described as 'Harry Potter Syndrome', which is a real thing for the (D)eaf people who actively become involved in the (D)eaf Culture/Community. Harry Potter Syndrome is when you feel disconnected from general society similar to Harry Potter and the non-magical population otherwise known as muggle in the HP fandom. Harry Potter feel at home at Hogwarts around wizards, similarly to how (d)eaf people will feel at home around other (d)eaf people. (Czubek & Greenwald, 2005). Or general culture shock which happened to Alexander when they moved from aboard to Nova Scotia.

Alexander noticed little things like dogs being allowed inside in Canada while their birthplace does not allow dogs inside the house. Alexander remembers going to oralism school in their birthplace. But once they moved to Canada, they were put in a hearing school because their family was not fully aware of resources they could get for their child at the time. Once they became aware, Alexander was put into (D)eaf classes in a mainstream school with interpreters provided. Alexander experienced the typical immigrant situation of learning English in addition to American Sign Language (ASL). Once they became fluent in sign language, they say that interpreters changed how much they understood and learned from the materials. *"The interpreters were better than the teacher. They actually help me more than the teachers. No* *questions. Without them I won't be able to success*" (Alexander). They claimed that they couldn't have done it without their interpreters. Once they entered the (D)eaf class, they developed a strong sense of (D)eaf identity and cultural pride. This followed them throughout their life to this day.

PARTICIPANT FOUR: HERMES 4.3.4

Hermes grew up in rural Nova Scotia with two (d)eaf sibling and hearing parents. They started their secondary education at the local school in a class known as the "(D)eaf class". They, along with a few fellow (d)eaf students, were taught, primarily in oralism, by a single teacher who came from the Amherst School for the (D)eaf. Hermes was eventually sent to Amherst School for the (D)eaf, but their younger (d)eaf sibling stayed behind at the local school. Later on, Hermes mentioned that they wish they could had stayed with their younger sibling because – from their point of view– their younger sibling got a better education than Hermes did. Hermes did not graduate from high school, but that was common for Amherst School for the (D)eaf.

The students were generally sent to vocational school at 16 to learn carpentering, mechanics, sewing, and such. Hermes said that it was decided by the government that vocational training was the best way for the (d)eaf people to become gainfully employed. Rather than education or preparation for the work force, Hermes thought: "*Really, the top benefit of going to the (D)eaf School was the socialization*" (Hermes). Hermes' favourite teachers happened to be the (D)eaf teachers who use sign language. Their reason for this is because of the stories the teacher told the classes about things like Gallaudet University and general life experiences. I find this very interesting because of the current standard of knowledge for the (D)eaf community is very similar to Hermes' favourite teachers' story telling. However, in Hermes' comments, it appears that education was an after-thought for most of the students because of the lack of emphasis on how important education is.

For example, Hermes did not fully understand how important education was until they were looking back at their experiences as an adult. Hermes also comment that the memories of education was disorganized and hazy. When they transferred to the school, they were taught things they already knew, along with things they didn't have any foundation of knowledge in. That was the major cause of Hermes' comments of wishing that they had stayed with their younger sibling.

In the last several decades, Hermes has been working at the same job and they say they don't mind working there. However, it was not a job they were originally trained for at the vocational school. They tried to search for jobs in the field they were trained in but were unable get on because they only communicate in sign language and are not skilled enough in oralism. Hermes is an active participant in the (D)eaf community, volunteering with several (D)eaf organizations, committees, and associations. Hermes is worried about the shrinking (D)eaf community because there is a strong lack of (D)eaf youth who are willing to take over positions for the older (d)eaf people.

PARTICIPANT FIVE: RONALD 4.3.5

"*Growing up, I was confused about who I am. My siblings were all grew up and leaving. I was isolated because I couldn't understand what people talk about as well"* (Ronald). Ronald grew up the baby of a large family, and as the only (d)eaf person. Ronald was not recognized as hard of hearing (HOH) until they were six years old. This was after their first year of school, where they failed at everything. Ronald was confused about who they were and why they could not hear everything. Once it was established that they were hard of hearing, they were sent to the

Amherst School for (D)eaf. "*But I learnt how to sign naturally, I no longer get teased or bullied. I feel happy because I found where I belong"* (Ronald).

Ronald was confused when they entered the school and saw hands flying around (ASL). Their brother left them at school because the (d)eaf school is a boarding school. Ronald was scared, but once they learnt how to use ASL they felt like they were no longer alone and that they belong. However, the school primarily use the oralism method. This affected Ronald's viewpoint of the school.

> *"Some teachers would go behind the law and principal's back to sign to us. But the others don't like it and want us to learn how to oralism. To be honest, it was very boring. The thing I remember clearly from grade 5 and 6 was that I learn from the other students. At night-time, socializing with the other students using sign language. I learn from them. Very small percentage of what I learnt come from the teacher"* (Ronald).

For the students to see teachers fighting to teach (d)eaf students in their rightful language in secret evoked strong feelings in the (d)eaf children. The strong feelings ranged from comradeship to extreme emotions. Ronald shared that they learned more from friends and teachers through socializing and using ASL than in the classroom.

However, a very small percentage of what they learned in school was from teacher. Ronald did not graduate high school, and similarly to Hermes, they attended vocational school. Unlike Hermes, Ronald was able to work in the field they were trained for. Through a great deal of hard work Ronald eventually owned a business. Ronald also suffered from depression throughout their adult life but combated it by going to the church, speaking to their family, and trying to be positive. Ronald also suffered from isolation from their family due to their family's lack of fluency in sign language. They commented that at their mother's funeral they told their siblings to "Fuck off" because they broke their mothers' heart by leaving Ronald in a cold corner. That was the only time Ronald told their siblings how they really feel about their entire life with their family. Sadly, the experience of isolation from family is a common feeling among (d)eaf people who are born into a hearing family. Hearing families can lack the awareness or knowledge that the (d)eaf family member comes from a beautiful and proud culture with strong language.

Overarching Themes 4.4

During my analysis process, I identified five overarching themes that cross over all participants' stories and experiences: Privacy, (D)eaf Community, Education, Mental Health, and Accessibility. The five major themes are themselves inter-related and tightly intertwined. In order to explore each theme adequately they need to all be positioned within the (d)eaf individual's life accurately. In the following, I outline each of the themes and how they related to the participants.

PRIVACY THEME 4.4.1

Choices are one of the most important things an individual can have in their life. Choices can be considered a privilege and in the case of (d)eaf people, choice is of particular importance when it comes to privacy. For this research, we will talk about the levels of privilege available to (d)eaf individuals in general. If an individual has less privilege, it can negatively influence the choices they are able to make. For example, if an individual has less money, it leaves them with fewer choices in housing, food, opportunities, and leisure. Similarly, if an individual is less able-bodied, they too have fewer choices in jobs, activities, and leisure.

The loss of privacy is experienced by (d)eaf individuals through the deprivation of the ability to communicate in our natural language on a daily basis with full understanding of everyone around us. This act of deprivation of communication also clearly indicate that there is a loss of privilege because in such situations, the hearing people will not have any issues with communication. That decreases choices in education and access to information as well as job opportunities. Most job applications include the requirement to communicate orally. As signers, we do not communicate orally, we communicate with our hands —not our mouths. Many jobs come with the requirement that the applicant can communicate in oral and written language. This causes doubt and insecurity and keeps many (D)eaf individuals from applying for jobs we are qualified for. Fewer opportunities in education and access to information also can cause us to become dependent on government, family, and friends for support in finding jobs and finishing education careers.

There are a variety of privacy issues represented in the participants interviews. The dictionary definition of privacy is: "*the state or condition of being free from being observed or disturbed by other people"* (Lexico, n.d.d). The UN Declaration of Human Rights identifies privacy as a human right (United Nations General Assembly, 1948). Along with that, the UN's Convention on the Rights of Persons with Disabilities (CRPD) Article 22 includes the following:

> No person with disabilities, regardless of place of residence or living arrangements, shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence or other types of communication or to unlawful attacks on his or her honour and reputation. Persons with disabilities have the right to the protection of the law against such interference or attacks. (United Nation, 2006)

I interpret that interference of privacy occurs when a (D)eaf individual signs, or uses a visible hearing assistive technology; it indicates to the hearing society that they are (d)eaf without the (D)eaf individuals express permission. Josie mentioned the strong desire to have a less obvious hearing aid device, because as a child they used a device that was strapped to their chest. They couldn't play during recess in winter without unzipping their jacket to hear their friends if they tried to speak to Josie. According to the definition of privacy presented above, they were not free from being observed to be (d)eaf. In turn, Molly desires independence because they sometimes need to be able to find information on their own without asking people. For instance, they are more likely to use Google to find information rather than sourcing interpreters and hearing people who may know the information. They say that they ask interpreters and hearing people if they cannot find the information independently. Alexander, Hermes, and Ronald had similar comments, sharing that they did not want to be 'forced' to do things —like sit in front of the classroom— just because they're (d)eaf. This example shows how the participants lost the privilege of choice. It also reflects how their privacy was disturbed or impacted by other people. At various points in their lives, all of the participants had been disturbed by other people or observed by other people due to their (D)eafness. We feel insecure and have fewer choices in what we want to do for our career or future. In privacy terms, we are set apart by the fact we can't be fully independent in our career or education opportunities without requiring further accessibility. The UN Declaration of Human Rights, Article 12 states: "*No one shall be subjected to arbitrary interference with his privacy, family, home or correspondence, nor to attacks upon his honour and reputation. Everyone has the right to the protection of the law against such interference or attack*" (United Nations General Assembly, 1948). The article can provide guidance when considering how interference violates (d)eaf people's right to privacy.

Table 1 shows how the theme Privacy was coded within the specific time period and participant number. The title column includes the coded themes with the red fonts representing the changes I made to the themes if necessary. The description of the coding phases in Chapter 3 (Section 3.6.2.) articulates the decisions regarding changes the time thematic titles. The Time Period indicates time when the coded theme occurred —childhood, secondary education, teen hood, adulthood and post-secondary education. The third column contains the participant number for the code is relevant. This facilitated setting up a chronical timeline to give a better idea of what topics was the most important ones to individual participants in sections of their life. The reason I included adulthood and post-secondary education is due to the fact not all of the participants have a college education but all of them have reached adulthood.

Title	**Time Period**	**Participant**
Accessible Privacy Privacy and Accessible	Secondary Education	2
Accessible Privacy Privacy and Accessible	Secondary Education	2
Privacy	Secondary Education	3
Privacy	Teenhood	2
Privacy Accessible Design Privacy/Accessibility design	Adulthood	4
Privacy Accessible Design Privacy/Accessibility design	Adulthood	4
Privacy and Accessibility	Post-Secondary Education	1
Privacy and Education	Secondary Education	4
Privacy and Mental Health	Adulthood	4

Title	**Time Period**	**Participant**
Privacy and Mental Health	Adulthood	4
Privacy and Normalizing	Teenhood	5

Table 1: Privacy Coded Themes shown in the Phase Six of the coding process.

As can be seen in Table 1, the theme of Privacy was present for all participants. Josie was coded with the specific subtheme 'Privacy Accessible' due to their comments on how their hearing aid was not elegantly designed and did not help them hide their (d)eafness from the world's observation. Molly discussed how they like their independence and that was influenced heavily by how some (d)eaf people 'depend' on Molly to teach them things. That caused exhaustion, both mentally and physically, for Molly. However, when there were more resources in ASL, Molly felt the strain lessen. For instance, Daily Moth —an ASL news page on Facebook— became popular and Molly no longer had to describe news in sign language. (D)eaf people can look at the ASL news videos which allows Molly to be "free from being disturbed" (Lexico, n.d.d). Therefore, Privacy and Accessibility are intertwined for Molly and perhaps all other participants as well.

Hermes' experience was coded with the theme Privacy Accessibility Design. Hermes made several comments regarding how technology like Video Relay Service (VRS) is not designed for privacy. For instance, Hermes has to use VRS while at work because that was the only location the Wi-Fi works perfectly for Hermes. Since they have to use the VRS in public, Hermes is observed by other people while having what would amount to private phone calls in hearing world. Similarly, (d)eaf people who depend on and use interpreters for communication on general daily basis have to deal with interpreters knowing their private business. It is generally simple for hearing people quickly excuse themselves from a situation to have a private phone call. In comparison, (D)eaf people have to figure out where the Wi-Fi is and consider if they will be observed while they use sign language for the private phone call. The use of interpreters is also complicated. Though they are meant to provide accessible communication it takes extra time and energy for the (d)eaf individual to account for another person. Interpreters are present during incredibly personal situations like funerals, weddings, doctor appointments, emergency situations, and classes on a daily basis. They witness (d)eaf individuals in all moments of their life: crying when they are told someone in their family is going to die; laughing at inside jokes with friends in class; and smiling ear to ear when they get promoted. Interpreters see all of the good and bad moments in (d)eaf individuals' lives. They are bonded under the general confidence guideline. There are various different guidelines, however the ones relevant to this research are: The Registry for Interpreters of the Deaf. (RID)'s Code of Professional Conduct (CPC) and the Canada Association of Sign Language Interpreter (CASLI)'s Code of Ethics and Guidelines for Professional Conduct. CASLI was previously known as Association of Visual Language Interpreters of Canada (AVLIC) but officially changed to CASLI in 2019. (CASLI, n.d.) The guidelines require that the interpreter does not discuss any events with anyone expect their fellow teamer (interpreter) who are involved with the situation. This is only lifted in situations where the client may harm themselves or others (Registry of Deaf Interpreters, 2005; Canada Association of Sign Language Interpreter , 2000).

> Heightened public awareness of signed language interpreters
> during emergency briefings has contributed to the perception that
> signed language interpreting is a one-size-fits-all accommodation,
> similar to curb cuts or closed captioning. (Blankmeyer Burke, 2016, p. 270)

The problem with that is it fails to take in account that each individual has different preferences and accommodation requirements (Blankmeyer Burke, 2017). Along with that, hard of hearing and (d)eaf individuals' preferences for communication vary from ASL interpreters to speechreading. These issues are recognizable in Alexander's story about their personal frustrations with interpreters.

Privacy was a theme that came up in Alexander's story as well, specifically regarding privacy and interpreters and independence. Alexander told of an experience they had dealing with an interpreter in the classroom. Alexander had a strong preference for watching the teacher writing out equations on the blackboard rather than writing down notes. The interpreter, who was 'new' to Alexander, forcefully told them to pay attention. Alexander was deeply frustrated with the interpreter because the interpreter was blocking Alexander from learning using their preferred method. In this instance, the interpreter was not allowing Alexander to be independent or *undisturbed* in their learning process, which might have drawn attention to Alexander without their voluntary permission. Though the interpreter was there to provide accessible communication and education, Alexander did not feel that particular interpreter added value to their education.

The themes of Privacy and the effort of Normalizing were prevalent for Ronald. They prefer to make their own decisions and not being seen as different. For Ronald, not being seen as different isn't about popularity, they just don't want people to see them instantly as (D)eaf and stereotype them. Even with hearing aids, Ronald struggled to lip read and understand the teachers. This caused them to be identified as (D)eaf and kept them from being independent. They were not involved in or invited to special events like Christmas concerts because Ronald was told that they talk funny. This was heart-breaking and showed that the school was not inclusive and did not offer accessibility to the children. (D)eafness caused some mental and emotional trauma for Ronald, an experience that is shared by some of the other participants.

Analysis showed that privacy is important to all participants and is intertwined with them being (D)eaf. It is also clear that privacy is intertwined with mental health, accessibility, and education for all participants. Taking the (d)eaf-centric viewpoint illuminates how being (d)eaf affects the privacy and private rights of the (d)eaf individuals.

The range of inaccessibility and accessibility experienced by (D)eaf individuals is influenced by various factors. For instance, Alexander's complaint about what happened with the interpreter affected how the accessibility service work for them in this moment. Also, Josie's issue with being visually identified as (d)eaf due to their hearing aid technology. Josie was impacted by inaccessible privacy and design. These different stories made me think (d)eaf individuals experience accessibility and access in various 'levels'. The experiences shared by the participants regarding interpreters who know intimate details of your life, or impact your educational experience, or hearing technologies that make an individuals' (d)eafness visible led me to the question: Is accessibility worth the loss of privacy?

MENTAL HEALTH THEME 4.4.2

The theme of Mental Health is at the core of the experiences shared in this research. Mental health encompasses stress, fatigue, illness, trauma, physical, and emotional pain. Mental health is defined as the configuration of our emotional, psychological, and social well-being (U.S. Department of Health & Human Services, 2019). Mental health also includes how an individual responds to stress, intense situations, and life in general. For all participants in my research, mental health has some type of importance to them in various forms —unconsciously or consciously. During my analysis process, I realized the impact mental health can have on people’s perspectives. If an individual suffers trauma in school from interactions or a lack of accessibility, it affects them for the rest of their lives, which impacts their perspective on school. The perspective can twist school into something that hurt you and makes you never want to go to school. The trauma can range from mental to physical harm occurring from abuse of power, education, and deep shame or embarrassment. The individual may also associate the painful school experience with learning, which could have long term impacts on the desire to learn. According to psychology these types of long-term impacts are typical with trauma (Lerner & Keltner, 2000; Lewis, 2008). I also have to think about how stress, fatigue, and other factors affect the participants’ thoughts and feelings on the topic of education, life, (d)eaf community, and their general mental health.

Table 2 in Appendix D, which is too large to include in the body of the text, shows the Mental Health codes and their frequency per participant. Mental Health during the coding process was compounded with many different topics: (D)eaf Epistemology, Education, Family, Friends, Shame, Privacy, Expectations, and Stereotypes. The time of life periods that are of particular importance are childhood, teen hood, and secondary education. These life stages occur during the most formative and impressionable ages between birth to 18 years old. Molly emphasized how they wanted (d)eaf socialization during their early years. However, they were denied attending a (d)eaf school was because their parents feared that Molly would be abused like their grandfather. In this case, their (d)eaf family was trying to look out for their child’s well-being. However, by not attending a (d)eaf school they were also denying them opportunities to socialization and access to education.

Molly grew up going to mainstream schools without interpreters which was fatiguing and caused stress. As mentioned earlier one of the questions in the research involves considering the range, or ‘levels’ of accessibility. Is it worth having a better education with less accessibility at the price of mental health issues? Molly’s shared experience shows that the various levels of accessibility exist and influence their mental health. The complex interaction of factors is particularly important when considering accessibility resources for (D)eaf individuals. Accessibility cannot be good for the (d)eaf individual if it comes at the price of their mental health or education. Hermes discussed inferior education that occurred when they attend the Amherst School for the (D)eaf. They did not get to graduate from the (D)eaf school and had to attend vocational school instead. In direct opposition, their younger sibling stayed at the mainstream school –without interpreters at the time– and graduated from high school and went on to receive post-secondary education. Hermes said that the only benefit of going to the (D)eaf school was the socialization. Ronald attended the same school as Hermes, and they have similar comments saying that they also learned more from their (d)eaf peers than from the teachers. Molly emphasized the importance of mental health later on in their adulthood. They shared that their (d)eaf partner struggles with mental health issues because of the Amherst School for (D)eaf. They also notice that other (d)eaf people, even the most positive outgoing (d)eaf individual, can have severe mental health issues like depression.

It is important to note that ‘inferior’ education is not caused by schools for the (D)eaf. Rather, it is the practice of oralism and the decision to follow the governments’ out-of-date recommendations as mentioned in the Introduction chapter (section 1.1). Those recommendations caused Hermes and Ronald to attend vocational school because it was believed at the time that (d)eaf people should attend vocational schools if they are unable to pass as hearing people. Nowadays, Schools for the (D)eaf are much better and practice the bilingual approach, for example teaching English and American Sign Language. However, none of the participants in this study –except possibly Alexander– benefited from the bilingualism approach.

Josie and Molly attended mainstream schools without interpreters. However, Josie did not grow up with a (d)eaf family, nor did they have access to the (d)eaf community. Josie commented on how much work they had to do to ensure that they understood the materials because lip reading causes fatigue and is imprecise. I asked them if they knew they could have had interpreters and they responded that they were not aware that it was applicable to them. They saw another (d)eaf student with an interpreter but didn't think: "Hey, do that mean I can get an interpreter too." They thought the (d)eaf student was 'different' from them. How can a (d)eaf individual be expected to have accessible education if they do not know what resources are available to them?

Josie did not self-identify as having any mental health issues. However, I noticed that when they told me stories about their adulthood, that they were more positive in their outlook on people and general activities. This may be due to their ability to get interpreters in university and that around that time, accessibility technology had gained more momentum. For instance, they got to use technology like Text to Telephone (TTY) to call home instead of using snail mail. The usage of assistive technology and interpreters seemed to improve their outlook.

Alexander was an immigrant in their early teen-hood. Before they immigrant to Canada, they were in an oralism school without interpreters. One of the defining memories they told me about was when if they misspoke letters, the oralism teacher would use tools like metal vibrating spoon to put between their teeth to 'teach' them how to say a letter correctly. To this day, it's why they cannot roll their R's. They also had to deal with the stress of seeing war in their home before they immigrated to Canada. After they arrived in Canada, they were assessed by the

Atlantic Provinces Special Education Authority (APSEA) and put into a (D)eaf class. I noticed how they became more animated in describing their life from this point on. They had interpreters but had to learn English and ASL because they only knew their native language when they arrived in Canada. They also commented that they are happy to be able to communicate fully with other people. At one point, they were on a hearing soccer team, but they became isolated and sad because they were unable to communicate fully with the coach nor teammates. They quit soccer but when they found a (d)eaf team with a coach who know sign language, they had the best time. They also improved their soccer skills rapidly thanks to being able to communicate in sign language.

Ronald admitted to experiencing depression and some suicidal thoughts because of how rough their life was with their hearing family and school. They suffered isolation from their family and the trauma of abuse while in the Amherst School for (D)eaf. Ronald has a more positive outlook and they attribute that to their family —their children and wife—, religion, and the close friendships that they have developed over their lifetime. Their relationship with their extended family, like the experience they shared from their mother’s funeral, seemed more negative. Ronald told the story of what happened at their mother’s funeral with a stone face when during other parts of the conversation their face was very expressive. Ronald also told a story about how one of the younger members, a great-niece of their family, got cochlear implants, and how it made them feel unwanted by their siblings. Their family member’s choice to use CI for their own children made Ronald feel judged. Ronald commented that they understand that their family used that technology because they want what they perceive as best —hearing— for their children. Ronald’s insight on that is very empathetic and understanding despite feeling sad about it. That made me certain that family are a large part of mental health because Ronald, Josie, Alexander, Molly, and Hermes all attained some pain, happiness and success to their family in various forms.

Mental health is an important theme and it had a large impact on the (d)eaf individuals' life. To foster and support mental health requires taking into account various factors like (d)eaf community involvement, best educational approaches, family support, and understanding privileges and privacy.

DEAF COMMUNITY THEME 4.4.3

When a (d)eaf baby is born, they automatically gain entry to a linguistic minority community and culture. However, this automatic birth right entry does not mean they are immediately aware of their membership in the (D)eaf community. Josie, Alexander, Hermes, and Ronald did not enter the (D)eaf community fully until they were older. Molly lived in the (D)eaf community their whole life because they were born to a (d)eaf family. The (D)eaf Community theme is important in my research because I want to analyse the impacts of involvement in (d)eaf community on the participants' mental state and education. The exploration of the (D)eaf community in this thesis has many sub themes: (D)eaf Epistemology, (D)eaf Culture, Sign Language, Language Access, Stereotypes, and Audism. My identification of some of those sub-themes comes from my personal knowledge. For example, the word 'audism' is one that I am familiar with from my own experience. Audism means seeing (d)eaf people as inferior or something to be fixed —something that is closely tied to the privileges of hearing people (Canadian Assoication of Deaf, 2019a).

Molly was involved in the (D)eaf community and learned sign language from early on. Though she knew sign language fluently, she felt isolated from the (D)eaf community when untrue rumours and gossip was spread around about them from her ex-partner. They said they were “in the dark for five years” (Molly). Josie was not fully aware of the (d)eaf community until they were an adult. From their comments, involvement with the (d)eaf community has been a positive experience. Alexander became involved when they were a teenager, and they love the community voraciously. They built their career around the community, culture, and language. They no longer feel isolated or misunderstood while being involved in the community.

Hermes and Ronald became involved in the community at similar ages —between six and nine—when they began attending the Amherst School for the (D)eaf. Both share a common concern about the dwindling involvement of the (D)eaf Youth in the (D)eaf community. However, what Hermes and Ronald hope for regarding the involvement of the (D)eaf youth may differ from the perspectives of the (D)eaf youths. For instance, Hermes and Ronald have been on several committees or a part of organizations over their lifetime. Nowadays, (d)eaf youth may prefer to become involved socially, online, and through events rather than entering committees, boards, and organizations. However, this is just speculation as I did not interview (D)eaf youth for this research. Another possible reason for the dwindling numbers could be the increases in hearing aid technologies like cochlear implants and the current stance of the medical profession that (d)eaf people need their ears fixed.

As you can see in Table 3 in Appendix D, the (D)eaf community theme is compounded with many other topics and themes, including accessibility. There are various aspects of accessibility to consider. First, sign language is a visual-gestural language unlike the general oral languages of the hearing people. That means technologies like landlines, sirens, oral announcements at the airport, speaking to other people, and the general noises of the world can befuddle us. We devised different approaches to get around the issue of our ‘inability’ to use the oral language fully. We do that by creating accessibility technology. Nowadays we have VRS instead of landlines and phone calls. We have ASL video announcements or closed caption announcements instead of oral announcements. We have interpreters instead of attempting to lip read the teacher for hours a day, writing on papers, and trying to communicate via various methods. However, the goal for those are the same goals for the oral language. We're all trying to communicate as that is the reason why languages exist.

However, the current society tends to "other" (D)eaf people and does not incorporate people into society well. As discussed in de Beauvoir's book, *The Second Sex* published in 1949, the viewpoint that women are secondary or 'other' to men is very similar to current society's view on (d)eaf people. Societal attitudes affect hearing people's view of (d)eaf babies. This 'others' (d)eaf people from hearing people. As shown through the life summaries, Josie, Alexander, Hermes, and Ronald did not become involved in the (D)eaf community from a young age because they were either raised to be 'hearing', sent to oralism school, or their families showed a lack of awareness of what the (d)eaf community. That cause issues like mental health, potential language delays, and isolation to occur — as is present in Josie, Alexander, Hermes, and Ronald's stories. Molly also suffers from some mental health and isolation by being denied going to the (d)eaf school.

EDUCATION THEME 4.4.4

Information literacy cannot be discussed without discussing education. Formal education is one of the major places where information literacy is taught —along with other institutions like libraries, governments, and non-profit organizations. Information literacy is the practice of understanding, breaking down, and distinguishing false and true information (ARCL, 2016). The varied experiences of education amongst the participants provides much insight to the possible correlations between successful information literacy skills and types of education.

The Introduction Chapter introduced the reader to mainstream school, (d)eaf school, (d)eaf classes, and oralism school was discussed in the educational context of the (d)eaf community. Molly attended the Halifax School for the (D)eaf for a very short time before they were transferred to a mainstream hearing school. Josie only attended mainstream school. Alexander attended oralism school in their native country, then attended (d)eaf classes and mainstream when they immigrated to Canada. Hermes attended oralist classes and the Amherst School for (D)eaf. Ronald attended mainstream for one year then Amherst School for the (D)eaf for the remaining years of their secondary education. Josie and Alexander were the only participants who have substantive post-secondary education in universities and colleges. Hermes and Ronald attended trade school and vocational school post-secondary education. Molly did not attend any academic post-secondary education but gained their knowledge through their employement and through participating in workshops.

One of the major things I noticed through analysing the code is the presence of (D)eaf Epistemology. It presents itself in various forms: Ronald mentioned how they learned more from their (d)eaf peers than the teachers. Josie shared that they like to ask experts for information if it's something specific and not easily found. Alexander shared that they like to learn information through ASL and not English. Hermes said they understand better in ASL rather than English, and Molly shared a similar sentiment. In Table 4 and 5 (Appendix D), I show how the themes presented themselves within the specific time periods of their lives. The reason for this is because I want to show that education's presence exists throughout life, not just in time period titled secondary or post-secondary education.

The codes in the Education theme ranges from 'Family' to 'Normalizing Extra Work'. The codes that I identified were not always what I expected. The unexpected codes are

Accessible Mental Health Resources, Employment and Likeability, and lastly, Family. I anticipated that there would be a greater emphasis on the (d)eaf community. Though there were several instances of the influence of the (d)eaf community, there was a greater emphasis on Accessibility, Access to Natural Language, and Family Support. Mental health is emphasised as well with crossovers in Family, Accessibility, and Language. That supports the intertwined nature of family, mental health, (d)eaf community, and education.

There are a lot of crossovers between the five tables in Appendix D. In Table 5, education codes relevant to only childhood, teen hood and adulthood, we can see that there are a lot of similarities between themes and their location on chronicled timelines. In my coding process, I assumed some themes are specific to childhood and secondary education based on the context of the stories. One of the codes I want to further discuss is 'shame' and 'embarrassment'. Josie and Ronald discussed this with me in different contexts. Josie is a librarian who has some experience helping (d)eaf people navigate the library. One of the things Josie said was that they noticed that sometimes shame or embarrassment could possibly cause (d)eaf individuals to refuse to come into the library. That could be due to their perceived level of intelligence, however, Josie was unsure if that was the reason. Ronald mentioned a story about helping (d)eaf people with lawyers. Ronald found out that the (d)eaf people were embarrassed to write statements with their current English level, so they ask other people who are 'better' with English to write the statements for them. Ronald was upset because, though they understand the shame and embarrassment, they said we have to show the government the state they left us in. If (D)eaf people read English perfectly, the government would assume that the (d)eaf people were sufficiently taught. This case shows how mental health and the lack of accessible education impact the (d)eaf individuals to feel deep shame about their perceived lack of skill in English.

This resonates with me because I suffer from this feeling throughout my academic career — despite having a Bachelor of Art degree and a future Master of Library Science and Information degree to prove that I do have sufficient English skills. I also have some trauma from the extensive number of English classes I had to take in middle school and high school, which affect me to the point that I refuse to take any university writing courses. Even if I rationally understand the writing courses will be helpful, the trauma stops me from taking the courses. This thesis in fact, cause me to feel unsure, out of my depth, and afraid about my writing skills but I am overcoming it with help from my supervisors and writing resources.

In conclusion, Education is one of the major themes because it has influence over how (d)eaf people feel, think, and learn over their lifetimes. Education could inspire them to learn happily or reluctantly or cause them to refuse learning at all based on the trauma they have experienced. This shows the connections to mental health, privacy, and (d)eaf community. If (d)eaf people lack access to their community or family for support, lack the ability to choose what they want to do, or access to their natural language, it impacts their perception of education and society.

ACCESSIBILITY THEME 4.4.5

The last major theme identified is accessibility. A theme that lies at the heart of my question of how accessibility and access affect the information literacy skills of (d)eaf individuals. In Table 6, Appendix D, it is clear that accessibility and access are connected to various terms such as technology, education, community, mental health, privacy, and information literacy and show that these factors are all context dependent. Many of Molly’s 11 themes involved accessibility —and nearly all of them are in the time period of post-secondary education or secondary education. From my analysis, it appears to me that the reason for the majority of the terms being connected to education is because of Molly's experience of barriers during their school experience. They did not have interpreters and they struggled with access to mental health resources. In adulthood, Molly volunteers their time to the (d)eaf community and their partner to help increase their education and understanding of topics. Molly commented how exhausting that can be, but it's also rewarding for them to see (d)eaf people have the ability to access resources —especially mental health resources. For Josie, the accessibility theme spans their entire timeline, based on how they have wildly different experiences with accessibility through their education and the rest of their life. For instance, Josie only gained access in adulthood. Josie also placed great emphasis on privacy and accessibility. They said that if they can't have privacy about their status as a (d)eaf individual, they do not consider the experience as accessible. They also discussed at great lengths their travelling and how inaccessibility caused great inconvenience for them. For instance, missing the change in their gate caused them to miss their plane being taken off. Josie and Molly both discussed how people are affected by their accessibility. People can cause drastic changes in accessibility by doing something as simple as having a large beard that cause lip reading to be very difficult for (d)eaf people in classrooms. Both Josie and Molly find this exhausting. For Alexander, the emphasis of accessibility is placed on secondary education and teen hood. Especially due to being an immigrant to Canada around that time and witnessing the differences between their native country and Canada's approach to education. Alexander also received higher level of accessibility than the other participants because Alexander had interpreters in their middle and high school. Though Hermes and Ronald attended (d)eaf school, it was during a time when oralism was emphasized and the teachers had to use sign language in secret. For Hermes, their early life (childhood and teen hood) consisted of accessing (d)eaf knowledge and trying to socialize with (d)eaf people. Based on their comments that they felt their education was inferior to their sibling who attended mainstream school, I surmised that accessible education means a great deal to them —even if they did not fully understand that when they were young. Over time, most participants experienced a change in attitude toward technology. Hermes emphasized that technology involved inaccessibility based on their experiences, for example the story of VRS mentioned in Privacy theme.

When discussing education, Ronald and Hermes shared similar experiences. Ronald said they are grateful for interpreters and think everyone who is currently in school is very lucky to have access to interpreters. Ronald did not place importance on technology —in fact, Ronald would prefer to not be obsessed with technology. Most (d)eaf people I know like technology a great deal because of how accessible it is. Ronald said they would rather not look at their phones, they want to look up and around the world.

Accessibility is a great thing for the (d)eaf community because it gives them a mouthpiece to sign and speak through and requires mainstream society to configure some things for them. Those things can be interpreters, CART, FM system, assistive hearing devices, vibrating alarm clocks, flashing lights for fire alarms, doorbells, baby cries, alarm clocks and phone calls. But it needs to be taken into account that, in a perfect world, if everyone knows sign language, most of those devices are not necessary expect perhaps the flashing lights. All five participants shared the theme Working Extra Hard Normalization. This ranged from staying after school for further help to asking people to take notes for them.

> Here, the (d)eaf person is tasked with the additional hidden labor of disability, which not only includes advocacy for one's rights to access and determining the appropriate fit of interpreters to the assignment, but managing the emotional toll of discrimination and oppression. (Blankmeyer Burke, 2017, p.274)

This shows just how important it is that (d)eaf individuals have the support of the people around them, including the (d)eaf community. Factors such as mental health, education and privacy are very important to any (d)eaf individual. We all have to work extra hard in various forms on a daily basis and it take a severe toll on our mental health and well-being without us fully realizing the heavy weight of it. Though it should not be normal, the current world and society is not configured to fit us in seamlessly. In addition to answering the research question, it my goal as a researcher to educate the readers on how to take in consideration all of the work and toll it can take for the (d)eaf community.

Overall, accessibility is intertwined with education, mental health, (d)eaf community, and privacy in various forms for each of the participant. It shows the importance of accessibility as the foundation of everything in a (d)eaf individual's experience. However, it is not a stand-alone word nor action: If we are to ensure successful accessibility, we need to ensure that all of the themes to be taken in consideration —at some level— for future actions to be taken.

Chapter Five: Conclusion

The coding and analysis of the data provided by the five participants of this study presents insight to possible recommendations for increasing information literacy in the (d)eaf community. I developed a model to help visualize the various aspects of my recommendations (see Figure 1). The model provides an exploration of my research question regarding how accessibility and access influence information literacy and I suggest potential paths (d)eaf individuals could take. The benefit of the research findings and the subsequent recommendations are not limited to the (D)eaf community. It will be of benefit to the disabled, immigrant, and general community because the recommendations focus on the language acquisition and accessibility for the children.

Recommendations 5.1

I have devised a model of my own invention to show the pyramid of information literacy skills. The model shows three levels you need to reach before achieving gains in information literacy. The levels include accessibility, mental health, and education (See Figure 1).

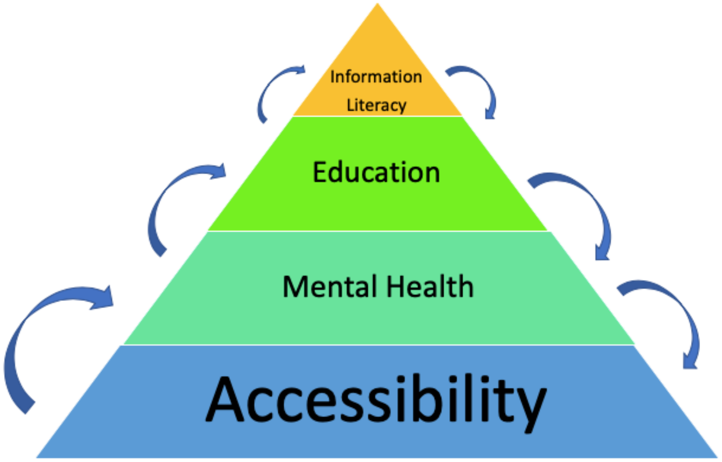
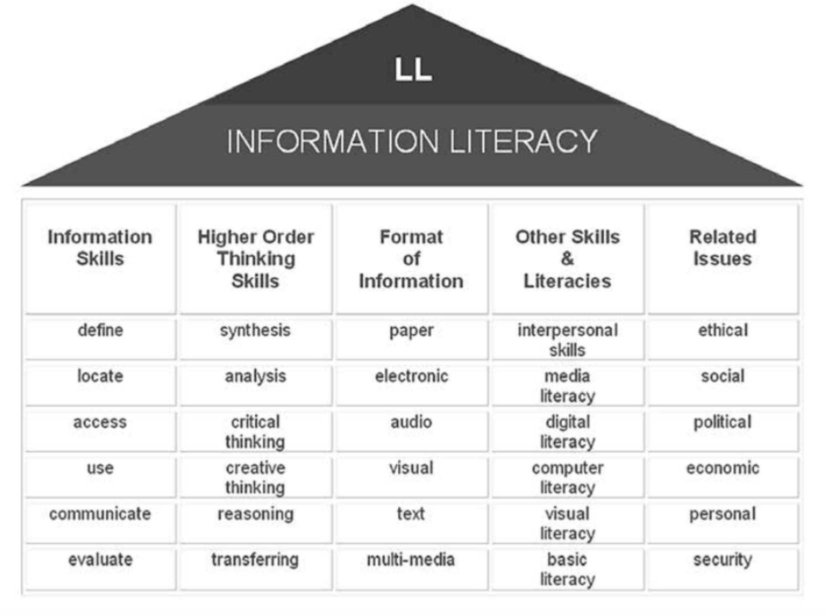


Figure 1: Preliminary Foundational Information Literacy Pyramid Model

As Serap Kurbanolgu (2013) suggests, information literacy can be considered an “iceberg”, which is much bigger than what can be seen.



Information Skills	Higher Order Thinking Skills	Format of Information	Other Skills & Literacies	Related Issues
define	synthesis	paper	interpersonal skills	ethical
locate	analysis	electronic	media literacy	social
access	critical thinking	audio	digital literacy	political
use	creative thinking	visual	computer literacy	economic
communicate	reasoning	text	visual literacy	personal
evaluate	transferring	multi-media	basic literacy	security

Figure 2: Components of Information Literacy: The Iceberg Model by Kurbanolgu pg. 83

In my model, I show the foundational aspects that may not be visible when looking at the tip of the information literacy iceberg. According to Kurbanolgu, information literacy skills come from different components such as critical thinking, analyzation, reasoning, creative thinking, transferring etc. In the following I explain the levels of the information literacy pyramid and the components that impact them.

GENERAL REQUIREMENTS GUIDELINE TO INFORMATION LITERACY 5.1.1

1) **Accessibility**
    a. Language Accessible
    b. Privacy Accessible
    c. Technology Accessible
    d. Education Accessible
    e. Resources Accessible
    f. Community Accessible

2) **Mental Health**
    a. Family support
    b. Community support
    c. Privacy
    d. Language Accessible
    e. Socializing Accessible
3) **Education**
    a. Language Access
    b. Accessibility
    c. Mental Health

Accessibility 5.2

As seen in Figure 1, accessibility is the foundation of the information literacy pyramid. Accessibility includes the components of language, privacy, technology, resources, education and community are accessible to the individual.

The world is designed to be inaccessible to the majority of (d)eaf community. This inaccessibility is experienced in various ways including hearing family members who don’t know sign language, education being provided orally, society functioning predominantly in oral, and sign language generally not being use by hearing people, with the exception of interpreters and supportive family members and children of (d)eaf adults.

This is also applicable toward other resources like technology, if a (d)eaf child grows up without any accessible technology like closed captions on all TV’s, it isolates them from their hearing peers. It also isolates them from their family if the family do not have knowledge of sign language (Pfister, 2017). Access to technology is also applicable in the education setting, including ensuring that the (d)eaf individual has books in ASL video or receive ASL interpreters or other assistive hearing devices if necessary. The difference between access and accessibility in this instance is that with any devices or interpreters, the individual need to be able to fully understand, able to use the information when needed, and reach the information when needed. If the individual only understands parts of the information, it means the devices or interpreters are not giving sufficient accessible service/serve to the individual. The same thing is true for all of the requirements under each of the three major stages before information literacy in my model. In order for information literacy skills to be successfully acquired, accessibility is foundational.

Mental Health 5.3

Mental health is the second level of the information literacy pyramid. Mental health is impacted by different factors and can be influenced by chemical imbalances which would require medicine. However, in this case we are discussing the emotional and physical component of mental health. This level includes the components of family support, community support, privacy, language accessibility, and socializing. If (d)eaf children lack in support from home or do not have access to their community it has a great impact on their mental health. In turn, if their mental health is not stable or well-supported by their friends and family, it can negatively impact their education, including grades and general enjoyment (Glickman & Hall, 2018; Bat-Chava: 1994; Leigh & Pollard, 2003). To support (d)eaf people's mental health I recommend that counsellors, psychologists, and other professionals in the health field either become fluent in sign language or become knowledgeable about how to hire interpreter services.

Another important component to support mental health is ensuring that the (d)eaf children have access to the (d)eaf community. Exposure to (d)eaf epistemology and sign language would allow them to experience talking to people who understand their experiences because they share them. It would also help them develop friendships and foster a strong foundation. All of this will give the mental health of the (d)eaf children a greater chance of being healthy.

It is my recommendation increase awareness of (D)eaf community, culture, and language within the medical fields. The reason for this is because 90% of (d)eaf babies are born to hearing parents who very likely have no knowledge or awareness of (D)eaf and what it means other than medical hearing loss (Mitchell & Karchmer, 2004). It is well known in the (d)eaf community that the doctors are generally not trained to have knowledge of what (D)eaf means in aspects of culture, language, and communities. Generally, the medical establishment strives to “heal” the baby from its hearing loss rather than ensuring that the parents become aware of the (D)eaf culture and community.

Education 5.4

The last step before information literacy is education. People may think education and information should be interchangeable. However, my response to this is that education is a path to information literacy. Education can come in many different forms: reading to your children at nighttime, going to the libraries, participating in art and crafts workshops, singing the ABCs song, as well as attending formalized school. Just as mental health is influenced by language, experience of education is intertwined with accessible. For instance, Josie said they struggled with getting good grades in secondary education without interpreters. It was not until they attended universities with interpreters that they received consistently good marks without expending as much effort. The level of the pyramid regarding education requires that the (d)eaf students have accessibility to language, which can come in the form of interpreters or a teacher who sign fluently. All other technologies such as CART, FM system, lip-reading, and other captioning technologies are not considered accessible based on the definition of accessibility. The reason for that is because those technologies give access via unnatural language for the (d)eaf community. Textual and oral words are limited; you can read the sentences, but it does not mean you fully understand what the words mean. You could be missing the context, tone, or the metaphorical meaning. The limits extend to lip reading, one can generally only successfully ‘see’ maybe one to three words out of a sentence. This leaves a lip reader to frantically figure out what the other missing words are based on what was said previously. Sign language provides context, metaphorical meaning, tone, all of which facilitate better understanding. This is particularly beneficial in an education setting where it is fundamental that a student is better able to understand the teacher. If language accessibility is met at the education level, it means information literacy become possible for the (d)eaf student to learn fully without any obstructions.

In the visualization an information literacy pyramid, I am proposing the foundational supports to ensure that information literacy models can be successful. For instance, my model shows that accessibility, mental health, and education needs must be met before information literacy skills can be gained. Regardless of how information literacy skills are taught, each of these three foundational aspects are important to the (d)eaf individual.

Limitations 5.5

The limitations that exist in this research is the lack of corroborating research in information literacy and (d)eaf community. Though research regarding education and the (d)eaf community exists, there is a gap regarding information literacy. I also have to take a critical eye to some of the existing research because it was done by hearing professionals who may not have a full understanding of what it means to be (D)eaf in the contemporary world. Some of the analysis I completed of the potential correlations and causes is also based on speculation. This is due to the small number of participants in a qualitative study. The data is nuanced and in-depth, but, cannot be generalized to a larger population. However, if desired, this study could be used as a pilot study for similar future studies, or as a basis for more quantitative studies to be generalized.

Conclusion 5.6

In conclusion, I am able to ascertain that the definition of accessibility versus access does have great impact on how (d)eaf individuals locate, evaluate and effectively use information based on their information needs (Association of College & Research Libraries, 2016). Accessibility, mental health, and education are intertwined, and the pyramid model presented in Figure 1 shows a possible approach to meeting components in order to achieve information literacy skill development.

However, the pyramid is not a clear path, rather the recommendation within each level inform each other and require constant reevaluation. The reason I present the model in a pyramid is to show how the narrative analysis informed the conclusion that accessibility has various components that influence different levels. To understand how the different levels inform each other researchers can ask questions like: “Are you willing to have a better education at the price of poor accessible and poor mental health?” This happened to Molly and Josie, while Ronald and Hermes were in the situation of having inferior education, but slight better mental health based on the socialization they receive. (D)eaf individuals should be able to make their own decisions as long as they understand all of the options they have.

For accessibility to be successfully achieved on each level, it is necessary for mental health, and education to be conjunct with accessibility —these aspects do not stand-alone. A particularly poignant example of a component that is vital to each level is that of privacy. Privacy is intertwined and moves throughout each level in constant pulses of actions. If the actions to ensure accessibility through constantly striving to understand the needs of the (d)eaf individual languish or even stop, the pyramid with information literacy at the pinnacle will crumble or break down. The relevance of this pyramid is not limited to a specific educational timeframe — elementary, middle, high school and college/universities. Nor is it limited to formalized education as it can be applied to the general work force. It can be used for hearing people as well.

In the following I present an in-depth hypothetical scenario to give an example of how the pyramid can work. The scenario is that of a young (d)eaf child because the foundation of knowledge starts at a young age.

A (d)eaf child in elementary school knows ASL but is not great at reading and is embarrassed by their skill level. You can start rolling the ball by speaking to the counsellor of the school, the parents of the (d)eaf child, and the teacher of the (d)eaf child. Each of these potential support systems could strive to make reading more fun and educational so that the child can progress to higher level of reading. The (d)eaf child would also benefit from having at least one (d)eaf adult that they can relate to and learn from. The reason for this is avoid isolation, which is a big factor of depression and mental health state of any (d)eaf child and adults. The (d)eaf child may experience embarrassment due to multiple reasons. For example, trauma from not understanding the teacher. Or maybe their parents read to them, but they don’t understand it *fully* because it was in oral. Perhaps their classmates make fun of them, or maybe they are just not interested in reading in general.

The counsellors, teacher, parents, and the (d)eaf adult in the (d)eaf child’s life can all work together cohesively to make strategies available to the (d)eaf child. By developing a small but great team, including the parents, who work with the (d)eaf child throughout their formative years, the foundational levels of accessibility, mental health, and education will work together throughout the child's life. However, it is extremely important that all members of the team become aware of (D)eaf community, culture, and language. Language deprivation is an important issue and it may not be known to all members of the team (Pfister, 2017; Glickman, Hall, 2018). For example, once parents are not aware of its importance, they may learn sign language fluently if they do not know it or only know the basics.

In addition to family and community support, I also recommend the importance of involving counsellors as part of the (d)eaf child's team. This is because they will be able to gauge the child's mental well-being and recommend steps for the child and the parents to take for a healthy mental state (Bat-Chava, 1994; Fellinger, Holzinger, & Pollard, 2012.) Some of those steps can be also taken for (d)eaf teens and adults. Counsellors can provide much needed support and facilitate strong connections to the (d)eaf community —no matter what their individual identify are. Once receiving the support provided by their previously unaware parents, counsellors, teacher and (d)eaf adult, the (d)eaf child can start flourishing. Their reading levels may improve as they are no longer embarrassed. They may understand their parents better through using sign language when they read to them and could learn from the (d)eaf adult about the best ways of reading to understand the information and story. A counsellor who values the importance of the (d)eaf community could also provide the child with mental health support. Further support in the educational setting can occur through an interpreter. These supports may also pave the road to less isolation for the (d)eaf child from their classmates, and (d)eaf community. Once their knowledge base strengthens, it will lead to gaining information literacy skills.

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Appendix A: Interview Questions

1. Tell me a story about a day in your life as a child
2. What was an average day like in school, as a Grade 5 student for example?
3. Did you ever have to do a research project for school? How did you pick your topic? Why did this interest you? How did you research this?
4. As you progressed in school how did you find the information you required to complete assignments? How did this change? Did you experience any challenges?
5. In your personal life, as you moved through childhood, where there moments when you found it hard to find the information you needed? What did you do?
6. Tell me about a more recent time when you could not find the information you needed? How did you handle this?
7. Tell me a story about the first time you used a new technology?
8. What is your favorite way of finding information and/or communication?
9. Thinking about the ways you work with information, and challenges you may have, are there any other stories you would like to share?
10. Are there similar incidents to the story you just told me? How do you solve them?

Appendix B: Consent Forms

DALHOUSIE
UNIVERSITY
Inspiring Minds
Faculty of Management

RESEARCH CONSENT FORM

We invite you to take part in a research project called “Access vs. Accessibility: (D)eaf Community’s Problem”. This study is being done by Elphege Bernard-Wesson. I am a master’s student in the Faculty of Management at Dalhousie University in Halifax, Nova Scotia. We are doing this research for a class project in Research Methods class. The project is supervised by Jennifer Grek Martin. The information below tells you about our research and what you will be asked to do. It also tells you about any benefits, risks, inconveniences or discomforts you might experience. You can take part in this study if you are a member of the (D)eaf Community. About eight people will be taking part in this research.

To help us understand the difference between accessibility and access for the (D)eaf community, we will ask you to participate in a series of two interviews to explore the personal experiences you had with any type of technology that either make your life easier or harder. That will help the researcher understand the general

The purpose of the research is to find out the difference between access and accessibility for the (D)eaf Community. What is considered access or accessibility to them? The research will be conducted through two sessions of interview per (D)eaf participant. The (D)eaf participants will be voluntary therefore it’s considered random sample. The interview sessions will follow the methodology of Narrative Inquiry which mean the researcher want to know your life experience, personal stories, and testimonies on access and accessibility as a (D)eaf individual.

The potential risk is that you may experience some type of psychological discomfort as the questions may provoke you to feel emotional if it prompts some type of bad memory or flash back. You as the participant are allowed to require a break, or decline to answer the question, or leave the interview room. I as the researcher will refer you to counsellors on Dalhousie campus or give you a few minutes of break or continue on with a different question.
Each interview will take 45 minutes to 1 hour, you as the participant is agreeing to two sessions of interviewing. In total that will be up to two hours.

It is your decision whether or not you want to take part in this research project. Even if you do take part, you can leave the study at any time for any reason. There will be no negative consequences to yourself. You may leave the interviews at any time, and withdrawal your answers at any time before the data from your answers had been coded. The reason for that is because it is not possible to withdraw the information without starting the coding all over again. You may choose not to answer a few questions the interviewer asked you as well.

All information you give to members of our research team will be kept private. When we share our project findings in the thesis, we will only talk about group results. This means that it will not be possible for you to be identified. Any identifying information about you (like your name) will be kept in a separate file, in a locked cabinet or password-protected, secure file.

If you agree to participate in this research project, please sign this form or record a video with the sheet of the paper while you signed that you agreed to the research project. We are happy to share our results with you in 4 months through emails or videos. You need to indicate your preference for them on this form.

I have read the explanation about this study. I understand what I am being asked to do and my questions about the study have been answered. I agree to take part in this study. I know that participating is my choice and that I can leave the study at any time.

________________________________ ______________________________

PARTICIPANT'S SIGNATURE **DATE**

________________________________ ______________________________

RESEARCHER'S SIGNATURE **DATE**

If you have any questions, comments, or concerns about your participation in this research project, please contact me, Elphege Bernard-Wesson at elphegemae@gmail.com, or text me at 902-293-3160 with your name and concerns.

☐ I prefer to be emailed the results of the research project in English

☐ I prefer to be emailed the results of the research project in American Sign Language.

☐ I give permission to be directly quoted with no identifiable names or appearances.

Appendix C: Recruitment Forms

Note: This was conducted in English and ASL. The ASL was done via Video.

Dear Nova Scotia (D)eaf and Hard of Hearing Community,

My name is Elphege Bernard-Wesson. I am profoundly (D)eaf and fluent in usage of American Sign Language (ASL). I am currently doing a research study on accessibility and information literacy in the Nova Scotia (D)eaf Community for my master's thesis at Dalhousie University. I am very interested in doing interview sessions with (D)eaf members of the Nova Scotia (D)eaf community who meet the following criteria:

(D)eaf or Hard of Hearing
Uses American Sign Language Fluently
Have completed high school
Resident of Nova Scotia

You will be asked to participate in two different sessions. In the first session, there will be a semi-structured interview, where you will be asked to tell us about your experiences finding and using information. In the second session we will show you a copy of the English version transcript of the first session and allow you to both check and reflect on your comments. Follow up questions may be asked at this time. We anticipate these two sessions together will take between four and six hours of your time, during which light refreshments will be provided. A $25 gift card to Tim Horton's will be given as an honorarium at the end of the second session. Your participation is voluntary, and you can withdraw your participation anytime until the coding process. Please email me at elphegemae@gmail.com if you are interested in participating or have questions.

Best regards,

Elphege Bernard-Wesson

Appendix D: Tables

Table 2: Mental Health Coding in the Phase Six of Coding Process.

Title	Time Period	Participants
Abuse and Education	Teenhood	5
Abuse of Power and Education	Teenhood	5
Access to Mental Health Mental Health Accessibility	Secondary Education	1
Accessibility and Medical	Adulthood	5
Accessible Mental Health Resources (Mental Health and Accessible)	Post-Secondary Education	1
Accessible Mental Health Resources (Mental Health and Accessible)	Post-Secondary Education	1
Accessible Mental Health Resources (Mental Health and Accesslibility)	Post-Secondary Education	1
Deaf Community and Mental Health	Childhood	5
Deaf Community and Mental Health	Adulthood	3
Deaf Culture/Knowledge and Mental Health	Adulthood	5
Deaf Epistemology and Mental Health	Adulthood	1
Deaf Youth and Mental Health	Adulthood	4
Education and Mental Health	Teenhood	1
Education and Mental Health	Secondary Education	1
Embarrassment and Mental Health Them	Teenhood	5

Title	Time Period	Participants
Emotions and Education (Change to Mental Health and Education?)	Post-Secondary Education	1
Expectation and Mental Health	Post Secondary Education	4
Family and Mental Health	Adulthood	5
Family and Mental Health	Secondary Education	3
Friends and Mental Health	Adulthood	5
Harry Potter Syndrome	Adulthood	3
Healthy Relationship	Teenhood	1
Language and Mental Health	Childhood	5
Languages Locations Education and Mental Health	Secondary Education	3
Locations and Mental Health	Adulthood	3
Mental Health	Adulthood	1
Mental Health	Childhood	5
Mental Health	Teenhood	4
Mental Health and Education	Teenhood	5
Mental Health and Family	Childhood	5
Mental health and family, friends, religion	Adulthood	5
Mental Health and General Life	Adulthood	3
Mental Health and Harry Potter Syndrome	Adulthood	3
Mental Health and Hearing Education	Secondary Education	3
Mental Health and Helpfulness	Childhood	5

Title	Time Period	Participants
Mental Health and Location	Adulthood	1
Personal Knowledge and Mental Health	Post Secondary Education	5
Personal Knowledge and Mental Health	Childhood	5
Privacy and Mental Health	Adulthood	4
Privacy and Mental Health	Adulthood	4
Shame and Mental Health	Teenhood	5
Shame and Personal Knowledge	Teenhood	5
Shame/Embarrassment and Education	Teenhood	5
Stereotypes and Mental Health	Adulthood	5
Struggle and Accessibility	Adulthood	5

Table 3: (D)eaf Community Code in the Phase Six of Coding Process

Title	Time Period	Participants
Accessibility and Culture	Secondary Education	3
Accessibility and (D)eaf Community	teen hood	3
Accessible (D)eaf Knowledge (D)eaf Knowledge and Accessibility	Childhood	4
Accessible (D)eaf Knowledge (D)eaf Knowledge and Accessible	Post-Secondary	2
Culture and Accessibility	teen hood	3
Culture and Education	teen hood	3
(D)eaf and Accessibility	Secondary Education	5
(D)eaf and Hearing World	Childhood	5
(D)eaf and Youth	Adulthood	5
(D)eaf Community	Childhood	1
(D)eaf Community and Family	Adulthood	1
(D)eaf Community and Mental Health	Childhood	5
(D)eaf Community and Mental Health	Adulthood	3
(D)eaf Culture and Community (D)eaf People and Importance of (D)eaf Culture	Adulthood	5
(D)eaf Culture and Epistemology	Childhood	4
(D)eaf Culture/Knowledge and Mental Health	Adulthood	5
(D)eaf Epistemology	Adulthood	1
(D)eaf Epistemology	Childhood	5
(D)eaf Epistemology	Adulthood	2
(D)eaf Epistemology	Post-Secondary Education	4
(D)eaf Epistemology	Teen-hood	4
(D)eaf Epistemology	Adulthood	2
(D)eaf Epistemology (remove knowledge)	Childhood	1

Title	Time Period	Participants
(D)eaf epistemology and General Education	Secondary Education	1
(D)eaf Epistemology and Mental Health	Adulthood	1
(D)eaf Family vs Oralism	Childhood	4
(D)eaf Knowledge and Community	Secondary Education	2
(D)eaf Knowledge and Education	teen hood	2
(D)eaf Knowledge Partly (D)eaf Knowledge	Adulthood	3
(D)eaf Knowledge/Community	Post-Secondary Education	3
(D)eaf Knowledge/Understanding	Childhood	2
(D)eaf Rights and Education	Secondary Education	5
(D)eaf Youth and (D)eaf Community	Adulthood	4
(D)eaf Youth and Mental Health	Adulthood	4
(D)eaf Youth Culture and Knowledge Culture/knowledge and (D)eaf Youth	Adulthood	4
Extinction of (D)eaf Community vs Hearing	Adulthood	4
Harry Potter Syndrome	Adulthood	3
Hearing/Oralism Education vs (D)eaf Community	Secondary Education	1
Helpfulness and (D)eaf Epistemology	Childhood	5
Helpless (D)eaf Avoidance—	Adulthood	3
Language and (D)eaf Knowledge	Adulthood	4
Language and (D)eaf Rights	Secondary Education	5
Location and (D)eaf Community	Adulthood	3
Location and (D)eaf Community	Adulthood	3
Normalizing Deafness and Accessibility	Adulthood	5
Personal Knowledge and Culture	Adulthood	5
Personal Knowledge and Culture	Post-Secondary Education	3
Personal Knowledge and (D)eaf Community	Adulthood	5

Title	Time Period	Participants
Stereotype	Secondary Education	2
Stereotypes and Mental Health	Adulthood	5

Table 4: Secondary and Post-Secondary Time Period in the Phase Six of Coding Process.

Title	Time Period	Participants
Access Technology Technology/Access	Post-Secondary Education	4
Accessibility vs Access	Post-Secondary Education	4
(D)eaf Epistemology	Post-Secondary Education	4
Employment and Likeability	Post-Secondary Education	5
Expectation and Mental Health	Post-Secondary Education	4
Normalizing Extra Work	Post-Secondary Education	4
Personal Knowledge and Education	Post-Secondary Education	4
Personal Knowledge and Information Literacy	Post-Secondary Education	4
Personal Knowledge and Mental Health	Post-Secondary Education	5
Access vs Accessibility Education	Post-Secondary	2
Accessibility vs Access	Post-Secondary	2
Accessible (D)eaf Knowledge (D)eaf Knowledge and Accessible	Post-Secondary	2
Awareness	Post-Secondary	2
Awareness and Accessibility	Post-Secondary	2
Education	Post-Secondary	2
Family and Education	Post-Secondary	2
Personal Knowledge	Post-Secondary	2
Personal Knowledge and General Knowledge	Post-Secondary	2

Title	Time Period	Participants
Accessible Education	Post-Secondary Education	1
Accessibility (remove in general)	Post-Secondary Education	1
Accessible Mental Health Resources (Mental Health and Accessible)	Post-Secondary Education	1
Accessible Mental Health Resources (Mental Health and Accessible)	Post-Secondary Education	1
Accessible Mental Health Resources (Mental Health and Accessibility)	Post-Secondary Education	1
(D)eaf Knowledge/Community	Post-Secondary Education	3
Emotions and Education (Change to Mental Health and Education?)	Post-Secondary Education	1
Interesting/Invested and Education	Post-Secondary Education	3
Location and Education	Post-Secondary Education	3
Personal Knowledge and Culture	Post-Secondary Education	3
Privacy and Accessibility	Post-Secondary Education	1
Size of Lens and Accessibility	Post-Secondary Education	3
Accessibility and Location	Secondary Education	2
Accessibility and Volunteer	Secondary Education	2
Accessible Education Education Accessible	Secondary Education	2
Accessible Privacy Privacy and Accessible	Secondary Education	2
Accessible Privacy Privacy and Accessible	Secondary Education	2
(D)eaf Knowledge and Community	Secondary Education	2
Education and Access	Secondary Education	2
Hearing and Accessibility	Secondary Education	2
Independence Independent	Secondary Education	2
Normalizing	Secondary Education	2
Stereotype	Secondary Education	2
(Emphasis of) Education and Personal Knowledge	Secondary Education	4

Title	Time Period	Participants
Access Education Education and Access	Secondary Education	4
Access Education Education and Access	Secondary Education	3
Access to Mental Health Mental Health Accessibility	Secondary Education	1
Accessible Education	Secondary Education	1
Accessibility and Culture	Secondary Education	3
Accessibility and Education	Secondary Education	4
Accessibility and Resources	Secondary Education	3
(D)eaf epistemology and General Education	Secondary Education	1
Education and (D)eaf	Secondary Education	4
Education and Location	Secondary Education	3
Education and Mental Health	Secondary Education	1
Family and Education	Secondary Education	4
Family and Education	Secondary Education	3
Family and Independence	Secondary Education	3
Family and Mental Health	Secondary Education	3
Happiness and Education	Secondary Education	3
Hearing/Oralism Education vs (D)eaf Community	Secondary Education	1
Interested and Education	Secondary Education	3
Interpreters and Education/General Accessibility	Secondary Education	3
Language and Accessibility	Secondary Education	3
Language and Accessibility	Secondary Education	3
Language and Accessibility	Secondary Education	3
Languages Locations Education and Mental Health	Secondary Education	3
Mental Health and Hearing Education	Secondary Education	3

Title	Time Period	Participants
Narrative inquiry	Secondary Education	3
Normalizing Extra Work	Secondary Education	3
Oralism vs ASL	Secondary Education	4
Personal Knowledge and Education	Secondary Education	4
Privacy	Secondary Education	3
Privacy and Education	Secondary Education	4
Understanding and Knowledge	Secondary Education	4
Accessible Language Accessibility and Language	Secondary Education	5
(D)eaf and Accessibility	Secondary Education	5
(D)eaf Rights and Education	Secondary Education	5
General Communication Communication General	Secondary Education	5
Language Acquisition and Education	Secondary Education	5
Language and (D)eaf Rights	Secondary Education	5
Oralism and Imitation	Secondary Education	5
Past vs Present Education	Secondary Education	5

Table 5: Education Code and Adult, Teen and Childhood Time in Phase Six of Coding Process.

Title	Time Period	Participants
Accessibility to Information Literacy	Adulthood	1
Benefits and Education	Adulthood	5
(D)eaf Culture/Knowledge and Mental Health	Adulthood	5
(D)eaf Epistemology	Adulthood	1
(D)eaf Epistemology	Adulthood	2
(D)eaf Epistemology	Adulthood	2

Title	Time Period	Participants
(D)eaf Epistemology and Mental Health	Adulthood	1
(D)eaf Youth and (D)eaf Community	Adulthood	4
(D)eaf Youth and Mental Health	Adulthood	4
(D)eaf Youth Culture and Knowledge Culture/knowledge and (D)eaf Youth	Adulthood	4
Independent Education (independent Education)	Adulthood	1
Information Literacy and Education	Adulthood	2
Information Literacy in Post-Secondary	Adulthood	1
Language and (D)eaf Knowledge	Adulthood	4
Language and Education	Adulthood	5
Language and Education	Adulthood	4
Normalizing Extra Work	Adulthood	2
Normalizing Extra Work	Adulthood	2
Normalizing Work Extra Hard	Adulthood	5
Past vs Present Education	Adulthood	5
Personal Knowledge and Information Literacy	Adulthood	4
Working Extra Hard Normalizing	Adulthood	4
(D)eaf Knowledge Partly (D)eaf Knowledge	Adulthood	3
Independence Independent	Adulthood	3
Personal Knowledge and Information Literacy	Adulthood	3
Accessible (D)eaf Knowledge (D)eaf Knowledge and Accessibility	Childhood	4
Accessible Education Accessibility and Education	Childhood	4
Better Education	Childhood	4
(D)eaf Culture and Epistemology	Childhood	4
(D)eaf Epistemology	Childhood	5
(D)eaf Epistemology (remove knowledge)	Childhood	1

Title	Time Period	Participants
(D)eaf Family vs Oralism	Childhood	4
(D)eaf Knowledge/Understanding	Childhood	2
Family and Education	Childhood	4
Family and Education	Childhood	2
Family and Education	Childhood	5
Friends Education and Language	Childhood	5
Helpfulness and (D)eaf Epistemology	Childhood	5
Language Deprivation and Education	Childhood	5
Normalizing Themes	Childhood	1
Socializing and Education	Childhood	5
Abuse and Education	teen hood	5
Abuse of Power and Education	teen hood	5
Accessible Academic Language Education Language and Accessibility	teen hood	5
Culture and Education	teen hood	3
(D)eaf Epistemology	teen hood	4
(D)eaf Knowledge and Education	teen hood	2
Education	teen hood	1
Education & Family	teen hood	1
Education and Mental Health	teen hood	1
Mental Health and Education	teen hood	5
Normalizing Extra Work	teen hood	1
Normalizing Extra Work	teen hood	4
Oralism vs. Sign Language	teen hood	5
Personal Knowledge and Information Literacy	teen hood	4
Relationship with Education (Education and Relationship)	teen hood	1

Title	Time Period	Participants
Shame/Embarrassment and Education	teen hood	5

Table 6: Accessibility Theme in Phase Six of Coding Process.

Title	Time Period	Participant
Access Education Education and Access	Secondary Education	4
Access Education Education and Access	Secondary Education	3
Access Technology Technology/Access	teen hood	4
Access Technology Technology/Access	Post-Secondary Education	4
Access to Mental Health Mental Health Accessibility	Secondary Education	1
Access vs Accessibility Education	Post-Secondary	2
Accessible Education	Secondary Education	1
Accessible Education	Post-Secondary Education	1
Accessibility	teen hood	2
Accessibility	Adulthood	2
Accessibility (remove in general)	Post-Secondary Education	1
Accessibility and Culture	Secondary Education	3
Accessibility and (D)eaf Community	teen hood	3
Accessibility and Education	Secondary Education	4
Accessibility and Inclusive	teen hood	5
Accessibility and Language	Adulthood	5
Accessibility and Location	Secondary Education	2
Accessibility and Locations	Adulthood	2
Accessibility and Medical	Adulthood	5

Title	Time Period	Participants
Accessibility and Resources	Secondary Education	3
Accessibility and Travelling	Adulthood	2
Accessibility and Volunteer	Secondary Education	2
Accessibility and Volunteer	Adulthood	1
Accessibility Perfectionist	Adulthood	4
Accessibility Present and Past	Adulthood	4
Accessibility to Information Literacy	Adulthood	1
Accessibility vs Access	Post-Secondary	2
Accessibility vs Access	Post-Secondary Education	4
Accessibility vs Access	teen hood	4
Accessible Academic Language Education Language and Accessibility	teen hood	5
Accessible (D)eaf Knowledge (D)eaf Knowledge and Accessibility	Childhood	4
Accessible (D)eaf Knowledge (D)eaf Knowledge and Accessible	Post-Secondary	2
Accessible Education Accessibility and Education	Childhood	4
Accessible Education Education Accessible	Secondary Educaition	2
Accessible Language Accessibility and Language	Seoncdary Education	5
Accessible Mental Health Resources (Mental Health and Accessible)	Post-Secondary Education	1
Accessible Mental Health Resources (Mental Health and Accessible)	Post-Secondary Education	1
Accessible Mental Health Resources (Mental Health and Accesslibility)	Post-Secondary Education	1
Accessible Privacy Privacy and Accessible	Secondary Education	2
Accessible Privacy Privacy and Accessible	Secondary Education	2
Accessible Technology	Adulthood	2
Accessible technology and language Technology Accessibility and Language	Adulthood	4

Title	Time Period	Participants
Accessible Technology Technology Accessible	Teenhood	2
Accessible Technology Technology Accessible and Location	Adulthood	2
Accessible Technology Technology and Access	Adulthood	5
Accessible Technology Technology and Accessibility	Adulthood	4
Accessible Technology Technology and Accessibility	Adulthood	4
Accessible Technology Technology and Accessibility	Adulthood	4
Accessible Technology Technology and Accessibility	Adulthood	3
Accessible Travel Travel and Accessible	Adulthood	2
Awareness and Accessibility	Post-Secondary	2
Culture and Accessibility	Teenhood	3
(D)eaf and Accessibility	Seoncdary Education	5
Design Technology and Accessibility	Childhood	3
Education and Access	Secondary Educaition	2
Hearing and Accessibility	Secondary Educaition	2
Interaction and Access	Adulthood	5
Interpreters and Education/General Accessibility	Secondary Education	3
Language and Accessibility	Adulthood	4
Language and Accessibility	Secondary Education	3
Language and Accessibility	Secondary Education	3
Language and Accessibility	Secondary Education	3
Location and Accessibility	Childhood	3
Normalizing Deafness and Accessibility	Adulthood	5
People and Accessibility	Adulthood	2
Personal Knowledge and Accessibility	Adulthood	2

Title	Time Period	Participants
Privacy Accessible Design Privacy/Accessibility design	Adulthood	4
Privacy Accessible Design Privacy/Accessibility design	Adulthood	4
Privacy and Accessibility	Post-Secondary Education	1
Size of Lens and Accessibility	Post-Secondary Education	3
Struggle and Accessibility	Adulthood	5
Technology Accessible	Adulthood	2
Technology and Accessibility	Adulthood	2
Technology and Accessibility	Adulthood	2
Visual Technology and Accessibility	Childhood	3