"EXPLORING DEAFHOOD": INVESTIGATING THE EXPERIENCES OF d/DEAF AND HARD OF HEARING PEOPLE WHO FACED BARRIERS TO DEAF CULTURE

"Exploring Deafhood": Investigating the experiences of d/Deaf and Hard of Hearing
people who faced barriers to Deaf culture

By

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Dedication

This is dedicated to every single d/Deaf and Hard of Hearing person who has felt like they don't belong. You deserve to feel secure, supported, and celebrated for who you are. I hope this reminds you that there will be a place for you, even when it doesn't always feel like it.

Abstract

Throughout the literature, there is existing research on the experiences of people in the Deaf community from a culturally Deaf perspective and from a medicalized perspective of the condition of hearing loss; however, there is very literature on the experiences of people who do not fall within either of these binary views of what being d/Deaf and HoH is. This research aims to build upon existing literature and explore the experiences of d/Deaf and HoH people who grew up in Southern Ontario and were raised outside of the d/Deaf and Hard of Hearing community, and/or without access to signed language. This research is theoretically underpinned by critical disability theory and deaf critical theory—otherwise known as deaf crit—to broadly understand the nuances of how d/Deaf and HoH people are impacted by structural, systemic, and interpersonal experiences of audism, power, and oppression. This study relied on Photovoice as the research methodology to best center the perspectives of the participants through visual and textual analysis.

Three participants participated in four virtual Photovoice workshops where they shared photographs in response to different prompts about their experiences as d/Deaf and HoH people. The ensuing discussion found the key themes: 1) the ability to explore their self-identity as d/Deaf and HoH people; 2) the importance of developing pathways to community early on in life; 3) the need for multiple supports when receiving care. This research contributes to the literature that centers the nuanced perspectives of those who are d/Deaf and HoH but raised without access to Deaf culture, community, and/or sign language and makes suggestions for future practice and policy that centers diverse needs and desires for support.

Table of Contents

Chapter 1: Introduction

The focus of this thesis work is to better understand the diverse and nuanced perspectives of people who are d/Deaf and Hard of Hearing (HoH). Specifically, this research will explore the experiences of d/Deaf and HoH people who grew up in Southern Ontario and were raised outside of the d/Deaf and Hard of Hearing community, and/or without access to signed language. While there is a great deal of information on American perspectives within this area, there is a significant gap in the research from an Ontarian context.

1.1 Researcher Positionality

I am approaching this thesis as someone who cares passionately about research and the d/Deaf and Hard of Hearing community at large. To critically engage within this research, it is first important to ground myself and my orientation as a researcher.

My experience with deafness began at birth when I was born premature and had various complex health needs. Throughout my life, these health needs have fluctuated in prevalence, diagnosis, and requirements for care. I received my first hearing aid at six months old. At the time, I was diagnosed with moderate to profound hearing loss in both ears and Auditory Neuropathy Spectrum Disorder. My hearing has always been in flux. When I was fifteen years old and lost my hearing entirely due to complications with other health issues. At seventeen I made the choice to receive cochlear implants.

Throughout my life, I have had some contact with the d/Deaf and HoH community. Before I was mainstreamed into a French Immersion program, I was enrolled in a Deaf and Hard of Hearing preschool program. I attended speech therapy for several years, as well as foundational Exact Signed English and later American

Signed Language (ASL) classes. I mainly communicate orally, but also use some sign language with family and close friends who know some of ASL. Overall, I grew up in a hearing environment. I am grateful for the experiences and connections that I have had so far, and I would not change them. I have been lucky to have family who has followed my lead on every path in life and has shown me unwavering support. However, I have also personally struggled a great deal with understanding my own d/Deaf and HoH identity while growing up in a hearing world. I have faced a lot of ableism, and audism, throughout my life. This has occurred in my relationship with others, and within every single institution I have been in.

During my post-secondary education, I became involved with Maccess, a peer support service run for and by disabled people. At this time, I began to ask more questions about myself as a deaf/disabled person and the rest of the world around me. Through the social work program I became much more critical of the systems, structures, and power that privilege certain bodies over others. In the process of better understanding myself and connecting to others in the d/Deaf and HoH community, I began to wonder how to support others who are part of the d/Deaf and HoH community but do not have access to Deaf community and culture. This process of interrogation was the beginning of the ideas that made way for this thesis.

1.2 Research Question

This master's thesis aims to explore the experiences of d/Deaf and Hard of Hearing (HoH) people who were raised in Southern Ontario without access to Deaf culture, the deaf community, and/or sign language. The primary object of this research is to answer the question: How do d/Deaf and HoH people who were raised without

access to Deaf culture, the deaf community, and/or sign language see themselves within the d/Deaf and HoH community?

1.3 Research Objectives

The purpose of this research is to generate information from a small group of d/Deaf and HoH people who were raised in southern Ontario, without access to Deaf culture, community, or signed language through this qualitative study that uses Photovoice to investigate:

- The ways that d/Deaf and HoH individuals who were raised without access to the d/Deaf and HoH community view, understand themselves in relation to, and interact with the d/Deaf and HoH community;

- Understanding experiences related to accessing the d/Deaf and Hard of Hearing community.

Chapter 2: Critical Literature Review

Exploring the concept of identity within the d/Deaf and HoH community is a task that needs to be rooted in the context of history, and with respect for complexity and nuance. The aim of this critical literature review is to consider the different ways that labels can be used within the community, and what this means for access to connection and support within the d/Deaf and HoH community. Furthermore, this literature review will provide a foundational understanding of how these labels and identities are taken up within research and how this impacts who is and is not represented throughout society within the hearing and d/Deaf and HoH community.

It should be noted that this literature review is not an exhaustive account of the literature and knowledge that is based on the experiences of d/Deaf and HoH people. The intention of this critical literature review is to summarize key themes, findings, and knowledge that pertain to the conversations surrounding identity and connection to the d/Deaf and HoH community as a broad and foundational base of knowledge.

2.1 d/Deaf and HoH People in Canada

While 90% of d/Deaf and HoH children are raised by hearing families, it is estimated that 10% of Deaf children will have access to signed languages and Deaf culture (Ladd, 2003). In Ontario alone, it is estimated that 95% of Deaf youth are raised by hearing families (Deaf Youth Collective, 2022). It has been reported that sometimes these youth experience isolation, lack of access to language acquisition as children, lack of access to or barriers to learning, education, career development, information, and communication, and supports (Deaf Youth Collective, 2022).

As of 2023, no fully credible census of Deaf, deafened and HoH people has ever been conducted in Canada (Canadian Association of the Deaf, 2015; Deaf Youth Collective, 2022). While there has been data produced by Statistics Canada about the experiences of disabled people in Canada, there is limited information on the experiences of d/Deaf and HoH people exclusively. Some of the information has been archived on the Statistics Canada website, however, it is still available for analysis (Government of Canada, 2016). While there has been research conducted prior, for the sake of relevancy in this literature review, I will only be analyzing the reports published from 2012 onwards.

According to the 2012 survey on Canadians with Disabilities, 874,600 (3.2% of Canadians aged 15 and older identified as having a "(…) hearing disability that limited them in their daily activities". Among the respondents, 75.2% reported that they had "some difficulty hearing", while 22.5% had "a lot of difficulty". Within this study, 0.4% of respondents reported being between the ages of 15-24, while 14.6% reported being over the age of 75 and older (Government of Canada, 2016).

However, more recent data has been published which approximates that in 2015, the were roughly 3.57 million people with some degree of hearing loss. Of those 3.57 million people, one-tenth or roughly 357,000 would be culturally and linguistically Deaf and there are approximately 357,000 profoundly deaf and deafened Canadians and possibly 3.21 million hard of hearing Canadians (Canadian Association of the Deaf, 2015; Malkowski, 2021 as cited by Deaf Youth Collective, 2022). From these statistics, it is estimated that there are 144,990 deaf Ontarians and 1,449,000 hard-of-hearing Ontarians (Malkowski, 2021, as cited by Deaf Youth Collective, 2022).

Interestingly, these statistics were based on definitions where being 'deaf' refers to people who are unable to use the telephone regardless of whether they are profoundly deaf or hard of hearing and where 'hard of hearing' refers to people with any form of hearing loss (Malkowski, 2021, as cited by Deaf Youth Collective, 2022). Overall, there is a limited amount of data on the number of d/Deaf and HoH youth in Ontario due to different ways of collecting data, statistics, and the lack of efforts made to track D/HH children in the province (Deaf Youth Collective, 2022).

Importantly, the Canadian Association for the Deaf (2015) notes that the Census and the Participation Activities Limitation Survey (PALS) are only offered in English and French, and is not translated into American Signed Language, or Quebec Signed Language, making it inaccessible to many d/Deaf and HoH people (Government of Canada, 2016). Furthermore, the Canadian Association of the Deaf also notes that the questions are not in plain language and can be worded in ways that are confusing to d/Deaf and HoH community members, especially those whose first language not is English or French (Canadian Association of the Deaf, 2015; Government of Canada, 2016).

Finally, the census data centers those who identify as "having a hearing disability that limits their daily activities." (Government of Canada, 2016). Information from the census data mainly focuses on the supports that d/Deaf and HoH people use, such as hearing aids (Government of Canada, 2016). Very little information is provided about those who are immersed within the Deaf community and use sign language, only 3.6% of respondents reported using sign language (Government of Canada, 2016).

As noted by the Canadian Association of the Deaf (2015), this framing of the definition of hearing loss can be confusing to d/Deaf and HoH people who do not view their hearing loss as something that limits their daily activities—especially those who are immersed in Deaf culture and are accommodated accordingly. Framing the d/Deaf and HoH community in this fashion also eliminates those who are d/Deaf and HoH who do not use assisted listening devices, and those who are d/Deaf and HoH but do not label themselves as such (Canadian Association of the Deaf, 2015).

This gap in the research demonstrates that there is a significant lack of literature and information on the experiences of d/Deaf and HoH people in Canada. This can be due to the inaccessibility of data collection, knowledge sharing process, through not making material available in signed language, and not writing in plain language (Canadian Association of the Deaf, 2015; Deaf Youth Collective, 2022). Furthermore, identifying these gaps in the research points to an overarching theme that the ways in which data is collected on d/Deaf and HoH people are done without consideration for the diversity of lived experiences that the community shares that do not necessarily fit into one standardized understanding of what deafness is.

2.2 Identity and Connection within the d/Deaf and HoH Community

There are many different identifiers that represent different experiences in the d/Deaf and HoH community. Lowercase "deaf" is used to refer to community members who experience the audiological—or medicalized—condition of not hearing (Leigh, 2009a; Leigh, Andrews, González Ávila, & Harris, 2022; Padden & Humphries 1988). Furthermore, hard-of-hearing (HoH) individuals are members of the community who have mild or moderate levels of hearing and often rely on other assistive technology as

support, such as hearing aids (Ladd, 2003; Leigh, et al, 2022). This reality contrasts with the experiences of those who identify as the term uppercase "Deaf". This refers to culturally Deaf community members (Ladd, 2003; Leigh, 2009; Leigh, et al, 2022; Woodward, 1972, as cited by Padden & Humphries, 1988). Those who are culturally Deaf have been in a community with other Deaf people and communicate values, norms, and beliefs through sign language (Ladd, 2003). Some seek out Deaf education programs and community groups (Ladd, 2003). Often, this is the identity of Deaf children who were raised by culturally Deaf parents. In this scenario, Deaf culture is seen as something that was passed along through generations (Leigh et al, 2022; Padden & Humphries, 1988).

It is estimated that 95-96% of deaf children are born to hearing parents (Deaf Youth Collective, 2022; Leigh, et al, 2022). Often parents may go through different emotions such as shock, grief, anger, and frustration at their child's diagnosis (Estrada Aranda, & Raaij; 2015; Leigh, et al, 2022). In other cases, some parents struggle to cope with having a deaf child, especially if they view hearing and speaking as core traits of themselves and expect their child to act accordingly (Erting, 1982 as cited by Estrada Aranda & Raaj, 2015). Additionally, there are several factors that can add to high-stress levels for parents in these situations such as having low income, low interpersonal support, stresses in daily life, and additional disabilities on top of hearing loss (Estrada Aranda & Raaj, 2015). Importantly, research has found that hearing families often do not have the same resources that Deaf families have. This can include access to accurate signed language, knowledge of deaf culture, access to Deaf education, and access to other members of the Deaf community (Leigh, et al, 2022).

One explanation of why this is can be found within the Ontario Infant Screening

Program. Pertaining to hearing loss—the infant screening program is used when

children are born to determine whether they have hearing loss or not. According to

Hamilton & Clark (2020); Snoddon & Paul (2020); Snoddon & Underwood (2014) and

Hecht (2020) when families find out their child is Deaf, they are often provided with

limited or no access to resources beyond hearing aids, cochlear implants or other

devices that focus on auditory processing, this is in hopes of encouraging the child to

acquire spoken language. From a culturally Deaf perspective, parents are encouraged

to seek out perspectives of d/Deaf and HoH identity that move beyond medical

interventions and additionally consider d/Deaf and HoH community, culture, and signed

language (Estrada Aranda & Raaj, 2015). However, when families' first interactions

surrounding hearing loss are with medical professionals, they are not given a diverse

view of resources to support d/Deaf and HoH people. Furthermore, the Ontario Infant

Hearing Program has frequently not supported access to ASL services for families of

children with cochlear implants (Snoddon, 2008). This limits the family's ability to have a

holistic and informed choice on the kind of care and support that their child may

require.

Snoddon & Paul (2020) note that there are significant gaps in the ways that

service providers communicate their knowledge and support to families. For example,

audiologists are not required to have knowledge of signed language; nor are family

support workers. Consequently, most families are not exposed to signed language as

an option, which results in barriers to Deaf specific care. Often Deaf professionals are

not involved in the screening process and families are often only presented with

information on spoken language processes; indeed, some parents are told that accessing sign language will have a negative impact on their ability to process spoken language (Hamilton & Clark, 2020)

Throughout history, there was a movement in the education sector known as the "oral movement" that forced deaf children to conform to hearing standards of communication (Leigh, 2019). This gave rise to the oral-manual controversy, that resulted in tensions between those advocating for the use of sign language to educate and support d/Deaf and HoH children, and those who supported the idea of "mainstreaming" d/Deaf and hard of hearing children into schools where they were encouraged to use spoken language over signed languages (Snoddon & Underwood, 2020; Leigh, 2019). It is beyond the scope of this thesis to debate the complexities of the oral manual movement. However, it cannot go without saying that the oral manual movement has been incredibly impactful to the community. The purpose of mentioning the movement is to acknowledge the impacts that it has had on d/Deaf and HoH identity within the last century.

Barriers to Deaf specific care including access to learning signed language impacts d/Deaf and HoH people's ability to have a connection to themselves and a broader community that can support them in understanding their own Deaf identity and relation to the rest of the world (Ladd, 2003). Many deaf and HoH people do not know sign language, or some learn it later in life but do not master it (Leigh et al., 2022). Some describe connecting to d/Deaf communities later in life, and some prefer to remain within the hearing community that they are familiar with (Leigh et al., 2022).

These examples are merely a few of the many different labels, identities and ways of living that can be found within the d/Deaf and HoH community. There are also identities that range from those who are late-deafened, DeafBlind, and Deaf Disabled (Leigh et al., 2022; Leigh, 2009a). While all these identities are unique and important to explore in further research, the purpose of the Exploring Deafhood study is to investigate a broad understanding of d/Deaf and HoH identity that overarches these categories.

2.3 Identity and Membership within the d/Deaf and HoH Community

Literature suggests that d/Deaf and HoH identity is difficult to categorize and is deeply dependent on context, positionality, connection to community, or lack thereof. Padden & Humphries (1988) state, "Although the term "deaf" is the group's official label for itself, people who are Deaf can have a range of hearing abilities from "hard of hearing" to "profoundly deaf", and, conversely, there are people with severe or profound hearing impairment who do not participate in the deaf community." (p. 4). This section seeks to understand how identity and a sense of membership in the d/Deaf and HoH can be incredibly nuanced and personal to everyone's experience.

2.3.1 Deaf Identity Development Model

There is of great deal of literature that explores different identities to the d/Deaf and HoH community. However, for the scope of this project, my focus in on the Deaf Identity Development Model (DID), which is defined as the process in which audiological deaf people develop their culturally Deaf identity (Glickman, 1993, as cited by Leigh, 2009b; Goldblat & Most, 2018). The DID model includes four categories of identity: cultural hearing, cultural marginal identity, immersion, and bicultural identity.

"Culturally Hearing" is when a d/Deaf or HoH person perceives their deafness as medically pathological, and the hearing world is their normal environment. Often this mentality pertains to individuals, sometimes those who are late-deafened or raised with spoken English (Glickman, 1996, as cited by Leigh, 2009b). In this category, being deaf is considered a major disability and has manifested in the loss of meaningful connections with others, which exacerbates loneliness and isolation (Leigh, 2009b). According to Glickman (1996), this stage is one that is not healthy, as individuals are essentially, "denying their deafness" and the reality that they will never again be able to hear (as cited by Leigh, 2009b). However, other literature has suggested that it is possible for individuals to feel psychologically supported depending on how they are connected to their deaf identity and which aspect of their deafness is being denied (Leigh, 2009b).

Maxwell-McCaw (2001) suggests that depending on their attitude toward their hearing loss, an individual can feel supported in their deaf identity amongst the hearing community. However, to do so the individual must understand and accept their deafness. The individual must also not limit their access needs to better fit in with hearing society (Maxwell-McCaw, 2001, as cited by Leigh, 2009b).

The second identity in Glickman's DID model is "culturally marginal identity" where individuals do not feel like they belong to a hearing or deaf environment and struggle to be immersed in d/Deaf/HoH and hearing society due to inadequate access to spoken language, accommodations, and no experience with deaf peers (Leigh, 2009b). This can lead to people feeling confused about their identity, and potentially

21

having a poor understanding of themselves and their connection to others (Leigh, 2009b).

The third identity is "immersion" or Deaf identity, where the individual has a positive identification of their Deaf identity, connects with other d/Deaf and HoH people, uses signed language, and is critical of the enforcement of spoken language (Goldblat & Most, 2018). Leigh (2009b) positions this as an "(…) exuberant love affair with Deaf identity and Deaf cultures at the same time that hearing cultural values, including spoken language, are disavowed." (p. 29). While being surrounded by a Deaf environment and community, anger may be directed at hearing people for creating barriers to connection from the Deaf community (Leigh, 2009b).

Lastly, the fourth identity is a "bicultural identity" wherein an individual feels comfortable in deaf and hearing contexts (Goldblat & Most, 2018). Glickman (1996) acknowledges that deaf identity is not linear and that many community members can cycle along these stages while processing feelings of conformity and marginalization. However, this model has been critiqued by many, particularly, Holcomb (1997) for failing to fully describe the cultural identity of an individual (as cited by Glickman, 1993; and Leigh, 2009b). Instead, Holcomb (1997) added the identity of those who have a bicultural identity into a "deaf dominant" and "hearing dominant" identity (as cited by Glickman, 1993; and Leigh, 2009b). Holcomb argued that once an individual seeks a positive connection to their deafness, a bicultural identity will potentially develop and could allow for them to form supportive relationships with hearing and d/Deaf and HoH people alike (as cited by Glickman, 1993; and Leigh, 2009b).

2.3.2 Nuances within d/Deaf and HoH Identity

Understanding some of the terminology and types of categorizations within the

d/Deaf and HoH community can clarify some of the lived experiences throughout the

community. However, it is also important to be critical of them as well. Ladd (2003)

describes the labels "deaf", "Deaf, and "Hard of Hearing" as sometimes being used to

signify "degrees of membership" (p. 239). It has been suggested that they are

problematic as this is not inclusive for those who were born or grew up deaf but raised

without access to the community and those who became deaf later in life (Ladd, 2003,

Leigh, 2019). For example, Ladd (2003) states:

"With that loss of hearing comes a loss of status in mainstream societies and a
loss of the opportunity to continue to acquire 'cultural capital'. In these respects,
whether hearing impairment is interpreted through the medical or social model, the
fundamental reality is one of loss." (p. 33).

In comparison, those who were raised in Deaf culture or community were said to

grow up in environments where their closest peers are other Deaf people whom they

communicate with through signed language. Even once they leave their home

environment, these individuals often seek out Deaf centered communities throughout

the rest of their lives (Ladd, 2003). Alternatively, some individuals are born deaf but do

not accept their identity until later in life because of their situation or experience (Leigh

et al., 2022). Often narratives of d/Deaf and HoH identity fall into the assumption that

there can only be a singular Deaf identity incorporating signing Deaf people (Leigh,

2019). As Leigh (2019) succinctly notes, there are many reasons why, "Not all deaf

people are signing individuals or part of a signing Deaf community." (p. 5).

These ridgid definitions of d/Deaf and HoH identity assume that there are

prescriptive or predetermined ideals for how one becomes and understands themselves

as a d/Deaf/HoH person and does not consider the cultural context and environment that individuals are impacted by (Leigh, 2009b). This is exemplified through Leigh's (2009a) reflection on their own positionality when they state, "Internally, I identify myself as a person navigating the continuum between Deaf and deaf. The tension in identity commitment reveals itself when my self-perceptions collide with how others perceive me." (p. 43). Therefore, while these labels and identities can be helpful to understanding one's positionality and orientation to the d/Deaf and HoH community, they are not intended to be used as a rigid or all-encompassing view of what hearing loss is or can be. Rather, they are a point of entry to understand the nuances, tensions, and complexities that can come within the d/Deaf and HoH community.

2.4 Exploring Deafhood

Ladd (2003), described the concept of finding "Deafhood" as "(…) the struggle by each Deaf child, Deaf family, and Deaf adult to explain their own existence in the world." (p. 3). Within this framework, Deafhood is not solely the medical definition or condition of deafness, but instead a way of understanding oneself and connecting to others through their deaf identity (Ladd, 2003; Leigh, 2009a; Leigh, et al., 2022). Leigh and colleagues (2022), further explain Deafhood as, "(…) processing and reconstructing of Deaf traditions related to becoming and staying, "Deaf". It is a way of actualizing oneself as a Deaf person." (Leigh et al, 2022, p. 23). Deafhood has various descriptions; however, the consistent theme is that the person is aware of their deafness in a positive sense regardless of how they experience their deafness, which is ever-changing (Ladd, 2003; Leigh, et al., 2022).

Through history, technology, policy, and practice, the d/Deaf and HoH community has faced many barriers to connection in many different areas of life. In coining the term Deafhood, Ladd recognized that there are many different perspectives that shape the deaf community and the process of how one comes to understand their identity. Rather than prescribing one type of narrative or standard of being Deaf, Deafhood recognizes that there are multiple entry points into the community. In this thesis, the concept of Deafhood serves as a foundation for understanding and compassion for how people see themselves within the d/Deaf and HoH community. Rather than assuming a singular narrative about d/Deaf and HoH identity, I seek to consider the nuances of different reasons individuals see themselves, or not, within the community to hopefully better understand how others can be better supported through different interventions interpersonally throughout the d/Deaf and HoH community, throughout hearing communities, and broadly by practitioners and service providers.

2.5 Conclusion

This literature review highlights the importance of understanding the medical, social, and cultural views of deafness. When data on d/Deaf and HoH people only consider an approach that is rooted within a medicalized understanding of deafness, there is a large portion of the community is excluded from the data. This is deeply problematic when data is being used to create policies, practices, and supports that are not rooted within a comprehensive view of who d/Deaf and HoH people are and what they need.

The summary of the literature showed that there is a significant need to explore the nuances of membership and identity within the d/Deaf and HoH community beyond

a monolithic view of what deafness is. Categories throughout the d/Deaf and HoH

community can clarify the process of exploring one's identity and positionality; however,

the literature emphasizes the importance of moving away from a singular narrative of

deafness. Positioning deafness as either medicalized or cultural portrays a notion of a

singular deaf identity that does not allow for nuance and flexibility. This manifests in

analysis of different community identities, such as deaf, HoH and Deaf, the Deaf

Cultural Identity Model, and even through data collection processes on d/Deaf and HoH

people. The purpose of this thesis is to contribute to research in centering the

experiences of d/Deaf and HoH people who are currently going through the process of

understanding themselves and their connection to the broader community beyond a

monolithic view of what deafness is and can be.

Chapter 3: Theoretical Framework

This research is grounded in both critical disability theory (CDT) and Deaf Crit as theoretical frameworks to better understand the systemic, structural, and historical underpinnings of oppression, ableism, and audism that impact the d/Deaf and HoH community in complex ways. The experiences of those who are d/Deaf and HoH who were raised without access to d/Deaf and HoH community, culture, and signed language are incredibly nuanced. This chapter will explore these theoretical underpinnings, and how they work with one another to better understand the diverse perspectives that can range throughout the community.

CDT and Deaf Crit are informed by critical social theory. Critical social theorists aim to understand how power dynamics are manifested and reinforced throughout everyday life (Meekosha & Shuttleworth, 2009; Solorzano, 1997 as cited by Gert, 2016). Critical social theorists viewed science as progressively restricting the development of critical consciousness and autonomy within society, it rejects a vision of social science that is modeled on natural science as they believe that society cannot be captured quantitatively (Meekosha & Shuttleworth, 2009; Solorzano, 1997 as cited by Gert, 2016). Both critical disability studies and Deaf Crit look beyond a science-based—or positivist—perspective of bodily experience.

Critical social theorists advocate for a particular version of autonomy, one that involves "(…) emancipation from hegemonic and hierarchical ideologies that structure personal consciousness, representations, social relations and practices in everyday life." (Meekosha & Shuttleworth, 2009, p. 53). Both critical disability theory and Deaf Crit seek to understand how power dynamics, control and undermine the autonomy of the

disabled and d/Deaf and HoH community at large (Meekosha & Shuttleworth, 2009; Gertz, 2003; Gertz, 2016).

3.1 Critical Disability Theory

3.1.1 Medical Model of Disability

Critical disability theory emerged as a response to the medical model of disability. Overarchingly, the medical model of disability is deeply concerned with maintaining "normality". Within the medical model, "(…) the priority of the 'normal' body is maintained as either medicine or technology (or both) are used to 'correct' and therefore hide or reinscribe the deviant or abnormal body." (McRae, 2019, p. 220). The medical model lays the way for the process of medicalization, which describes how society understands conditions through using medical language, thinking, and frameworks (Maudlin, 2016). In this sense, the medicalization of disability is seen through the ways individuals that are labeled as "sick" are placed within the confines of a medical establishment and professionals to "treat" the condition to return people to "normalcy" (DasGutpa, 2015, p. 120). The start of the medicalization of disability was seen as a shift in terms of how bodies were commodified and classified—specifically through labeling disabled bodies as less or non-productive (DasGutpa, 2015).

Ontology is the understanding of how one's perspective of the nature, character, and essence of the social world is formed (Ejnavarzala, 2019; Mason, 2018). In other words, the ontology of a theoretical framework explains how the environment, people, and perspectives are understood. The medical model often adopts an essentialist ontology when considering disability. Essentialism positions the human body to have an essential set of attributes and characteristics to be considered a person which can create a sense of belongingness, shared truth, or stability (Feely, 2016; Leigh, 2009a).

28

This perspective has continued to be harmful to people with bodies or minds who do not have these "essential" attributes and has led to the exclusion of the disabled community from having a "full human" status in society (Feely, 2016, p. 864).

When promoting access to hearing environments, the medical model positions a life with hearing loss as one rooted in tragedy and difference that is filled with "(…) isolation, tension, and struggle" because deaf children cannot connect to hearing peers and family (Leigh, 2009b, p. 107). The solution then, is often an attempt to integrate children with hearing loss into different mainstream environments without appropriate support beyond listening devices, such as access to other d/Deaf and HoH community, sign language (Hamilton & Clark 2020; Hechet, 2020; Leigh, 2009a; Leigh 2009b; Mauldin, 2016; Snoddon & Paul, 2020; Snoddon & Underwood, 2014). Through this lens, the medical model often focuses on enabling access to sound via hearing aids, assistive listening devices, cochlear implants, and auditory speech training therapy to facilitate the use of spoken language (Hamilton & Clark 2020; Hechet, 2020; Leigh, 2009a; Leigh 2009b; Mauldin, 2016; Snoddon & Paul, 2020; Snoddon & Underwood, 2014). This suggests that individuals would be better off if they distanced themselves from being identified as having a disability and strive to be perceived or "pass" as "hearing as possible" within hearing and spoken language environments (Leigh, 2009a, p. 13).

It is important to note that while the push toward using listening devices has this orientation within a medicalized lens, this is not a judgment on an individual's character for using devices. Rather, it is an observation that this inherently subscribes to a medical model of disability because it is an act of an individual adjusting themselves

through a medical intervention to access hearing society (Leigh 2009a; Leigh 2009b; Mauldin, 2016).

3.1.2 Social Model of Disability

To understand the development of critical disability theory, it is important to investigate the social model of disability and it shifts away from a medical model. Medicalized perspectives of disability viewed impairment and disability as interchangeable; however, the social model of disability alternatively argued that impairment signifies the physical or biological lack or functional limitation within the body (Mauldin, 2016; Meekosha & Shuttleworth, 2009; Ralph, 2015). Disability is then considered to be imposed on people because of their impairments through systemic discrimination throughout society due to support these impairments (Mauldin, 2016; Meekosha & Shuttleworth, 2009; Ralph, 2015).

In this way, the social model of disability is helpful in reframing disability as a nuanced product of social environment, attitudes, and ableism that impacts people in a variety of different ways (McRae, 2019). The social model of disability shifts the focus of disability away from an individualized perspective, and into one advocating for social justice changes through public policy to focus on access, assistance, and public welfare (McRae, 2019). Furthermore, the social model seeks to change the public perception of normative bodies, spaces, abilities, access, and mobility (McRae, 2019).

Importantly, there are aspects of the social model of disability that are subjected to critique. Over achingly, the social model of disability is not applicable to different experiences of disability beyond one that is related to physical—and often visible— disability (Boxall, 2019). Boxall (2019) argues that regardless of societal factors,

opinions, or influences, people can still be physically and mentally impacted by a disability. For some people—especially those with chronic pain—their disability is a key factor in their life, and not something that can be viewed as, "irrelevant or neutral" because it is debilitating, painful, or beyond control (Boxall, 2019). Furthermore, the social model can conflate people's experiences into one homogeneous group without considering how different identities, such as disabilities, race, sexuality, class, and more, can impact people's experience of being disabled differently (Boxall, 2019; Meekosha & Shuttleworth, 2009).

3.2 Critical Disability Studies and Critical Disability Theory

Throughout the literature, it appears that there is little consensus on a precise definition of critical disability theory (Meekosha & Shuttleworth, 2009, as cited by Hall, 2019). However, it appears that critical disability theory (CDT) and critical disability studies (CDS) are often used interchangeably to explain similar epistemologies and ontologies to better understand the broad perspectives of disability (Meekosha & Shuttleworth, 2009; Hall, 2019). According to McRae (2019), disability studies emerged as a response to the medicalized perspective of disability, which positions disability as an individualized disease that needs to be cured or corrected through medical research, treatment and/or technological intervention (McRae, 2019; Meekosha & Shuttleworth, 2009). The discourses that developed aimed to challenge the medical and individual pathologizing model of disability that centers the citizenship of disabled people.

Throughout the literature, there appears to be a great deal of different perspectives and approaches to explain what critical disability studies is, and how it is used. Broadly speaking, CDT refers to the interdisciplinary set of approaches to analyze

disability as a cultural, historical, social, and political experience (Hall, 2019). From an ontological perspective, critical disability theory adopts a social constructivist framework of identity (Leigh, 2009a). Social constructivists believe that identity is not inherently in the self, something that one is born with, or solely something that is created by an individual's surroundings. Instead, the process of building one's identity is ongoing and is shaped by the social environment through political, economic, and sociocultural factors that build upon already existing systems and contexts over time (Leigh, 2009a).

Importantly, CDT adopts tenets of the social model when considering how the environment shapes the experience of disability. Much like the social model, CTD argues that disability is a social construct, and not simply inevitable because one has an impairment (Hosking, 2008). However, differently from the social model, CDT looks at how disabled identity is constructed (Hall, 2019; Meekosha & Shuttleworth, 2009; Leigh, 2009a). Rather than it being a fixed identity or state, CDT seeks to understand disability as an identity that is constantly in flux depending on one's environment, social location, and circumstances of power, oppression, and privilege (Hall, 2019; Meekosha & Shuttleworth, 2009; Leigh, 2009a). Much like the tenets of CDT, disability is viewed as a complex relationship between the impairment, social environment, and an individual's response to the impairment all can shape one's experience with disability (Hosking, 2008).

Critical disability studies (CDS) gained a lot of traction within social sciences and humanities but have evolved into an interdisciplinary and multidisciplinary theoretical perspective that has been applied within architecture, design, engineering, medicine, and pure science (Meekosha & Shuttleworth, 2009). Another influence of shifting to

CDS is the influx of perspectives from humanities and cultural studies and post-modernism, suggesting that social justice and diversity continue in a way that is not just social, economic, and political but also psychological, cultural, and embedded in a wide range of discourses (Meekosha & Shuttleworth, 2009).

CDS is also developed through resisting the cooption of disability language within institutions that are often rooted within a pathologizing perspective of disability. This can be seen through language such as "quality of life" or regulatory or controlling undertones (Hall, 2019; Meekosha & Shuttleworth, 2009). Furthermore, CDS redirects its work to activism-centered approaches that go beyond academic institutions (Hall, 2019) and encourages centering the lived experiences, work, and perspectives of disabled community members within knowledge sharing and practice (Hall, 2019; Meekosha & Shuttleworth, 2009).

3.2.1 Critical Deaf Studies—Deaf Crit Theory

To better position the experiences of d/Deaf and Hard of Hearing (HoH) people, this research leans heavily on Deaf understandings of knowledge. The Deaf social movement has a longstanding relationship of being inspired and working alongside other social movements, such as pushes for Black and Latinx liberation (Gertz, 2003; Gertz, 2016). During the 1970s, Deaf people advocated for self-determination and for increased autonomy and power within society (Gertz, 2003; Gertz, 2016). The d/Deaf and HoH community strove to push against audism. In response to audism and activism demonstrated throughout the Deaf community, legislation was created to reduce the amount of discrimination against Deaf people, with the goal to support them in participating within hearing environments and institutions (Gertz, 2016). However, it has

33

also been argued that this approach to resisting audism has resulted in forcing Deaf people to assimilate within a hearing society (Gertz, 2016; Leigh, 2009a; Leigh 2009b).

3.2.2 Deaf Crit

Deaf Crit Theory has been developed by Gertz (2003; 2016). Much of the push toward liberation within the Deaf community was inspired by the activism demonstrated by other marginalized groups and was largely influenced by Critical Race Theory (CRT). At a basic level, CRT works as a framework that identifies, analyses, and transforms systems, structures, and cultural aspects of society that marginalize people of colour (Solorzano, 1997, as cited by Gertz, 2015; Gertz, 2003). According to Gertz (2016) CRT "(…) challenges a dominant group when the structural and cultural aspects present a dilemma for minority groups wishing to fully participate in the public sphere, to defuse the dominant group's linguistic/cultural snobbery, and to respect non-dominant discourses." (p. 160).

It is beyond the scope of this paper to go into the depth of the roots of CRT, however there are deep and meaningful connections to this theoretical perspective that seek to better understand the experiences of d/Deaf and HoH people, particularly those who are also people of colour. While Deaf Crit is a helpful foundation to frame the experiences of d/Deaf and HoH people, it is important to note that there are limitations to this theoretical framework. Chapple et al., (2021) noted that Deaf Crit has been said to evolve from CRT, it does not consider how racism can influence one's perspective of deafness/deafhood. Rather, Deaf Crit was used to compare experiences of oppression instead of critically analyzing how racism and deafness intersect with one another to shape the experiences of d/Deaf and HoH people of colour (Chapple et al, 2021, p.

573). Similarly, García-Fernández, (2021) notes how critical deaf theory often excludes racialized folks' perspectives and presents a very whitewashed and Eurocentric model of knowledge within the d/Deaf and HoH community.

Much like CRT, five similar key themes are used to explain Deaf Crit as a framework of analysis. Firstly, there is an emphasis on centering the perspectives of Deaf people and understanding the lasting and pervasive impacts of audism throughout society. Audism, a term coined by Humphries' (as cited Eckert & Rowley, 2013; Gertz, 2003; Gertz, 2016; Lane, 1999) is the discrimination and oppression against the d/Deaf and HoH community.

Through Deaf Crit, and other deaf-centered epistemologies, audism takes on many forms. Audism can have micro and macro components; take on institutional and individual forms; have conscious and unconscious elements; and, have a cumulative and lasting impact on both individuals and groups (Gertz, 2003; Gertz, 2016). Audism can also be understood as a sense of hearing superiority and hearing control (Gertz, 2003; Padden & Humphries, 1998; Lane, 1999, as cited by Gertz, 2016). Furthermore, Lane (1999) calls attention to institutionalized audism and how it can manifest interpersonally, describing it as, "the corporate institution for dealing with deaf people," (p. 43). This includes policies, practices, and procedures that influence and act as an authority over how deaf people are viewed, observed, and behave. Institutional audism can manifest in where deaf people go to school, where deaf people live, and even how deaf people can act. In short, institutionalized audism is, "(…) the hearing way of dominating, restructuring, and exercising authority over the deaf community." (Lane, 1999, p. 43). Understanding the different ways in which audism arises throughout the

d/Deaf and HoH community will provide context and nuance to experiences shared throughout this project.

The second tenet of Deaf Crit is to challenge the hearing-dominant ideology (Gertz, 2003; Gertz, 2016). Deaf Crit aims to challenge the power, privilege, and control that hearing-dominant society has over the Deaf community (Gertz, 2003; Gertz, 2016). In recognizing this dynamic, Deaf Crit aims to give agency back to the Deaf community to better understand their history, language, education, community, culture, and identity (Gertz, 2003; Gertz, 2016). This analysis could serve as useful throughout the thesis dissertation as it considers deafness beyond a hearing lens and affirm their Deaf identity.

The third tenet of Deaf Crit is committed to social justice by offering a liberative and transformative response to oppression against deaf people by viewing the Deaf community as a cultural group, that has autonomy rather than under a strictly medicalized or deficit-based view of understanding that is encouraged through the medical model (Gertz, 2003; Gertz, 2016). Moving forward, I am curious about how Deaf culture is understood with individuals who do not have experience within the culture. My research hopes to extend Gertz's frame work by asking the question of how community, connection, and liberation can be defined and facilitated to better reach community members with different experiences.

The fourth tenet of Deaf Crit emphasizes the importance of centering the experiential knowledge of Deaf and Hard of Hearing people (Gertz, 2003; Gertz, 2016). Deaf Crits recognizes that the knowledge that Deaf people have is legitimate, appropriate, and critical to the understanding, analyzing, practicing, and teaching of

oppression against the Deaf and HoH community (Gertz, 2003; Gertz, 2016). Deaf Crit

values this knowledge and draws on lived experiences through storytelling and family

history in various methods (Gertz, 2003; Gertz, 2016).

The fifth and final tenet of Deaf Crit encourages multiple fields of learning work to

share Deaf ways of knowing through an interdisciplinary perspective to capture the

many different experiences of the community in a variety of ways (Gertz, 2003; Gertz,

2016). This thesis will contribute to knowledge in Deaf Crit, by using the interdisciplinary

methodology of arts-based method research to center the experiences, practices, and

knowledge of the d/Deaf and Hard of Hearing community.

3.3 Critical Disability Studies, Deaf Crit, and the Exploring Deafhood Study

It is important to note that these theoretical perspectives are incredibly different

yet nuanced, positions of disability. Critical disability theory seeks to understand how

systemic, structural, and individual oppression against disabled people manifests itself

in various ways. However, Deaf Crit seeks to push against the perspective that d/Deaf

and HoH people should not have to conform to society to gain access, support, and

acceptance. Rather, society should accept the distinct cultural and linguistic values,

needs, and connections that come within the Deaf community. In fact, some have

argued that connecting the term disability to the Deaf community is an action that is

heavily contested because it often undermines the distinct cultural and linguistic

autonomy of the Deaf community (Padden & Humphries, 1998; Lane, 1999). As Gertz

(2016) illustrates,

> "Historically, hearing people's ultimate goal has been to recast Deaf people into
> the image of hearing people, but as lesser citizens. Deaf educational systems
> created by hearing people continue, even today, to perpetuate a myth of
> success, regardless of the failings of Deaf children and adults in those systems.

Even the history of Deaf community/culture has no meaning to such hearing people. In the name of their so-called expertise, such hearing people felt, and feel, obligated to eliminate deafness, by any means." (p.160).

However, considering that this study seeks to better understand the supports and barriers that d/Deaf and Hard of Hearing people face within accessing community— either within the hearing world or the Deaf world—it is important to highlight the nuances within these theoretical approaches. While Deaf Crit clarifies how audism, power, and oppression shape the lives of d/Deaf and Hard of Hearing folks, it is not representative of the community if they are not immersed within Deaf culture. However, critical disability theory clarifies the experiences of d/Deaf and Hard of Hearing people who were raised without access to Deaf culture, community or signed language because it's consideration of historical, environmental, political, and social factors that impact their lives.

The purpose of this thesis is to better explore the nuances and complexities that d/Deaf and HoH face when understanding their own identity, positionality, and connection to d/Deaf and HoH culture and community. As Leigh (2009a) notes, it is impossible to completely divide Deaf and hearing culture, as they "exist in relationship with each other" (p. 17). Similarly speaking, the connections that a critical disability and Deaf Crit framework have within one another, as very closely tied to one another, as they both contribute to the nuanced understanding of d/Deaf and HoH people.

Chapter 3: Methodology

As a deaf researcher, it is important for me to conduct research that focuses directly on the lived experiences of people who are d/Deaf and/or HoH. This is largely informed by the theoretical underpinnings of critical disability studies and Deaf Crit, which both encourage centering the lived experiences of people who are marginalized within research (Gaetz, 2016; Meekosha & Shuttleworth, 2009). My methodological process is informed by these theoretical frameworks including my approach to recruitment, consent, data collection and analysis, dissemination (or knowledge mobilization), and my own attention to researcher reflexivity.

4.1 Choosing Photovoice

The main goals of Photovoice include enabling people to record and reflect upon the strengths and concerns of their own communities. Photovoice as a methodology strives to center the perspectives of community members with lived experience through capturing photographs and reflecting upon their circumstances to promote change in their own communities (Wang & Burris, 1994; Wang & Burris, 1997).

Photovoice also facilitates critical dialogue and knowledge sharing between community members to discuss issues within the community (Wang & Burris, 1994; Wang & Burris, 1997). Photovoice bridges the connection between people's private lives and the public sphere by connecting personal struggles to broader social issues and politics through using photography, critical conversation, and social action (Sutton-Brown, 2014). In turn, Photovoice uses the knowledge that the community generates to advocate for social and policy change (Wang & Burris, 1994; Wang & Burris, 1997).

As a methodology, Photovoice is largely informed by empowerment education, feminist theory, and documentary photography (Wang & Burris, 1994). Empowerment education was originally coined by the work of Paulo Freire, who argued that community knowledge sharing, collaborating, and action are critical to achieving social change and equity (Freire, 1993, as cited within Sutton-Brown 2014; Freire, 1997). Furthermore, tenets of documentary photography inform the theoretical makeup as it captures the everyday lives of a specific community of people to communicate their testimony through photography (Jing & Yun, 2007, as cited by Sutton-Brown, 2014). By enabling people to reflect upon their environment and communicate with one another, it allows for a critical conversation on what they see and hope to move forward.

I chose to use Photovoice as my research methodology for my thesis because I wanted to create a project that was accessible to d/Deaf and HoH people with different communication preferences by relying on both textual and visual data. This is aligned with previous research which found that Photovoice is well suited for d/Deaf and Hard of Hearing participants, as it relays on a visual expression of communicating rather than a complex emphasis on spoken language (Mabruroh, Gunarhadi & Widyastono, 2022; Pfister, 2013). Furthermore, in line with critical disability studies, Deaf Crit, and research conducted by others within the d/Deaf and HoH community, I wanted to center the lived experiences of people who are within the community to share their own narrative and story (Gertz, 2015; Hall, 2019; Leigh, 2009a; Meekosha & Shuttleworth, 2009).

Photovoice is a branch of photo-elicitation. The critical difference between photovoice and photo-elicitation is that in Photovoice, "(…) the photographs must make it possible to know the point of view of the participants who take them on a problem or

40

community issue, in other words, their experience or individual knowledge and also social, through dialogue, with the aim of conveying their views to social and political leaders who can introduce changes and improvements." (Romera Iruela, 2023). While in photo-elicitation, is the process of inserting a photograph into an interview that elicits responses and memories (Harper, 2002; Latz, 2017; Romera Iruela, 2023). The Exploring Deafhood study aims to challenge perceptions of what it means to be d/Deaf and HoH by highlighting the participant's diverse and different experiences.

Often the term Photovoice can be misleading, as it implies that it provides a voice to those whose perspectives are often not considered (Wang & Burris, 1994). The 'photo' of photovoice is the process that turns the camera lens on those lived experience of the issue and provides people with the opportunity to record, reflect, and critique personal and community issues in creative ways (Wang & Burris, 1997). The 'voice' aspect of photo*voice* is understood to mean the articulation of lived experiences and experiences of oppression, silencing, agency, and control (Liebenberg, 2018). This term can be contested within the d/Deaf and HoH community, as it implies that one needs a voice to be paid attention to. For the purposes of the study, it is imperative to note that the focus is ensuring communication is conveyed through whatever way is most comfortable to the individual—whether that be through using their voice, signed language, a combination of both, or using other means. There are no specific structures or requirements for conducting a Photovoice (Sutton-Brown, 2014) however, I followed Wang and Burris' (1999) general guidelines and approach to photovoice documented in the following sections of my thesis.

4.2 Recruitment

4.2.1 Sample Size

I originally intended to recruit four to six individuals for my study. However, this became difficult due to the time constraints of when the research needed to be completed, and participants' ability to commit to such a time-consuming project. I decided to conduct the research with three participants in total. The rationale for this small sample size is a combination of feasibility and accessibility. Importantly, Photovoice requires a considerable amount of time and resources (Wang & Burris, 1994). Mason (2018), stresses the importance of considering feasibility within research, explaining that a small qualitative sample is useful when considering the cost, time, money. Considering that this project is to fulfill a Master of Social Work requirement, within a considerably short period of time, three participants is enough to process while also portraying a robust set of experiences within the community. This sample size was also feasible to account for the cost and resources needed as participants received a $50.00 e-visa honorarium for participating in the entirety of the project.

4.2.2 Eligibility Criteria

The eligibility criteria for the research project was, as follows:

- You must identify as someone who is d/Deaf, Hard of Hearing or someone with hearing loss;
- You must identify as someone who was raised in a predominately hearing environment/without access to signed language/or, have found Deaf community later in life;
- You must be over the age of 18 years old;

- You must currently reside in or were raised in, Southern Ontario.

As previously discussed, Padden & Humphries (1988) state, "Although the term "deaf" is the group's official label for itself, people who are Deaf can have a range of hearing abilities from "hard of hearing" to "profoundly deaf", and, conversely, there are people with severe or profound hearing impairment who do not participate in the deaf community." (p. 4). It is of the utmost importance to stress that the labels used in the study do not cover all the different ways in which one connects to hearing loss or deafhood. Fundamentally, as a researcher, I am much more concerned about their experiences rather than a specific label for identification.

Furthermore, participants need to be above the age of 18 years old. This was an intentional choice. I am curious about any reflections that participants might have, after the formative years of their childhood, not during it, and how they hope to or have proceeded later in life.

Finally, participants must currently reside or be raised, within Southern Ontario. Within a Western context, there is a great deal of information on the experiences of d/Deaf and Hard of Hearing people within the United States. However, there is a significant gap in research, on the experiences of d/Deaf and Hard of Hearing people within Canada, and more specifically Southern Ontario. Ethics was obtained by the McMaster Research Ethics Board (appendix A).

4.2.3 Recruitment Process

This thesis used a snowball method of recruitment strategy. Snowball sampling is a referral model of sampling, where one person is contacted about a study, and the researcher asks them to refer the project to another person, and so on and so forth—

until there are enough participants for the study (Geddes, Parker & Scott, 2017). I also leaned on my connections as someone who is involved with disability-centered organizing and community work. I began recruitment in May and conducted individual interviews and workshops via Zoom in June-August 2023.

I reached out directly through email (Appendix B) to d/Deaf and HoH centered non-profits and organizations, to discuss their perspectives. I also reached out by email to community members I know who do disability work within McMaster university and throughout Hamilton. I asked if they could spread the research poster (Appendix C), the research poster description (Appendix D) and letter of information (Appendix E), to anyone they think would like to participate. I also shared the poster on social media and asked community members to share it with their networks.

I approached recruitment by considering a few things. Firstly, by working directly with people in or alongside the d/Deaf and HoH community I wanted to present a more robust perspective in my research. Secondly, as stated earlier, not everyone is connected to their experience of hearing loss or deafhood in the same way. They might not have found d/Deaf and HoH community, might not know of d/Deaf and HoH-centered organizations, and might believe that they are "Deaf enough" to do so. By using various types of social networks, within d/Deaf and Hard of Hearing community, and beyond, I connected with a wide range of individuals with varying experiences.

4.2.4 Accessibility and Accommodations

Prioritizing accessibility was at the forefront of this research. To account for various access needs, the project had an American Sign Language (ASL) interpreter and Zoom-enabled closed captioning available. Both the ASL interpreter and

transcription were required to sign an oath of confidentiality prior to supporting work on this thesis (Appendix C). Ultimately, all participants stated that an ASL interpreter was not required for the workshops. However, it was still a priority to ensure that the option was made available should the participants require it. Instead, the workshops relied on automatic closed captioning to allow for easier communication. Furthermore, the small sample size was the most accessible for participants, as there was less likelihood of crosstalk and interruption. Each participant was given the opportunity in the individual introductory interview with me to express if they needed additional accommodation. Furthermore, image descriptions (Appendix E) were provided on all recruitment posters and of the Photovoice photos throughout this thesis. This is to ensure that the findings are accessible to individuals who are blind or experience low vision.

4.3 Data Collection

Prior to beginning the data collection process, I met with every participant individually over Zoom, to explain the study and to go over the Letter of Information (Appendix E). Once the conversation was completed and I confirmed that they were still interested in participating, I obtained their verbal/visual consent (Appendix F). Although I expected that participants would attend all four of the photovoice sessions, there were some unanticipated challenges in people's schedules that prevented them from always being in attendance. In this instance, I arranged a time to meet individually post-workshop, for a makeup session. During these individual sessions, I took the participant through the same process of sharing photos and the meaning of these photos as they related to the weekly questions.

After being reminded of the questions, the participant once again reflected on their photograph and how it responds to the prompt. While they were speaking, I would screen share their photograph on the screen for the other participants to see. After both participants shared their reflections on their photographs and prompts, they briefly discussed how they were impacted by one another's stories and related to each other. All group and individual photovoice sessions were video and audio recorded and transcribed verbatim.

4.3.1 Photovoice Workshop Process

Session 1: Introductions and Explaining Photovoice

Before this session, I also sent a list of mental health resources to the participants, should they need to access support throughout the Photovoice workshops (Appendix J). I also sent a copy of the Photovoice workshop guide, so they could be prepared for what the following sessions contained (Appendix K). While other topics ultimately came up, which will be touched on below, this served as the main guide for this workshop series.

This session was an opportunity for the participants to meet each other and explain why they were interested in taking part of the study. Furthermore, I also explained how Photovoice workshops are conducted, and how to take photos and save them in MacDrive to share for the next group session. I lead the group in the process of identifying individual and group expectations and ground rules.

Following the discussion surrounding the photos shared in session 3, one participant suggested adding the question, "What are some societal barriers that you have experienced based on assumptions of who a d/Deaf person is especially within a

hearing world?" I was worried about participants not having enough time to allow for an additional set of photographs to respond to the question. However, after some conversation, one participant decided that this would be a good question to follow up on in the conversation and analysis of discussing the barriers that participants have had in accessing the d/Deaf and HoH community. This question was added as an additional question to consider when reflecting on the original questions provided in the third workshop.

Session 2: Defining Community

This session occurred the following week over Zoom and lasted 60-90 minutes. Participants uploaded their photographs to MacDrive before the initial workshop began. During this session, the participants responded to the first question: "What does the d/Deaf and HoH community look like to you?" Participants chose themselves at random to individually speak about their photograph and how it related to the prompt. While they were speaking, I would screen share their photograph on the screen for the other participants to see. Once everyone shared their photograph, the participants were asked, "In what ways are your experiences similar and different?"

At the end of each session, I asked the participants to prepare two photographs in response to two questions each. The first question, "In what ways do you feel supported in connecting to the d/Deaf and HoH community?" The second question the participants were asked to respond to was, "In what ways have you experienced barriers in accessing the d/Deaf and HoH community?"

Session 3: Supports and Barriers to Community

This session occurred the following week over Zoom and lasted 60-90 minutes. Participants uploaded their photographs to MacDrive before the initial workshop began. During this session, the participants responded to the second and third questions: The second question, "In what ways do you feel supported in connecting to the d/Deaf and HoH community?" The third question the participants were asked to respond to was, "In what ways have you experienced barriers in accessing the d/Deaf and HoH community?"

At the end of the session, I asked the participants to prepare a photograph in response to the prompt, "Take a photograph that reflects your time during the Exploring Deafhood study, in preparation for session 4: debrief and participatory analysis.

Session 4: Debrief and Participatory Analysis

This debrief zoom session lasted 60 minutes. The first half of the session was a space for me to share the preliminary findings from the data that the community members provided and connect them to the broader themes, ideas, and impacts beyond this project. I gave the participants a chance to provide feedback and suggestions for what to do with the information moving forward. Furthermore, the participants had a chance to share if their information was portrayed accurately or if adjustments should be made.

For the second half of the session, participants were asked to bring a photograph that reflected their experience of being a part of Photovoice workshops and this research process. Once again, participants uploaded their photographs to MacDrive before the initial workshop began. During this session, participants were reminded of

the final prompt, "Share a photograph of what your experience has been like during the Exploring Deafhood study." Participants chose themselves at random to individually speak about their photograph and how it related to the prompt. While they were speaking, I would screen share their photograph on the screen for the other participants to see.

This session was the same as the original workshop for that week except they were able to share their general reflections on each other's Photovoices. At the end of this session, I thanked all participants for their time and energy during the workshops. I let them know I would follow up by providing them the honorarium and with a final summary of the key findings and themes from the workshops.

4.4 Data Analysis

The data was analyzed within the workshop itself, by participants, and after the workshop through thematic analysis. Once the participant provided an analysis of the photographs and explained how it was connected to the prompt or question for that week, their narrated experience was then used as the data to analyze (Latz, 2017). The interpretation or analysis of the data was done collaboratively with myself and the participants during session 4, when I shared the findings and asked for their input, thoughts and feelings surrounding them.

The data in this study were generated through the participants' photographs', contributions to the group discussion in the photovoice sessions and through individual photovoice interviews. To spend as much time with the data, I attempted to transcribe each transcript as best as possible. Shelton & Flint (2019) note that the process of transcribing can provide a unique opportunity for researchers to practice reflexivity, in

examining themselves, the participants and the ways they shape and inform one another (Shelton & Flint, 2019). However, transcribing was difficult for me to do given my hearing loss. In anticipation of this, I hired a transcriptionist to assist me in transcribing. This looked like verifying any transcripts I transcribed myself and transcribing certain sections entirely. Truthfully, I found obtaining a transcriptionist to be deeply difficult. When trying to find a transcriptionist, there were many hoops to acquiring funding to support me in paying for one as well as an ASL interpreter. Furthermore, there seemed to be limited options available to me that were affordable, and satisfied McMaster Research Ethic Board requirements by not using a third-party automatic transcription app. I am grateful to have found someone to transcribe at a very affordable rate. However, I believe that there needs to be more resources and funding made available to graduate students who need accommodations when conducting research.

4.4.1 Thematic Analysis of Transcripts

Once the audio and video recordings were transcribed, I began my process of thematically analyzing and coding the transcripts using both a literal and interpretative reading of the data. Literal readings of data involve focusing on the literal form, content, structure, style, layout, and flow of the transcriptions (Mason, 2018). I took note of the words and language used within the interview transcripts, the structure and form of how the conversation flowed within the interviews themselves, and how this impacted the analysis of the photographs.

I also applied a literal analysis to the Photographs themselves by documenting a literal version of what appears in the photograph or "what is there" (Mason, 2018).

Following Latz' (2017) approach to analysis, I made note of what is present in the photo on its own, without context that was provided by the participant within the workshop. It is important to note that my goal when conducting a literal reading of the photographs, was for the purpose of communicating and sharing the research. My analytic process was primarily concerned with elevating the participants' own interpretations of their photographs. Ultimately, the main purpose of this practice was to write image descriptions of the photographs so that people who are blind or have low vision can access the material.

Interpretive reading of data involves a researcher documenting what they think the data signifies or represents, or what can be inferred based on what is shown or discussed (Mason, 2018). This can look like analyzing implicit norms or rules that the participant operates by based on the transcripts or underlying influences of societal norms or expectations. This can also look like the absence or what is not discussed within the transcripts (Mason, 2018). I applied an interpretive analysis throughout the data when I examined what was and was not being mentioned by the participants. I also examined their influence on how levels of connection to their self-identity has developed within their own perspective, others in their lives and in the rest of society. I also considered how underlaying themes of audism, ableism, power and oppression impacted their perception of themselves, the world around them and in accessing community. Lastly, I also considered how themes of empowerment, and autonomy arose within their reflections.

4.4.2 Coding and Sorting

My analytic approach was operationalized through a process of coding and

sorting the data for the purpose of identifying emerging themes across the participants'

experiences. While applying literal and interpretive analysis of the transcripts, I

employed a cutting and sorting method of organizing and analyzing the data. Cutting

and sorting involves identifying quotes, expressions, or themes that seem relevant or

reoccurring throughout the transcripts and placing them into piles of things that go

together (Ryan & Bernard, 2003).

When going through this process, there tend to be researchers who employ

either a "splitter" or "lumper" method of sorting. Splitters are those who seek to better

understand the difference between the passages and are more likely to have very

specific themes. Lumpers are those who minimize the differences between passages

and are more likely to focus on overarching and meta-themes throughout the data

(Mason, 2016; Ryan & Bernard, 2003).

In the first pass of organizing the data, I employed more of a broad, lumping

method, to familiarize myself with the material. Rather than sorting the quotes into

physical piles, I employed a method of colour coding the quotations into general themes

that appeared to be the most prevalent throughout. From there, I sorted the quotations

into categories or "piles" into a document. This was done by sorting through the

transcripts and colour-coding each instance of a certain theme, quote or expression by

hand (Mason, 2018).

As I began to analyze more, themes and sub themes grew to be more specific

and fine-tuned. However, I realized that the information that the participants provided

were more narrative in nature. Many of their comments appeared to overlap in context and certain key themes appeared to be repeated in response to different contexts. My goal in showcasing the findings was to tell an overall narrative of the key themes in a way that allows each participant to share their own story in as much of their own words and images as possible.

4.5 Researcher Reflexivity

Research is inherently political in nature, and it is essential that I ground myself within this project. Mason (2018) notes that it is important for researchers to be honest about how they inherently benefit from research, this can include personal gain, such as a degree, social influence, and funding. It is important for researcher to acknowledge the influence the research can have on a particular community (Mason, 2018). It is also important to consider how the interest of a particular group can be diverse and contested, and the ultimate objectivity of the research. The aim of this research is to center the experiences of d/Deaf and HoH people who exist on unique margins. Going into this project I was aware that the conversation of community membership in the d/Deaf and HoH community is a polarizing topic throughout history. Throughout this project I tried to be aware of highlighting the nuanced, while also centring the experiences of those directly marginalized within both communities, d/Deaf and HoH and hearing.

When exercising either reading of data, it is critical for me as a researcher to be reflexive of how my own positionality and basis influence the reading of the data. Mason (2018) describes reflexive reading as a researcher's responsibility to locate how their interactions with participants influence the data gathering and analysis process.

Reflexivity has been helpful to qualitative researchers who aim to counter the claim that objectivity can be achieved in social sciences research (Shelton & Flint, 2019). This has been useful in the aim to not position researchers as "unquestioned experts" or as the authority on people's lived experiences (Shelton & Flint, 2019).

As noted previously, I have lived experience as a deaf person who was raised with minimal access to d/Deaf and HoH community and signed language. I believe that this lived experience was helpful in conducting the workshops with other participants. Furthermore, I think that my previous experience in working with disability community organizing efforts was helpful to me in navigating the planning and facilitation of the workshops. However, while I do have some research experience, I am still new to doing research studies and planning and facilitating multiple workshops on my own.

5. Findings

5.1 Participants—Brown, Echo, and Jay

Three participants contributed their knowledge, experiences, and photographs to the Exploring Deafhood study. To ensure confidentiality, all participants choose their own pseudonyms for the study. All participants ranged from the ages of nineteen to mid twenties. Brown is a young Black cisgender man, who uses he/him pronouns and is hard of hearing. Echo is white, a cisgender woman, who uses she/her pronouns, and is hard of hearing. Jay is a Black cisgender man who uses he/him pronouns and is hard of hearing.

5.2 Introduction to Findings

The following section will explore the four major themes from the Exploring Deafhood photovoice workshops. These themes include motivations for community connection, understanding their own identity, how participants felt supported in connecting to the d/Deaf and HoH community, technical supports that facilitate connection to the d/Deaf and HoH community, and how the connection to others in the d/Deaf and HoH have supported the participants in having a stronger connection to their own identities.

5.3 "Being Part of the Same Thing"—Motivations for Community Connection

At the beginning of our first virtual Photovoice workshop, the participants had an opportunity to share their motivations for joining the Exploring Deafhood study. All testimony from this section was in response to an ice breaker question that asked, "Why are you interested in participating in this research?" Because it was the first workshop, participants did not bring photographs to share their experiences. Broadly, all

participants expressed that their motivation behind joining the study was to share their experiences, connect with others in the community and learn from one another. For example, Echo was raised and currently resides in Southern Ontario. She described that she grew up in a hearing family; however, she has d/Deaf and HoH extended family members who she has some contact with, many of whom reside in Halifax. Echo noted that she wants to connect with the d/Deaf and HoH community but has difficulty knowing where to start given that she has limited knowledge of the d/Deaf and HoH community in the city she lives in:

> *"I want to learn sign language I want to be more involved with the deaf community, but I have no idea where to start, and so, finding people who have similar experiences to me. Oh, I think we'd be very beneficial as well as being able to share my experience of being feeling in like in the middle, on the line of not fitting into like either community…"*

Brown noted that he was born in the United States and lived there for some time before residing with family in Southern Ontario during his teenage years. Although he once again moved back to the United States and currently resides there. He later expressed a desire to use this experience to learn from others as one way to more effectively cope with his hearing loss with people who have similar experiences:

> *"I think I need more knowledge about having hearing problems, you know? So, I was thinking that this would be important to be in and for me to know how to deal with these things. I mean, it's actually difficult to deal with. And a lot of people are part of the same thing. So, I was thinking it will be great if I could have knowledge about it and I don't have to go through the problems other people do."*

The third participant, Jay, described that while he was born in the United States, he did spend a significant portion of his childhood in Southern Ontario, before moving back to the US. Similarly, Jay shared that his motivation for joining the study was because:

"It's interesting to me that a lot of people that went through the same thing I am. Because it's not—hasn't been easy for me. You know, being a Black person of color and hard of hearing…I'm hoping to get the feedback like (…) get that from the other participants and hopefully I will be able to learn from their experiences also. And get support."

Echo identified her experiences of being in flux with her own understanding of her d/Deaf and HoH identity. Specifically, she felt like by growing up in a hearing environment she often felt like she needed to "*pass as hearing*". This is expressed when she said,

"Especially when I was younger, I wished that I could hear like a hearing person. That I didn't have constant ear infections, that I didn't have to get my ears sucked with a little vacuum, that I could do things without having to ask people to repeat themselves or I didn't have to say at the front of the class or have to tell people I need these accommodations. And so, I wished that I could change that and I could be like everybody else?"

All the participants identified that there are aspects of their experiences that they feel are not understood by their hearing peers, and unique to others within the d/Deaf and HoH community. As explained by the quotation stated by Echo below:

"Because a lot of the people that I'm around just like they're interested in it, but it's not like. They don't truly understand. Like all the things I go to, what I went through and I go through. Like they don't understand that like, when you put the water thing-y on your hearing aid and it makes the really annoying sound. They don't. Like, they'll be like, "oh that sucks," but they don't really understand like It's either that or swimming, like I can't do both and like I can't really swim because I don't want to wear that and then I – but I wanna hear and like they don't understand the dilemma that causes and all of the weird experiences that come with having to go to an ENT [Ear, nose and throat] doctor for so many years and yeah, They just. They don't have the same connection."

Importantly, all participants noted that they joined the Exploring Deafhood study in hopes of finding other individuals with common experiences, and to learn from one another in the hopes of connecting to the d/Deaf and HoH more broadly.

5.4 "Split Between Two Worlds": Feelings Surrounding d/Deaf and HoH Identity

A critical theme that emerged from the Photovoice workshops was the ways in which the participants talked about their identities in relation to the d/Deaf and HoH community. This section will detail how the participants felt that growing up in a hearing environment impacted their self-identity as d/Deaf and HoH people, how a sense of isolation impacted their own self-identity, and how self-empowerment through connecting to the communities around them shaped their identities as d/Deaf or HoH person.

For example, Echo shared how growing up in a hearing environment often made her feel like she was "split between two worlds" due in part to her limited access to the d/Deaf and HoH community. She further explained:

> *"…I grew up around hearing people and in a hearing environment and I've had very limited access to the deaf and hard-of-hearing community. And I've always felt out of place, and like I was split between kind of two worlds, on my own…"*

This perspective is further emphasized through Jay's experience as well. Jay described that he was the only d/Deaf and HoH person in his family and how this influenced his nervousness in initially connecting to the d/Deaf and HoH community:

> *"No one in my immediate family or my extended family is hard of hearing, so I'm just the only one in the family using hearing aids and all that. Being able to locate or find the deaf and hard of hearing community also and seeing other kids there, it really gave me a sense of belonging I don't feel at home. Like, I'm not the only Black person suffering from this. The other kids suffer from this as well. I'm not the odd one or the weird one in the family gathering or in the group. Just, I can…there are people I can relate to."*

Brown added that he also relates to Jay's experiences of having a difficult time connecting to others because they are both Black.

Another key experience that emerged for all participants in the context of their

identities, was a sense of isolation from the hearing world around them. For example,

Brown detailed the different experiences he had in friendship while being a person with

hearing loss. This is expressed through figure 1, where Brown described it as:

> *"This picture is actually trying to explain the difficulty I went through the hearing loss. You know, after the hearing loss, it was difficult to be among people. To meet good people. To have a very strong friendship."*

(fig, 1) A photograph taken by Brown, of two fortunes from fortune cookies. The top one

says, "Through hard times you will find new friendship." And the bottom fortune says, "A

new love is waiting around the next corner."

Brown detailed that throughout his life he struggled to connect to peers and

friends, because of a lack of support or understanding for his hearing loss. When

reflecting on this photograph, Brown discussed how he felt isolated because he was

unable to participate in events such as parties with his friends. As a result, he felt

disconnected from his friend group. Brown's experiences of isolation also impacted his

mental health, and he was provided with resources by a healthcare professional on

where to access support in the d/Deaf and HoH community out of concern for his

mental health. Brown reflected on this experience in the quotation below:

> *"Because I wasn't able to go out to parties, my friends anymore. And at some point, I felt like I just wanted to be alone. I need some peace around me. I needed some silent environment as soon as I had the disability. And…I just felt I needed a silent place to always be in. And these places we always visit are like, so much noisy places. So I would say it is part of it, actually. Yeah. And as I said earlier, it's not like I don't talk to them anymore."*

Brown's reflections highlight the struggle that he had in finding connections to

friends who were supportive of his hearing loss and access needs. Echo also reflected

her experience of isolation when sharing a photo of her hearing device (fig. 2).:

> *"And then like not only were they [her old hearing aids] were uncomfortable for me, but, especially when you're young and you don't grow up around deaf people and the deaf community and you grow up in a hearing environment and use a hearing aid—especially one like that—You think of old people. So one of like my biggest things with having to wear that one specifically was, 'Oh my god, like I'm like an old person' or like 'I'm so different from everyone else because of this and like I don't wanna wear this because nobody else is wearing it."*

(fig. 2) A photograph of Echo's old blue hearing aid and remote control.

Although all three participants identified struggles with developing their d/Deaf

and HOH identity, stories about self-empowerment also emerged as a significant factor

in developing their identities. During the workshops, Jay, Echo, and Brown all talked about the different reasons why they were able to feel more secure in their own d/Deaf and HoH identity as individuals. While this differed for each participant, they all shared a need to go through the process of challenging themselves to accept their identity as a d/Deaf and HoH person. As Echo stated:

> *"So there are a lot of times where my hearing exists as just…how it is at whatever level it's at and that it's probably gonna get worse. And I can't automatically reverse it or there's no miracle that will make it to a normal level. And accepting that, and realizing that I'll have to make accommodations, but I get to be part of such an amazing community, and I get to have so many amazing experiences because of it, I was able to change my perspective on it and on myself and the whole situation."*

Importantly, Echo upon sharing a photograph of her cochlear implants noted that getting cochlear implants was a critical moment because it helped her in understanding and accepting her HoH identity (fig. 3):

> *"But again, getting my cochlear implant has allowed me to be part of so many new and different communities, part of the cochlear family, as they like to say. And has allowed me to connect with people who are part of the deaf and hard-of-hearing community as well as people who aren't. And I'm not afraid to say that I'm hard of hearing anymore for fear of being judged. I am excited because people – now they think it's so cool. And yeah, so it's really helped me solidify my identity. And what my cochlear implant means to me."*

(fig. 3) A photograph of Echo's brown cochlear implants next to a remote that controls their volume.

Brown also notes that an important way of empowering himself emerged through working on understanding himself and his needs:

> *"While I was growing up, I had the hearing loss already. You know, when I was growing up actually, at some point I just said like, I need the peace, maybe. When I get some silence, please. I'm actually going to be able to figure out things myself. And—you know—it's so important to sometimes…get…[speaking to himself] like, how am I gonna say this? It's important to have time for yourself."*

Throughout the Photovoice workshops, all the participants noted that in some way they all developed the ability to empower themselves to embrace their d/Deaf and HoH identity. Jay described himself as having "*negative tools*", being a "*loner*" and being introverted before connecting to the d/Deaf and HoH community. Although he still is most comfortable on his own, he has expressed that it has been deeply helpful for him to connect to others in the d/Deaf and HoH community to get emotional support and advice on navigating his hearing loss. Jay said that this is a photograph that someone once shared in a group he was in (fig. 4).
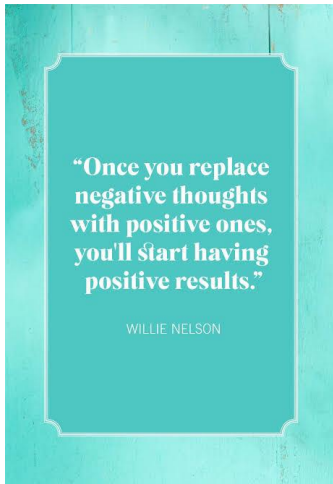
(fig. 4) A photograph Jay shared of a quote by Willie Nelson which states, "Once you replace negative thoughts with positive ones, you'll start having positive results."

Reflecting on this photograph, Jay stated that:

"Being the only one hard of hearing and finding out that there were others like me, I was able to make friends. So I was able to change my negative tools from being a loner and obviously kind of an introvert. I've been able to open up it's now an extrovert."

Jay's reflections highlight the fact that while reaching out to the community supported him in better understanding his identity, he also had to empower himself to reach out and connect to others.

Overall, Brown, Echo, and Jay's experiences highlight the fact that through exploring the community, they felt empowered to question their thoughts on being d/Deaf and HoH and eventually accept their own identities.

5.5 "Hearing is a spectrum"—Connection to Community and Coming Full Circle

Throughout the Photovoice workshops, all the participants discussed how having a connection to the d/Deaf and HoH community has been deeply beneficial in

developing a positive sense of their self-identities. Brown described his first experience

in connecting to the d/Deaf and HoH community made him feel:

> *"But at some point I had to like, try to like be, be free with them and it was actually very nice to know people in there. So sometimes when we share opinions, they just listen. Is that what you meant? Yeah. So, the deaf community was so much helpful for me too."*

Even though he was nervous to do so, Brown noted that reaching out and connecting to

others within the d/Deaf and HoH community was helpful to him. A similar reflection was

made by Jay when he shared a photograph (fig. 5) that described how connecting to the

community:

> *"The reason I show this picture was…the picture of people who are holding hands. First of all, not just white people here or Caucasian or Asian or…you can see there's like all the races, all the colors, Black…doesn't really depend on your race now. Because no one's judging. And in this community…we're striving to make it better. Just trying to help each other from our experiences. "Oh yeah, this happened to me. So if you're facing a similar situation, this is what you should do and this is what you shouldn't do." So…feels like…I make my experience from what she gets, what this person gets. Basically just…what you tell us in that group. He can – like, maybe he's if he is in a similar situation, he will know how to handle it better or how to deal with his family better. And so…it feels like a shared experience, something like this, yes, like this meeting we're having now. My experiences could help the other participants. Like, I experienced this, I experienced this and this is how I overcame this. So it doesn't really matter your race, or your colour, or anything."*

(fig. 5) Two photographs Jay shared of multiple people of different ethnicities holding hands.

In this quotation, Jay talked about how although members may have different identities, backgrounds, or knowledge, what is important is the ability to connect to one another through shared experience. Echo, notes a similar theme when talking about how even though there can be different identities one can have within the d/Deaf and HoH community, a sense of membership is still shared:

> *"The deaf and hard of hearing community is a spectrum. Hearing a spectrum. Whether you wear one or bilateral cochlear or in-ear hearing aids or none at all. If you sign or you lip read or you don't, you're still part of that community. It's not absolute. Some people do wear hearing aids and it works for them and they can go their whole life with one hearing aid or two hearing aids. And some people wear bilateral cochlear implants and some people wear one. Some people don't have any devices and they're all still part of the deaf and hard of hearing community. Because there it's not like your scale of hearing is—it's not like your deaf, or you're like if you can't hear anything, that's it. You can be you can have very minimal hearing loss and you can identify as deaf and be part of the deaf community. It's a spectrum like almost everything."*

5.5.1 "We support each other by talking about our experiences"— Reflecting on the Exploring Deafhood study

During the last Photovoice workshop, the participants were asked to bring a photograph that reflects their time of participating in the Exploring Deafhood study (fig. 6).

(Fig. 6) A photograph Brown shared of his garden.

Brown shared a photograph of the flowers he takes care of. He explained that even though he can feel bored or depressed at times, he still findings a lot of enjoyment in taking care of these flowers and taking time to himself. However, he noted that when he is not taking care of them, he also finds it helpful to continue to connect with the Deaf community.

For his last photograph, Jay talked about a photograph of hands giving a thumb up gesture of support (fig. 7). He used this photograph as a place to talk about his experience in connecting with the other participants throughout the study. Jay stated that:

> "We support each other by talking about our experiences. And learn from it. And um…you get to tell a person about your experience and then you hear about a person's situation and how they handled it and if its not to your liking you can take it and modify the person's answer and experiences. Make other choices. So the support and connecting to other people is great (…) It's really supportive."

(Fig. 7) Jay's photograph of hands giving a thumbs up gesture.

Echo shared a photograph of a doodle she drew (fig. 8). She said that this photograph described her experience in two different ways, the anxiety that she felt beforehand and the sense of community she felt. First, Echo described her anxiety, stating that:

> *"So like, through my experience with photovoice and this entire project in general, one of the things that this represents is the anxiety that I was feeling with like, just meeting new people and being vulnerable about all these experiences that I had. I'm just an anxious person in general. So like…it was just a little bit nerve-wracking to meet like, a bunch – like a couple of new people."*

However, Echo also stated that:

> *"And then this also represents the community that I've gotten out of this and…kind of like, a connection so like it's kind of in a circular shape so the connection that I felt with people going through this who had similar experiences to me and different experiences to me."*
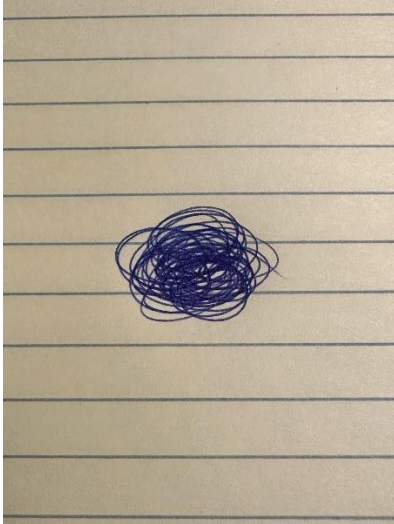
(fig. 8) Echo's last photograph of a spiral doodle she drew.

A common theme throughout their reflections is that the participants all felt a sense of support through accessing a community space to reflect on their experiences together. These thoughts were summarized well when Echo stated that she hopes the study shows that:

> *"And give…kinda like an inside peak into what it's like in our lives for deaf and hard of hearing, but also hearing people so that hearing people can see like, the challenges that we face and all the stuff that we do and maybe…or consciously are able to change the things that they do to make things more accessible without us having to ask. So…just it getting out there? So that people see it and people can just…know that there's people like them out there and that they're not alone. As just as humans in general, everybody has a different story. And everybody deserves to have their stories told. And a lot of people are similar, but in the end, everybody's different. Everybody experiences the world differently. And getting to listen to and see other people's stories, and other people's thinking makes us all more compassionate to what people are going through and broadens our knowledge of each other and the world."*

Throughout this theme, Brown, Echo, and Jay all touch on their past and ongoing experiences of connecting to others in the d/Deaf and HoH community. Through the testimony and photographs, they have all detailed how connecting to others in the community informs, supports, and shapes their identities as d/Deaf and HoH people.

68

5.6 "We wanted to have connections to make things easier for us": Supporting

Connection to the d/Deaf and HoH Community

Throughout the workshops, the participants identified a range of factors that supported them in obtaining a deeper connection to the d/Deaf and HoH community. This included family support, and support from health care professionals, who helped to break down barriers to accessing the d/Deaf and HoH community.

All participants identified that their connection to their family impacted their perspective and connection to the d/Deaf and HoH community. Both Echo and Brown expressed that their families have supported them in the process of connecting to the d/Deaf and HoH community. Echo described her connection with her family as a positive one stating:

> *"I think that it's really beneficial to be supported by family and friends in any way. Because it makes you feel less alone and it makes you…it encourages you to keep going and to learn new things. Especially when you are the only one facing it. And it's different and it can be a little bit scary. But having the support of people behind you encouraging you to keep going is a great thing."*

Echo also explained that while she was raised in a hearing environment, she does have family in Halifax who are d/Deaf and HoH. Throughout the workshops, she spoke of how this family was very supportive of her in better understanding and accepting her identity as a hard-of-hearing person and shared a photo of a screenshot of Halifax to reflect this experience (fig. 9).

(Fig. 9) A photograph Echo shared of a screenshot of Halifax on a map.

Brown highlighted his family support when discussing this photograph of a painting his fiancé made him (fig. 10).

(fig. 10) A photograph that Brown took of a painting his fiancé made of clouds overtop of a sunset.

Brown described this photograph as a painting his fiancé made for him when he

was feeling upset. He described that this painting reminded him of the ways in which his

fiancé would support his access needs and encouraged him to connect to the d/Deaf

and HoH community. During a workshop Brown said:

> *"She knows I don't wanna go out and avoiding outside. Sometimes I just feel like I don't wanna talk to anybody so she's trying to show me love. There was actually a letter present added to this. I can't really remember the words? But it was just like, motivation that I'll be fine. And I can at the same time…our friends, even with the disability and is not gonna affect me. So that was not how it was written on the letter. But something like that. It was just like, motivation from her. So at that time, that was when I decided to start getting some friends from the deaf community and attending some ASL language classes."*

Through the explanation of this photograph Brown highlighted the value of being

cared for in ways that centered his needs as a d/Deaf/HoH person.

However, not all participants experienced supportive family environments. Jay

shared how he has not felt supported by his family while attempting to connect with the

d/Deaf and HoH community:

> *"My experience generally with my family not being able to understand me. It's… just pretty horrific. I would use that word exactly, it's horrific. It's not really nice because being the only one in the family having hearing loss… it's hard. So certainly it's very hard."*

However, Jay, in demonstrating resistance to this environment, found a way to

connect with people outside the home.

> *"…but we still had to go out and find connections or make friends outside our homes. Outside our homes with the deaf and hard of hearing community. We wanted to have connections to make things easier for us."*

Through these reflections, Jay, Echo, and Brown explore the nuances between a

d/Deaf and HoH person and their hearing families. While they have different narratives,

71

both participants note that ultimately, they wanted to find a connection to support them through the process of moving forward with life as a d/Deaf and HoH person.

Both Brown and Echo explained that medical professionals supported them in different ways. Echo explained that when she got her cochlear implants, she met a Doctor on the team that had hearing aids. Echo stated that, *"However, one of the reasons that I think I was so open to it [getting cochlear implants] was because I noticed that Doctor he had hearing aids and he's a doctor and he experiences this to and he is able to accomplish so much and now he's helping people like him."* Although they did not talk about them, she noted that seeing a medical professional who had hearing aids was very empowering to her.

Furthermore, Brown talked about his experience of going medical professional to talk about his mental health. *"Sometimes when I visit to my healthcare provider, he sometimes links me up with some of the people, cause I told him."* Brown explained that this professional was worried about him isolating himself and encouraged him to connect to the d/Deaf and HoH community and provided Brown with resources.

Both examples from Echo and Brown highlight their experiences of receiving indirect and direct support from healthcare professionals in connecting to the d/Deaf and HoH community.

5.7 "I Think it should be more widespread"—Tools and Material Supports in Accessing d/Deaf and HoH Community

All the participants identified facilitators that increased their connection to the d/Deaf and HoH community. These factors include material tools, such as a service dog, transportation, and American Sign Language (ASL).

In the workshops, Echo talked about how her hearing service dog has helped her in her connection to accessing the d/Deaf and HoH community. Echo shared a photograph of her service dog when discussing how her service dog has been an essential partner to her in connecting to others with hearing loss, and in the broader disability community (fig. 11).

> *"…I've been able to access a unique part of the deaf and hard-of-hearing community and individuals with service dogs. So I've joined a couple of different communities through her…where I can connect with other people with disabilities who understand inaccessibility issues and the amazing things that these dogs can do. But who also understand what it's like to struggle and not be able to hear even with or without, like, support."*

(fig. 11) A photograph of Echo's hearing service dog.

Transportation also emerged as a facilitator for accessing the d/Deaf and HoH community. Both Echo and Jay talked about transportation being another fact that factor in their ability to access d/Deaf and HoH community. Throughout the Photovoice workshops, Jay discussed his experiences of attempting to access the d/Deaf and HoH community. Jay noted that when he lived in Southern Ontario, accessing d/Deaf and HoH communities was difficult because he lived in a small city without reliable access to transportation. This is exemplified in both photos he shared below (fig. 12).

(Fig. 12) Photographs Jay shared to represent different modes of transportation. The first is of a very busy highway filled with different vehicles. The second is of a city bus.

Jay drew on these photographs to explain how lack of transportation is a barrier to accessing community:

> *"That's the transport barrier. When I was in Ontario so, transportation was an issue because I had to go quite far from the house. Getting to the community and it wasn't really easy for me. I wasn't able to meet up with the time for meetings and everything, but I tried my best."*

Jay noted that he was only able to access the Deaf community center in his area once he moved to a home near one in the United States.

"That's when I came back to [his current location] it was more easier because the community wasn't too far from my house so I could have a better time with community because it was more accessible (…) when I moved back to [his current location] it was more easier because it's not It's not like I had to get in the bus or something or I had to get a cab or something. I can just, to me so I could just walk down."

Jay's perspective highlights how a lack of transportation can impact community members' ability to connect with and receive support from the d/Deaf and HoH community. Echo also talked about the different ways in which transportation has impacted her access to the d/Deaf and HoH community. Echo most explicitly discussed this when sharing a photograph of a screenshot of a local Deaf community center in Southern Ontario (fig. 13).

(fig. 13) A photograph Echo shared of a screenshot of a map where a Deaf community center is located. There is a red line indicating heavy traffic near the center.

When describing the photograph, Echo noted,

"I wanted to show this picture because one of the main issues I've had with accessing the deaf and hard and hearing community was physically, in that, based on my location and where a lot of the deaf and hard-of-hearing community centers or kind of community hubs are, are very far from me and not very

accessible. And so I wanted to highlight that inaccessibility and that barrier of not being able to physically access it."

Echo even noted, "This was a good screenshot to use because the red lines noted heavy traffic within the area." Echo also said that the center is not easily accessible to her by transit because her service dog tends to draw a lot of attention from people who do not know how to interact with the dog appropriately.

In both their photographs and testimonies, Jay and Echo highlighted that a lack of efficient, accessible, and reliable transportation impacts community members' ability to connect with the d/Deaf and HoH community, specifically, community centers. Throughout the Photovoice workshops, both Jay and Brown described how Deaf community centers were essential to them in finding ways to connect to other d/Deaf and HoH people they related to. While Echo did not describe accessing a specific Deaf community center, she did describe her experience in accessing d/Deaf and HoH-centered events in a major city, and that connecting with other community members had a profoundly positive impact on her. Jay noted that he hopes to see these resources become more available.

> *"I would recommend also it [d/Deaf and HoH centers] should be more so it's easily accessible too since I've had trouble experiencing it myself. So, I think it should be more widespread places where it should be more accessible. There should be more. They should put as and there should be more communities or more outlet to before like he had issues in accessing them."*

Overall, the participants' experience demonstrates that there is a significant benefit when being able to access these spaces, but there is also limited physical access to them due to a lack of accessible transportation outside of major cities.

Although all participants identified as not finding sign language until later in life, both Brown and Echo's experiences highlight that learning ASL can be a point of connection to accessing the d/Deaf and HoH community.

Echo describes of knowing even a limited amount of sign language as something that helped ground her and connect with some of her peers at the time. Echo also noted that she learned some ASL so she could connect with her Deaf family members when she visited them. Echo said, *"So I asked my great grandpa, I asked him like in sign language. 'How is the game like the get the hockey game?' And he was like so amazed and so like—So happy like that I was able to do that."*

Similarly, Brown also noted that ASL has allowed him to better connect with his d/Deaf and HoH peers.

> *"I just have the feeling that if I am able to use the ASL language that will be easier for me to have some more friends from the deaf community. And yeah, I actually – I actually love making friends with people that doesn't have this disability. But at the same time, I have to like be inside the deaf community. Maybe things will go easier for me than ever before."*

However, both noted that it was and still is difficult to learn sign language, especially in the beginning, without material and community support.

> *"And which brings up another thing is – sign language classes are not the easiest to enroll in. They can be very expensive. Also. It's difficult to find the time to do them. Especially to keep up with it over a long period of time. So that's another barrier. And along with that…I've watched videos, learning some sign language. I've been able to do that. However, learning through a screen. Through a video…signs and having an actual conversation with somebody."*

This further explains that while learning sign language online can be helpful in providing a basic understanding of the knowledge, it is much different when signing in person. Echo's reflection highlights the importance of in-person interaction within the

d/Deaf and HoH community, especially when learning sign language. However, this can

be difficult for community members as well, as stated earlier when exploring the

nuances that come with inaccessible or available transportation. Echo also noted that

ASL classes can be financially inaccessible to access. This perspective if further

highlighted when Echo explains that,

> *"Even if the like the class itself is not super expensive. There's still getting there. If you drive, gas is really expensive now. If you take the transit, transit can be expensive if you're going frequently. As well as being somebody that identifies as female, being out late at night in a downtown core city setting can be very dangerous and very scary and especially someone who has hearing difficulties – already I'm always on edge. But having such a vital sense taken away in a situation where you have to use all of your senses to be aware of what's going on can prevent a lot of people from going because of the time of the class."*

Brown notes that learning sign language was very intimidating, especially when

interacting with d/Deaf and HoH peers who were fluent while he was still a beginner.

> *"I'm gonna say, the first time, it was very difficult because I didn't even know how to communicate with these people. It was so difficult. I just felt like (…) because I would say I hated it at that time. And even when I go back home, I had to like complain. Like, you know, I can't do this. It's so difficult to get it."*

However, Brown also noted that while he was uncomfortable, he found

motivation—from both himself and encouragement from a close loved one—to continue

going to classes.

> *"(…) The motivation was just making me – I just had to do it. But at some point I think, after like, 2 weeks, I was so comfortable with everybody. It wasn't that difficult as I thought it would be. Actually, at the first time, it wasn't difficult, though. I made it difficult for myself. I didn't go there with the aim of getting connected with the people in the deaf community. On the first day I made it difficult for myself. So, I had to like, try to change my mentality at some point and I think."*

Both Brown and Echo's experiences in learning sign language are incredibly

important perspectives to highlight. Both participants identified that learning sign

language has been incredibly important to them in connecting with other people within

the d/Deaf and HoH community. Furthermore, both experiences highlight the fact that

learning sign language with others in their community—whether hearing or d/Deaf and

HoH—helps them to better connect with the language itself. However, there is some

difference in their experiences too. Echo's experiences highlight the fact the systemic

and structural factors that can impact one's ability to learn sign language.

Chapter 6: Analysis and Discussion

6.1 Introduction:

The aim of this thesis was to explore the experiences of d/Deaf and HoH people who were raised in Southern Ontario without access to Deaf culture, community, and/or sign language. The themes of exploring self identity as d/Deaf and HoH people, facilitating pathways to community connection and the need to receive holisitic support, were significant throughout the findings. The findings highlight the need to challenge existing binary views of d/Deaf and HoH identity and the importance of community connection, family support, and concrete resources that can lead to a positive experience of d/Deafness and HoH identity and community supports.

6.2 Exploring Self Identity as d/Deaf and HoH People

Among the participants in this study, there was a diverse range of experiences that shaped their understanding, development, and connection to their own d/Deaf and HoH identity. Overall, this study found that an individual's d/Deaf and HoH identity is influenced by a range of factors which include their existing social connections, other intersecting identities, supports they access and their overall environment. This is consistent with the literature demonstrates that there are different points of orientation that one can come into the community with, whether they are born within a Deaf community, raised in a hearing environment, or find Deaf community later in life (Leigh, 2019; Leigh et al., 2022). Furthermore, the findings suggest that other aspects of individual's identities shape the view of their d/Deaf and HoH identity. For example, when looking back at the experiences of Brown and Jay, it appears that race was an important factor in their overall experience. While they did not go into detail about these

experiences, the fact that it was mentioned suggests that, just like hearing people, d/Deaf and HoH people have intersecting identities that shape experiences.

All participants shared the experience of being raised as children without accessing the d/Deaf community until later in life. This is consistent with literature by Hamilton & Clark (2020); Snoddon & Paul (2020); Snoddon & Underwood (2014) and Hecht (2020) when families find out their child is Deaf, they are often provided with limited or no access to resources beyond hearing aids, cochlear implants or other devices that focus on auditory processing, this is in hopes of encouraging the child to acquire spoken language.

What emerged as most significant is that all participants believed that connecting to others in the d/Deaf and HoH community as young adults would have had a positive impact on their own understanding of their d/Deaf and HoH identity. This is consistent with the idea of Deafhood itself, which is the process of exploring and coming to an understanding of one's Deafhood by connecting to others through their deaf identity (Ladd, 2003; Leigh, 2009a; Leigh, et al., 2022). Overall, the findings showed that what appeared to be important to the participants was the journey to understanding themselves through the connection of others in the community, rather than needing to justify or legitimize themselves within the d/Deaf and HoH community in the first place. This research contributes to earlier arguments that it is not necessarily important how community members identify, but that they feel supported in exploring their identity through relating and connecting to others with shared experiences (Maxwell-McCaw, 2001, as cited by Leigh, 2009b). Some participants noted that they felt more secure in their identity at different parts in their lives. Echoing Maxwell-McCaw (2001), the

participants photographs and narratives in this study emphasize the importance of d/Deaf and HoH being viewed as complex people with different experiences, thoughts, and feelings toward their own identity.

6.3 Developing Pathways to Community

All participants noted that connecting with others in the d/Deaf and HoH community supported them in better understanding their own identities as d/Deaf and HoH people. These findings expand upon those of the deaf identity developpmeny model, which argues that while there are different degrees of connection to the d/Deaf and HoH, the important factor is that d/Deaf and HoH people accept their own identity. Holcomb, in their research on deafness, argued that once an individual seeks a positive connection to their deafness, a bicultural identity will potentially develop and could allow for them to form supportive relationships with hearing and d/Deaf and HoH people alike (as cited by Glickman, 1993; and Leigh, 2009b). All participants noted that they did in fact form some kind of supportive relationship with others in the d/Deaf and HoH community as they developed their own positive sense of self-identity.

This is consistent with research conducted by Gegory, Sheldon & Bishop (1995) who interviewed young Deaf children who were raised in hearing families. All participants ranged from growing up using different communication styles and with varying degrees of access to the d/Deaf and HoH community. The research found that over half of the 122 Deaf children they interviewed indicated that they accepted their deafness and that it was an integral aspect of their life though few participants spoke about being proud of their Deaf identity or being a part of the Deaf community (Gegory et al., 1995). A major tenet of Deaf Crit is to challenge the power, privilege, and control

82

that hearing-dominant society has over the Deaf community by giving agency back to the Deaf community through a better understanding of unique history, language, community, culture, and identity (Gertz, 2003; Gertz, 2016). This study highlights the process by which d/Deaf and HoH go through to better connect to others they relate to.

The findings demonstrated that a reason why the participants sought out the community was to learn from and connect to others who had shared experiences with them. The literature demonstrates that social inclusion is an important factor in building one's well-being, as identities are said to be formed and maintained in relation to others (Cagulada & Koller, 2020). The participants noted that they often felt like they could not connect or relate to their hearing peers within their environments; rather, they felt like they could relate more to their d/Deaf and HoH peers that they connected to later in life. This lead to feelings of isolation throughout different points of their lives. This is consistent with some of the literature, as Heffernan et al., (2020) indicates that medical professionals, such as audiologists, warn that isolation can have negative impacts on the mental health of those who are hard of hearing. While the literature widely states that social isolation within the d/Deaf and HoH community is a concern, there are few resources provided on how to address the concerns beyond acknowledging that community support is helpful in fostering a stronger sense of identity.

The research also found that having a strong sense of motivation and consistent access to the d/Deaf and HoH community helps facilitate these bonds. While there are barriers to this access—which will be explored later in the discussion—all participants expressed that they felt a more positive sense of connection to the community, and themselves, when engaging connection with others. For example, some participants

used the example of learning ASL from others in the Deaf community. They noted that while it was uncomfortable at times due to a language barrier or being in a new environment, they felt it was important to continue to try to connect to others in the d/Deaf and HOH community. The noted that a valuable aspect of connecting with community was the increase in access to knowledge, resources, and emotional support that others who are d/Deaf and HoH can provide to one another.

Furthermore, all participants noted that connecting to their own d/Deaf and HoH identity and others in the community is an ongoing process for them. Interestingly, all participants noted that they sought out community for themselves either in their teenagehood, or early adulthood. This is consistent with some literature, that reflects on similar experiences of young people exploring their deafhood. Ladd (2003) states that, "It is only in teenagehood or later in life that the truth begins to emerge—that many are simply left without meaningful membership to any community, whether that be Deaf or hearing." (Ladd, p. 36). This suggests that it could be helpful for d/Deaf and HoH people to have access to a diverse set of community supports earlier in life to attempt to mitigate feelings of isolation, disconnection, and loneliness throughout their lives.

All participants noted that they had limited or no connection to d/Deaf and HoH community within Southern Ontario. This is consistent with findings from the Ontario Deaf Youth Collective (2022) who published a report where they interviewed Deaf and HoH youth in Ontario to explore the gaps and barriers that come with representing the community within research. In their research, Ontario Deaf Youth Collective surveyed 31 Deaf and HoH youth and found that 49% of respondents did not know about resources or services that were available to support them (Ontario Deaf Youth

Collective, 2022). Overall, the Ontario Deaf Youth Collective (2022) notes that there are

very few programs and services that are available to D/HH youth; furthermore, they also

identify that youth may not be aware of the resources and supports that are available

throughout Ontario. These findings highlight the need to provide a holistic perspective of

what life with hearing loss can be that extends beyond a medicalized perspective,

especially earlier in individual's lives.

6.4 The Need for Multiple Supports

For all participants, connecting to the d/Deaf and HoH community did not mean

that they were closed off from the hearing world they grew up within. The findings from

the Photovoice workshop indicate that while the participants have found it helpful to

engage with the d/Deaf and HoH community, they also remained connected to the

hearing community that they grew up within. The findings demonstrated that a large

motivation for connecting to the d/Deaf and HoH community was external support from

others in existing social networks, such as encouragement and support from family

members.

Everyone noted that they received support in accessing the d/Deaf and HoH

community through a combination of community connections—such as family, friends,

and health care providers—as well as material supports, such as hearing devices, a

hearing service dog, ASL, and reliable transportation. This points towards the necessity

of providing holistic care, or multiple approaches to support, to people who are d/Deaf

and HoH.

Findings demonstrated that there were differing perspectives on how family

facilitates access to the d/Deaf and HoH community. While participants all had different

experiences with their families—some supportive and some less so—they all identified that the family unit was critical to influencing their understanding of their own d/Deaf and HoH identity. Furthermore, the findings also found that family members can provide emotional support in accessing the d/Deaf and HoH community later in life. How a family supports their d/Deaf and HoH child is impacted by their beliefs about what it means to be d/Deaf and HoH. Literature suggests that it is important for families to go beyond the view that hearing loss is something that needs to be "fixed and overcome to be comparable to a hearing person" and instead view deafness as another aspect of their identity (Avrahami-Winaver, et al, 2020, p. 2). This can be supported through understanding and exploring d/Deaf community, culture, and signed language (Avrahami-Winaver, et al, 2020, p. 2).

The findings also indicated that healthcare providers impacted their ability to access the d/Deaf and HoH community. This came through providing different resources to others in the d/Deaf and HoH community and through providing technical interventions such as hearing devices. This is consistent with findings which show that hearing service dogs (Hall, et al., 2015, as cited by Lalancette, 2023), ASL (Snoddon, 2008; Snoddon & Paul, 2020) can be incredibly helpful to provide support to d/Deaf and HoH people in accessing different communities that they are a part of. Furthermore, all participants noted that in accessing these different tools they felt more secure in their identities as d/Deaf and HoH people. However, there were also findings reported of experiences barriers to accessing these tools. Some participants noted that it can be expensive to enroll in ASL classes, or that they cannot access community without reliable transportation which was not available to them in the smaller cities they resided

in. However, the findings also identified that they needed more support in education for hearing communities around deafness. This is consistent with the literature which found that often hearing parents of d/Deaf and HoH children do not have access to signed language, knowledge of Deaf culture or community, or Deaf education (Leigh, et al., 2022).

The findings from this study point toward a need for a more critical approach to tools that support d/Deaf and HoH people in accessing the community. This perspective is further supported by findings by, Cagulada & Koller, (2020) who explored the perspectives of parents who have children who are d/Deaf and HoH within Ontario. This research found that reaching out to services that centered on the experiences of d/Deaf and HoH children and other parents who had d/Deaf and HoH children was helpful in navigating their children's experience with hearing loss (Cagulada & Koller, 2020). More resources that center on diverse connections to the d/Deaf and HoH community need to be explored and introduced to people with hearing loss.

Chapter 7: Implications

Drawing upon critical disability theory and Deaf Crit are important theoretical orientations to understanding the diverse ways in which systems of power and oppression uniquely impact those in the d/Deaf and HoH community in diverse ways (Gertz, 2003; Gertz, 2003; McRae, 2019; Meekosha & Shuttleworth, 2009). Particularly, those who are providing services to members of the d/Deaf and HoH community should have more knowledge on the fact that different d/Deaf and HoH people have different access needs and attachments to the community. Moving forward, more research, policies, and practices should be conducted on these unique experiences.

7.1 Implications for Practice and Policy

7.1.1 A Holistic View of Deafness

Throughout this thesis, all participants noted that having access to others in the d/Deaf and HoH community supported them in better understanding their own self-identity as d/Deaf and HoH people. Participants felt the most secure in their own identity when they were connected to broader community supports, rather than solely viewing hearing loss through a medicalized lens. While all participants identified different barriers to this process, it is important to note that they did not engage in the process of connecting to the d/Deaf and HoH community until they had the choice to do so later in life. This points toward a need to implement early intervention strategies that better support hearing families of d/Deaf and HoH children, and d/Deaf and HoH people later in life. This argument is strengthened which considering a deaf crit perspective, which advocates for knowledge produced by Deaf people to be key in developing processes and practices that impact them. Policies and practices need to be informed by the very

d/Deaf and HoH that they seek to support. These perspectives need to be viewed as legitimate, appropriate, and critical to the understanding, analyzing, practicing, and teaching of oppression against the Deaf and HoH community (Gertz, 2003; Gertz, 2016). Furthermore, this also points to a broader systemic and structural concern, where there needs to be more widespread access to more Deaf community-centered supports.

7.1.2 Need for Comprehensive Supports

This research found that there is a lack of knowledge on where d/Deaf and HoH people and their families can receive support in navigating d/Deaf and HoH identity and access needs. Practitioners need to be prepared to offer a comprehensive number of resources to community members that provide a comprehensive view of d/Deaf and HoH people's lives that exist beyond confirming that a hearing standard exists.

Overall, there needs to be a more critical approach to creating and implementing policies that seek to support d/Deaf and HoH people need to be more holistic in their approach to navigating hearing loss that goes beyond solely utilizing hearing devices extends to other methods of providing support. This can include ASL, hearing service animals and overall access to other role models within the d/Deaf and HoH community to support them along their journey of identity and access. However, the findings demonstrate that these resources may not always be easy to access for folks who do not live in major cities. This research also found that there were significant barriers to accessing these community supports. Specifically, transportation poses a significant barrier to accessing d/Deaf and HoH center events and resources that are outside smaller cities or urban areas. This is consistent with findings from other research

studies which note that community members often meet in physical spaces or clubs that can be geographically limited (Ontario Deaf Youth Collective, 2022; Kožuh, Hintermair, & Debevc, 2016). The Ontario Deaf Youth Collective note that there is a significant need for more outreach programs for Deaf/HoH youth, stating that, "The Deaf community is not in a specific location; members are spread out, and many D/HH community members are isolated, which means they often do not know where to find resources." (p. 33). Practitioners should be more mindful of the locations and availability of the resources that they provide to d/Deaf and HoH people who want to engage in community-based events.

Some resources within Southern Ontario include Silent Voice, which is a non-profit organization that provides an array of accessible programming and services for Deaf adults, youth, children, infants, and their families (Silent Voice, 2023). Their programming is conducted in ASL; however, they also provide a service called "The Family Communication Program" which supports family communication for families with Deaf and HoH family members by teaching them ASL, and information on Deaf community and culture (Silent Voice, 2023). Another resource is the Deaf Youth Hub, which falls under Silent Voice. Deaf Youth Hub is a service that has been established to be a place for Deaf and HoH people to access resources in finding employment and education (Deaf Youth Hub, 2022). Furthermore, there are virtual resources that provide classes to learn ASL. For example, Queer ASL is an organization that provides online and in-person classes that focuses on introducing ASL and Deaf culture to 2SLGBTQQIA+ learners and allies. This organization runs on donations only and

suggests participants donate on a sliding scale between $100-$350; however, no one is denied attendance if they cannot donate (Queer ASL, 2023).

This is by no means a comprehensive list of resources that are available to d/Deaf and HoH people in Southern Ontario. However, these resources show that there are opportunities for people to get involved in a more diverse understanding of what is available to people in the d/Deaf and HoH community. Furthermore, the findings suggest that there need to be more resources available for access to members of the d/Deaf and HoH community, and their support systems.

7.2 Implications for Research

Importantly, findings demonstrated that other identities, such as race and gender, shape the participant's identities as HoH people. While they did not go into much more detail than that, it is still important to acknowledge the intersectional understanding of their own identity. Moving forward, practitioners and community members need to be mindful of the ways in which d/Deaf and HoH people's identities are not limited to hearing loss and encompass an intersectional understanding of the self in relation to the environment around them.

Interestingly, the participants in this study were all young adults. However, in conducting research for the Exploring Deafhood study there appeared to be limited information on the experiences of late teenagers/adults who are d/Deaf and HoH. More research is to be conducted into the experiences of d/Deaf and HoH people who are adolescents or adults under the age of 65. For example, a great deal of literature detailing the experiences of d/Deaf and HoH people's isolation and mental health is geared toward people over the age of 65 (Heffernan et al., 2022; Bott & Saunders,

2021; Castiglione, 2016; Mick et al., 2013). Highlighting this perspective is not intended to be disparaging against elderly people with hearing loss. However, the findings indicated that there is a lack of knowledge on more broad perspectives of d/Deaf and HoH identities and that this has led to complex perceptions of a participant's self-identity.

8. Conclusion

8.1 Limitations and Considerations for Future Research

This thesis has explored the different ways in which d/Deaf and HoH people who were raised without access to Deaf culture, community, and sign language understand their own identities and connection to the community. An important strength of this study was its ability to capture the everyday ways in which d/Deaf and HoH people understand their own identity within a sociopolitical context rooted in audism, ableism, and other forms of oppression (Gertz, 2003; Gertz, 2016). My findings are reflective of particular perspectives within the d/Deaf and HoH community, and I cannot claim that this is reflective of the experiences of all members of the d/Deaf and HoH community. This is a consistent limitation of both critical disability theory and Deaf Crit that there are multiple different ways in which structural, societal, interpersonal, and political factors influence one's understanding of their own social location and identity as d/Deaf and HoH individuals (Chapple et al, 2021; García-Fernández, 2021; McRae, 2019; Meekosha & Shuttleworth, 2009).

Another limitation of this project is the fact that the research question is broad. This was an intentional choice on my part, from the beginning. I have never conducted research into the d/Deaf and HoH community before. I wanted to be aligned with suggestions from community-based research practices that emphasize the importance of ensuring that research is for community benefit (Access Alliance Multicultural Health and Community Services, 2011). I was worried about forming a research question that was too specific without understanding the broader perspective that people who d/Deaf are HoH but were raised without d/Deaf and HoH community or sign language. Moving

forward, I will aim to select more specific areas of focus that are relevant to the d/Deaf and HoH community.

Importantly, there are limitations to utilizing a snowball recruitment strategy. As noted by Geddes et al., (2017) a snowball sampling method is often contingent on the researcher's access to the community and social capital. When this method is taken up, the quality of research can be impacted if you are not considered an "insider" within the community (Geddes et al., 2017). As a researcher with lived experience of being deaf and raised outside of the Deaf community, I may not have as much access to the community as others who might have been raised within it. While I can appreciate that it is a potential limitation to use snowball sampling, I want to note that I hope to continue doing this research later in life. Moving forward, I desire to make connections with d/Deaf and hard-of-hearing-centered organizations through this project, to be able to continue research or other work within the community. I see this sampling method as one that demonstrates that while the community may be difficult to access at times, it is possible to do so in an organic fashion that centers the process of building lasting peer relations.

There were benefits and limitations to using Zoom to host the workshops. At times it was hard to connect to the participants and organize a schedule that worked for everyone, as all participants had differing schedules that were subject to change. Furthermore, some participants noted that they felt more comfortable connecting with others in person rather than online because they felt uncomfortable at times being on camera. The online space did provide an opportunity for flexibility. Since the workshops were conducted on Zoom, I had a chance to talk to two participants who lived outside of

Ontario but fit the study's parameters. Having sessions on Zoom also allowed for the opportunity to easily host make-up sessions when the participants needed to reschedule. Furthermore, using Zoom allowed for more accessibility as there was automatically enabled closed captioning for participants to follow along with. Moving forward, I do think there are benefits to utilizing an online space; however, I would suggest having multiple dates or times to allow for participants to attend comfortably.

8.2 Celebrating Deafhood

Overall, this thesis has drawn attention to the fact that there are many ways in which d/Deaf and HoH people come to understand and accept their identities in relation to the communities around them. Participants found it helpful to relate with others to better understand their own identity as d/Deaf and HoH people, share their experiences with others, and learn from the community. The findings demonstrate that there are significant barriers to finding community resources, support, and guidance. This is particularly the case for those who reside in non-major cities throughout Southern Ontario.

Moving forward, I aim to better consider the specific ways in which policies can be enacted to better support access between d/Deaf and HoH community and hearing environments. In future research, I hope to partner with other stakeholders within the d/Deaf and HoH community, such as Deaf resource centers or organizations. I think that this is an important step in being more aligned with community members' needs, and desires to better facilitate tangible tools and resources to better support the community.

Based on the results of this thesis, I feel firm in stating that more research needs to be conducted into exploring the experiences of d/Deaf and HoH people who were

raised without access to d/Deaf community, culture, and sign language. This research

needs to go beyond understanding of identity, rather focus on tangible supports, and

resources that respect the diverse experiences and needs of all people within the

d/Deaf and HoH community. Fundamentally, this thesis has demonstrated that we need

to move toward a society where d/Deaf and HoH are embraced completely and

celebrated for their own unique perspectives and experiences of Deafhood.

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Appendices

Appendix A—Ethics Approval

McMaster | Research Ethics
University | Board

McMaster University Research Ethics Board (MREB)
c/o Research Office for Administrative Development and Support
MREB Secretariat, GH-305
1280 Main St. W.
Hamilton, Ontario, L8W 4L8
email: ethicsoffice@mcmaster.ca
Phone: 905-525-9140 ext. 23142

CERTIFICATE OF ETHICS CLEARANCE TO INVOLVE HUMAN PARTICIPANTS IN RESEARCH

Today's Date: May/01/2023

Supervisor: Dr. Saara Greene
Student Investigator: Mx. Julia (Jules) Koncovy
Applicant: Julia Koncovy
Project Title: Exploring Deafhood: Using Photovoice to consider the different perspectives of what community means for d/Deaf and Hard of Hearing people in Southern-Ontario
MREB#: 6365

Dear Researcher(s)

The ethics application and supporting documents for MREB# 6365 entitled "Exploring Deafhood: Using Photovoice to consider the different perspectives of what community means for d/Deaf and Hard of Hearing people in Southern-Ontario " have been reviewed and cleared by the MREB to ensure compliance with the Tri-Council Policy Statement and the McMaster Policies and Guidelines for Research Involving Human Participants.

The application protocol is cleared as revised without questions or requests for modification. The above named study is to be conducted in accordance with the most recent approved versions of the application and supporting documents.

If this project includes planned in-person contact with research participants, then procedures for addressing COVID-19 related risks must be addressed according to the current processes communicated by the Vice-President (Research) and your Associate Dean (Research). All necessary approvals must be secured before in-person contact with research participants can take place.

Ongoing clearance is contingent on completing the Annual Report in advance of the yearly anniversary of the original ethics clearance date: May/01/2024. If the Annual Report is not submitted, then ethics clearance will lapse on the expiry date and Research Finance will be notified that ethics clearance is no longer valid (TCPS, Art. 6.14).

An Amendment form must be submitted and cleared before any substantive alterations are made to the approved research protocol and documents (TCPS, Art. 6.16).

Researchers are required to report Adverse Events (i.e. an unanticipated negative consequence or result affecting participants) to the MREB secretariat and the MREB Chair as soon as possible, and no more than 3 days after the event occurs (TCPS, Art. 6.15). A privacy breach affecting participant information should also be reported to the MREB secretariat and the MREB Chair as soon as possible. The Reportable Events form is used to document adverse events, privacy breaches, protocol deviations and participant complaints.

Document Type	File Name	Date	Version
Confidentiality/Data Security	Oath of Confidentiality	Mar/06/2023	1

An Amendment form must be submitted and cleared before any substantive alterations are made to the approved research protocol and documents (TCPS, Art. 6.16).
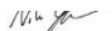
Researchers are required to report Adverse Events (i.e. an unanticipated negative consequence or result affecting participants) to the MREB secretariat and the MREB Chair as soon as possible, and no more than 3 days after the event occurs (TCPS, Art. 6.15). A privacy breach affecting participant information should also be reported to the MREB secretariat and the MREB Chair as soon as possible. The Reportable Events form is used to document adverse events, privacy breaches, protocol deviations and participant complaints.

Document Type	File Name	Date	Version
Confidentiality/Data Security	Oath of Confidentiality	Mar/06/2023	1
Recruiting Materials	Email Appreciation Letter	Mar/06/2023	1
Letters of Support	Counseling Resources Info Sheet	Mar/20/2023	1
Test Instruments	PhotoVoice Workshop Guide_V2	Apr/22/2023	2
Consent Forms	Consent - Oral Consent Log_v2 Final	Apr/22/2023	2
Consent Forms	Consent - Oral Consent Script_Final_V2	Apr/22/2023	2
Consent Forms	Letter of Information_Final Draft_v2	Apr/22/2023	2
Recruiting Materials	Snowball Email Recruitment Script Final	Apr/22/2023	1
Recruiting Materials	Email Recruitment Script_v2	Apr/22/2023	2
Recruiting Materials	Recruitment - Social Media post template_V2_Final	Apr/22/2023	2
Recruiting Materials	Exploring Deafhood Poster_v2	Apr/22/2023	2
Recruiting Materials	Poster Image Description v1	Apr/22/2023	1
Response Documents	Second Summary of Revisions MREB 6365	May/01/2023	2

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Appendix B—Letter of Information and Informed Consent

LETTER OF INFORMATION / CONSENT

Exploring Deafhood: Using Photovoice to consider the different perspectives of what community means for d/Deaf and Hard of Hearing people

Student Investigator:

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Faculty Supervisor:

Dr. Saara Greene

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Introduction

There is a great deal of information on the experiences of hearing loss from a medical perspective. There is also a great deal of information on the experiences of people who are a part of Deaf culture. Canadian Hearing Services defines Deaf culture as, "(…) *the culture of Deaf people based on a signed language and values, traditions and behavior norms specific to the Deaf community. Deaf culture offers a strong sense of belonging and takes a socio-cultural point of view of deafness."* However, not all d/Deaf, Hard of Hearing individuals or people who identify as having hearing loss have access to other people with similar experiences, Deaf culture, or access to signed language. My research will fill a much-needed gap in understanding the experiences of these individuals as it relates to facilitators and barriers to Deaf Culture.

Through my research study, I am interested in exploring what community looks like to you and how your experiences of hearing loss have informed your experiences and views about Deaf culture, and how best to support people with similar experiences to access the d/Deaf and Hard of Hearing community.

We will explore these issues using an arts-based approach called PhotoVoice is an arts-based participatory action research method that employs photography and group dialogue as a means for research participants to deepen their understanding of a community issue or concern. The purpose of PhotoVoice is to draw on the photos and the stories they represent to influence changes in health and social care policy and programming that will better address the participant's concerns.

Jules Koncovy, is a deaf, cochlear implant user, and disability community member. Jules is conducting this research to fulfill the requirements for the Master of Social Work thesis. I hope that by putting your voices at the center of this research, this study will create new knowledge that can inform the policies and practices of social workers and other service providers as well as shape how the experiences of d/Deaf and Hard of Hearing people are understood and can grow.

Taking part in this study

You can decide if you want to be part of this study. Taking part in this study is totally voluntary and choosing to participate will not affect your right to receive services or access healthcare. You do not have to join this study if you don't want to.

In order to participate you must:

- Identify as someone who is d/Deaf, Hard of Hearing or someone with hearing loss;
- Identity as someone who was raised in a predominately hearing environment/without access to signed language/found d/Deaf and Hard of Hearing community later in life;
- Over the age of 18 years old;
- Be willing and able to participate in four photovoice workshop sessions that will occur one half-day a week over four consecutive weeks. Before you agree to take part in this study, it is very important for you to understand the information in this consent form. If there is anything that is not clear to you, we are here to answer your questions. You must sign the consent form at the end of these pages if you want to participate in the project.

The study

The Exploring Deafhood study was established to develop an understanding of the experiences of people who are d/Deaf, Hard of Hearing, and/or identify with having hearing loss who were raised or currently are without Deaf culture. Often these perspectives have been dominated by medical or healthcare-based perspectives. Furthermore, there is also literature on the experiences of d/Deaf and Hard of Hearing people who have access to Deaf culture or access to signed language. However, there is little information on people who do not fall entirely within these perspectives, or on the process of accessing or finding the d/Deaf and Hard of Hearing community within Southern Ontario.

This research asks how community is framed for people who have a shared identity of hearing loss but were raised without access to Deaf culture or community and/or signed language. Or, if they have not considered connecting to other d/Deaf/Hard of Hearing community members, why this is.

I will be conducting PhotoVoice workshops to: a) explore how people understand their experiences of deafness or hearing loss, b) their definition of community, based on these experiences, and c) what would be supports and barriers to accessing the d/Deaf and Hard of Hearing community in ways that are comfortable to them.

What will happen during the Research Process?

Introductory Meeting

Introductory Meeting: This meeting will be an opportunity to meet Jules and the other participants of the project. Here, Jules will once again go over the Letter of Information and consent and provide a chance for you to ask further questions. Jules will also explain the PhotoVoice process, and how to take photos, and save them in Dropbox to share for the next group session.

The PhotoVoice Workshops

The PhotoVoice workshop will occur one half-day per week over four consecutive weeks and will be facilitated over Zoom by Jules Koncovy.

Session 1: During session 1, you will meet the other participants of the study and go through ice-breakers. You will be provided with a prompt to guide you in taking digital photographs using your cell phone or camera. You will be asked to upload your photographs in advance of attending session 2. These photographs will be used to guide our discussion in session 2.

At the end of session 1, you will be provided with a prompt to guide you in taking digital photographs using your cell phone or camera. You will be asked to upload your photographs, in advance of attending session 2.

Session 2: During session 2 you will be asked to participate in a story-sharing circle in order to discuss the photographs you uploaded.

At the end of session 2, you will be provided with a prompt to guide you in taking digital photographs using your cell phone or camera. You will be asked to upload your photographs in advance of attending session 3. These photographs will be used to guide our discussion in session 3.

Session 3: Session 3 will follow the same process as session 2. However, the session will end with some closing remarks and brief reflections on the PhotoVoice process.

The sharing circles at the workshop will be video and audio-recorded. A transcriptionist who is affiliated with the research team will type out the discussions word-for-word so

that the text can be analyzed to identify common issues and themes. The PhotoVoices that are produced will also be analyzed for relevant issues and themes.

During the Fourth session, participants will gather to celebrate what was produced during the Workshops, discuss the next steps, and close the Workshop series.

Workshop Details:

- First session—Introductions and Explaining PhotoVoice
  - There will also be a chance to go over the prompts for the following weeks, and if the group thinks that these are appropriate questions to respond to.
  - Finally, there will also be a chance for everyone to share their personal group expectations for how to create an environment that is as safe and comfortable for all participants as possible.
- Second session—Defining Community
  - This session is an opportunity for you to share your photographs in response to the prompt, "What does community look like to you? How has your personal identity and experiences shaped this understanding?"
  - Sharing circles will be audio-recorded, however, any identifying information that may be shared will be removed during transcription.
- Third session—Supports and Barriers to Community
  - This session is an opportunity for you to share your photographs in response to the prompt, "What does are some things that support your access to community? What are some barriers? If you have not had access to other people who are d/Deaf and Hard of Hearing, why is that?"
  - Sharing circles will be audio-recorded, however, any identifying information that may be shared will be removed during transcription.
- Fourth session—Debrief and Analysis
  - This session will occur after the data has been collected and analyzed by Jules after sessions two and three. This should happen roughly around mid-July, and Jules will contact all participants to schedule a group to debrief.
  - This session will be a space for Jules to share the findings of the community members' data and connect it to broader themes, ideas, and impacts beyond this project.
  - In this session, you will have a chance to provide feedback and suggestions for what to do with the information moving forward. Furthermore, you will have a chance to share if your information was portrayed accurately or if adjustments should be made.
  - Should you want to provide more feedback privately, Jules will be happy to book individual Zoom meetings to discuss.

Accessibility Considerations

The focus groups will be conducted on Zoom to allow people to participate virtually in their comfort. There will be English automatically generated closed captioning enabled in Zoom, which has adjustable sizing for fonts. Furthermore, an American Sign Language (ASL) interpreter will be present in all focus groups. All administrative contact with the research team and participants will be conducted over email.

Should there be any additional access needs that you need to be considered, please let the research team know and they will be happy to support you in navigating this to the best of their ability.

What will happen with the photos you take and share?
The photographs you contribute will be stored on a password-protected electronic MacDrive folder. With your permission, we will also share your images in presentations, at conferences, and at other virtual and in-person events. Your photos will only be shared with your permission and with a name/label that you choose (e.g. with or without your name, using nickname or pseudonym).

What will happen after the Photo Voice workshop?

Sometime within the months following the PhotoVoice workshops, Jules Koncovy, will contact you and provide you with a draft summary of the story you shared about your PhotoVoice. You will have the option to set up a virtual meeting to discuss and revise the summary. You are welcome to provide input into the summary, make any corrections to make sure that it is accurate, and remove any details that you feel may be used to identify who you are. Participating in this part of the research is entirely voluntary – you do not have to attend these meetings, but you are welcome to it if you are interested in doing so. You will receive a copy of the final summary to keep.

Voluntary participation

Your participation in this study is voluntary. You may decide to stop participating and you have the right to withdraw from the study without consequence at any time. If you withdraw from the study, your medical care, education, or access to other services will not be affected. Any information gathered from you during the recruitment process and the research will be destroyed and will not be used in the study. We hope you are willing to fully participate in all project activities, but it is entirely your choice whether you do. If you choose to withdraw from the study during the workshop, you are free to do so. If you do withdraw during the workshop, you will still receive your full honorarium.

It is possible to withdraw from the study after you have created your photos. However, given the interconnected conversation between all group members within the workshop, it is not possible to entirely delete general themes or insights that you provide within the workshops. In this case, withdrawing from the study after participating in the workshops will mean removing photographs and direct quotations that you provide. We ask that you inform any member of the research team of your decision to withdraw by June 10th, 2023 to ensure your PhotoVoice photographs and direct quotations are not included in any project activities including in the study results. If you choose to withdraw from the study after you have participated in any or all of the workshops, including the group discussions, we will delete your comments and answers from the group sharing circle transcript to the best of our ability.

Are there any risks involved in this project?

I do not expect this study to cause you or others any harm. To the best of my ability, I have considered the systemic and structural barriers that can come with being d/Deaf, Hard of Hearing, or someone experiencing hearing loss.

Some of the questions you will be asked to think about and discuss during the Photo Voice workshop are personal and may make you feel emotional or upset. You are not required to answer any questions that may make you feel uncomfortable, and you are not required to share any information that you wish to keep private. You are welcome to withdraw from the focus group at any time and/or skip particular questions or exercises that you would prefer not to answer.

You may become emotional or upset after the PhotoVoice workshop when thinking about the stories and experiences that participants have shared. It is important to have to someone connect with and provide support following the PhotoVoice workshop in the event that this does happen. There will also be a list of resources within Southern Ontario, should you need to access support.

There is a possibility that other workshop participants feel tempted to share stories they heard during the workshop. Therefore, the importance of confidentiality, respect, and privacy will be discussed and stressed prior to the workshop and all workshop participants will be asked to respect the confidential nature of the shared. You and other workshop participants will be asked to sign a confidentiality statement (at the end of this consent form).

At the workshop, you do not have to share any information that identifies you in any way or that you are not comfortable sharing in a group setting.

What are the benefits of participating in this study?

You will have the opportunity to talk about issues that concern you. You may learn new skills that may benefit you in other areas of your life. You may also find it helpful to share your story and hear the stories of others, sharing the experience with other people. We will use what we learn from this study to help strengthen policy approaches, and health and social services for d/Deaf, Hard of Hearing, and people with hearing loss in Ontario. Therefore, in the future, there may be indirect benefits to d/Deaf and Hard of Hearing community members.

How will my privacy be protected?

You do not have to provide any information that will identify you to the other workshop participants or the workshop co-facilitators. Throughout the study including during the online group sessions you are encouraged to use a nickname or a name that you make up instead of using your real name. All workshop participants will be asked to not discuss the things said in the workshop outside of the group. Although this cannot be guaranteed, in an effort to protect the privacy of workshop participants, all participants will be asked to agree to a confidentiality statement that is outlined at the end of this form.

I will record the group discussions on a virtual and digital recorder through Zoom. This is to make sure that we do not miss any of your valuable ideas and opinions. The recordings will be transcribed by a transcriptionist who is affiliated with the study and has signed an agreement to maintain the confidentiality of the study content. The transcriptionist will remove any information that identifies you. (For example, if you mention any details during the group discussion such as your name, your hometown, your employer or the name of a friend that could identify you, we will remove this information from the transcript and all written notes).

All information will be stored on MacDrive. MacDrive is a customized McMaster version of Seafile, which is an open source EFSS (Enterprise File Synchronization and Sharing) solution, similar to Dropbox. It allows people and teams to store files on a central server

and access them via a web interface or client on a device. All information will also be held on an encrypted and password-protected hard drive, that will only be accessible to the principal student investigator.

This study will use a virtual platform called Zoom to collect data, which is an externally hosted cloudbased service. The following is an embedded link to the Zoom Privacy Policy. Before each of our meetings and PhotoVoice workshops, you will receive a link and a password to join our virtual Zoom meeting. It is important that you do not share the link or password with anyone, as this could compromise the privacy of our meeting.

We will destroy the audio recordings when we complete this study. We will also destroy all the study transcripts, written data, and other study materials five years after we complete the study.

There will also be an American Sign Language interpreter present, who will be asked to sign an Oath of Confidentiality as approved by the McMaster Research Ethics Board.

Future Use of Data

The data collected during the PhotoVoice workshop will be used for the sole purpose of fulfilling the aims of the research described in this consent form.

Payment

There will be no financial costs incurred by participating in this study. An honorarium of $50 CAD will be provided to all participants who attend the Photo Voice workshops.

How do I find out what was learned in this study?

We expect to have this study completed by approximately September 2023. If you would like a brief summary of the results, please let us know how we should contact you at the end of this form. We aim to disseminate research findings through community organizations, in addition to presenting study data at conferences, and publishing key findings in academic journals.

Questions about the Study

If you have questions or need more information about the study itself, please contact Jules Koncovy, Principal Investigator, McMaster University, via email at koncovyj@mcmaster.ca.

This study has been reviewed by the McMaster University Research Ethics Board and received ethics clearance. If you have concerns or questions about your rights as a participant or about the way the study is conducted, please contact:

> McMaster Research Ethics Secretariat
>
> Telephone: (905) 525-9140 ext. 23142
>
> C/o Research Office for Administrative Development and Support
>
> E-mail: ethicsoffice@mcmaster.ca

Please keep an extra copy of this consent form for your records.

Consent for Participation

1. Do you agree to have the PhotoVoice workshop recorded by a member of the research team, so that it can later be transcribed?

YES   NO

2. Do you agree to maintain the confidentiality of other participants in the PhotoVoice Workshop by not recording our meeting, or sharing any details about other participants?

YES   NO

3. Do you agree for the Photographs (that are not copy written, and that contain no identifiable– such as people, names, etc.) that you share during the PhotoVoice Workshop to be shared in potential publications, and/or presentations (including the art exhibit)

YES   NO

4. Do you permit the use of your direct quotes from this study in written work such as potential publications, and/or presentations?

YES   NO

5. Do you permit the use of this data in future research projects?

YES   NO

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HIREB). The HIREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the Chair, Hamilton Integrated Research Ethics Board at 905.521.2100 x 42013

Appendix C—Oath of Confidentiality

Oath of Confidentiality for Assistants Working for the Researcher

(*Check the following that apply*)

I understand that as an:
[ ] interpreter
[ ] transcriber
[ ] audio assistant
[ ] photo or video assistant
[ ] research assistant
[ ] other (*Please specify*) _____

for a study being conducted by _____ of the Department of

_____, McMaster University, and or under the supervision of Professor

_____, confidential information will be made known to me.

[ ] I agree to keep all information collected during this study confidential and will not reveal by speaking, communicating or transmitting this information in written, photographic, sound, electronic (disks, tapes, transcripts, email) or in any other way to anyone outside the research team.

[ ] I will tell the researchers as soon as I discover that I know any participant either as a family member, friend, or acquaintance or in any other way; so that the researcher can take the appropriate steps to manage or minimize any conflicts of interest that might occur because of any dual roles I may have.
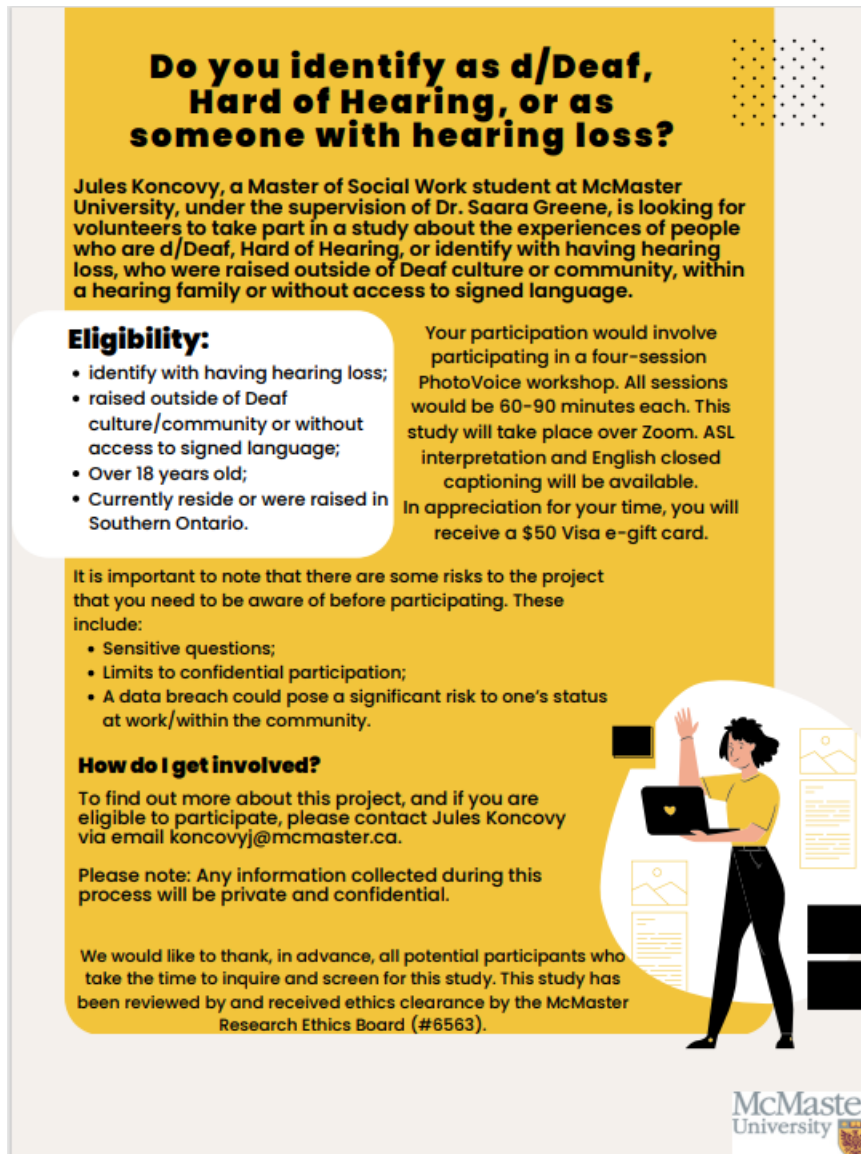
Name: _____ Signature: _____
        (Please Print)

Date: _____

Witness Name: _____ Witness Signature: _____
        (Please Print)

Appendix D—Recruitment Poster

Do you identify as d/Deaf, Hard of Hearing, or as someone with hearing loss?

Jules Koncovy, a Master of Social Work student at McMaster University, under the supervision of Dr. Saara Greene, is looking for volunteers to take part in a study about the experiences of people who are d/Deaf, Hard of Hearing, or identify with having hearing loss, who were raised outside of Deaf culture or community, within a hearing family or without access to signed language.

Eligibility:

- identify with having hearing loss;
- raised outside of Deaf culture/community or without access to signed language;
- Over 18 years old;
- Currently reside or were raised in Southern Ontario.

Your participation would involve participating in a four-session PhotoVoice workshop. All sessions would be 60-90 minutes each. This study will take place over Zoom. ASL interpretation and English closed captioning will be available. In appreciation for your time, you will receive a $50 Visa e-gift card.

It is important to note that there are some risks to the project that you need to be aware of before participating. These include:

- Sensitive questions;
- Limits to confidential participation;
- A data breach could pose a significant risk to one's status at work/within the community.

How do I get involved?

To find out more about this project, and if you are eligible to participate, please contact Jules Koncovy via email koncovyj@mcmaster.ca.

Please note: Any information collected during this process will be private and confidential.

We would like to thank, in advance, all potential participants who take the time to inquire and screen for this study. This study has been reviewed by and received ethics clearance by the McMaster Research Ethics Board (#6563).

McMaster University

Appendix E—Recruitment Poster Image Description

The poster has a yellow background and is written in black font. In the bottom right hand corner, there is a cartoon of a person waving at a laptop as thought they are on a Zoom call. Behind them are outlines of different images of landscapes and letters. The title states, "Do you identify as d/Deaf, Hard of Hearing, or as someone with hearing loss?". Blow this text it reads, "Jules Koncovy, a Master of Social Work student at McMaster University, under the supervision of Dr. Saara Greene, is looking for volunteers to take part in a study about the experiences of people who are d/Deaf, Hard of Hearing, or identify with having hearing loss, who were raised outside of Deaf culture or community, within a hearing family or without access to signed language."

The description of the study goes on to explain, "Your participation would involve participating in a four-session PhotoVoice workshop. All sessions would be 60-90 minutes each. This study will take place over Zoom. ASL interpretation and English closed captioning will be available. In appreciation for your time, you will receive a $50 Visa e-gift card." Furthermore, the eligibility criteria is that a participant needs to identify with having hearing loss; raised outside of Deaf culture/community or without access to signed language; is over 18 years old; and currently reside or were raised in Southern Ontario."

Furthermore, the poster states that, "It is important to note that there are some risks to the project that you need to be aware of before participating. These include being asked sensitive questions; limits to confidential participation; and a data breach that could pose a significant risk to one's status at work/within the community."

Underneath this section, there is a headline written in both that explains how someone can get involved stating, "To find out more about this project, and if you are eligible to participate, please contact Jules Koncovy via email koncovyj@mcmaster.ca. Please note: Any information collected during this process will be private and confidential."

Finally, at the bottom of the poster it reads, "We would like to thank, in advance, all potential participants who take the time to inquire and screen for this study. This study

has been reviewed by and received ethics clearance by the McMaster Research Ethics Board (#6563)."

Appendix F—Email Recruitment Script

Email Recruitment Script Sent on Behalf of the Researcher

Study Title: Exploring Deafhood: Using Photovoice to consider the different perspectives of what community means for d/Deaf and Hard of Hearing people

Sample E-Mail Subject line: McMaster study about d/Deaf and HOH People's experiences outside of Deaf culture

Dear [insert name here],

My name is Jules Koncovy, and I am a Master of Social Work student and student principal investigator conducting a research study from McMaster University's School of Social Work. I also identify as someone who is deaf and a cochlear implant user. I am exploring the experiences of those who identify as d/Deaf, Hard of Hearing, or with having hearing loss, who were also raised outside of, or without access to Deaf community, culture, or connection, within a hearing environment or without access to signed language. Furthermore, this study is being supervised by Dr. Saara Greene.

The following is a brief description of the study.

There is a great deal of information on the experiences of people who are a part of Deaf culture—this is a broad term, often associated with those with access to signed language and other d/Deaf or Hard of Hearing community members. While these experiences are incredibly important to highlight, the majority of people who are d/Deaf, Hard of Hearing, or identify as having hearing loss often do not have access to other people with similar experiences, Deaf culture, or access to signed language.

I am interested in exploring what community looks like to you, how your experiences have informed this, and what would better support you in accessing the d/Deaf and Hard of Hearing community.

I will explore these issues using an arts-based approach called PhotoVoice. PhotoVoice is a qualitative research approach that invites participants to use and take photos to record and reflect on their experiences and concerns, to promote discussion about important community issues, and to reach healthcare, social service provider, and policymakers who can facilitate change. Each workshop will be approximately 60-90 minutes each, for a total of four meetings.

In order to participate you must:

- Identify as someone who is d/Deaf, Hard of Hearing or someone with hearing loss;
- identify as someone who was raised in a predominately hearing environment/without access to signed language/found Deaf community later in life;

- Over the age of 18 years old;
- be willing and able to participate in a four-day workshop to create a PhotoVoice project.

If you are interested in participating, please contact the Student Principal Investigator, Jules Koncovy, at koncovyj@mcmaster.ca.

I will not disclose any information about who contacted me, about what was shared, or about who participated in the study. Since confidentiality is upheld, taking part or not taking part in this study will not affect any services you receive in any groups or support services. Please see the attached Letter of Information for detailed information on the study, the consent process to participate, and how confidentiality will be protected at every stage of the project.

Closed captioning via Zoom, and ASL interpretation will be made available for each workshop session. If you would like to meet individually and require interpretation or other accommodations, please let me know.

I would like to thank all potential participants who take the time to inquire and screen for this study. We are grateful for your interest. All potential participants who complete the screening will be notified regarding whether or not they have been selected for the study.

This study has been reviewed and cleared by the McMaster Research Ethics Board. If you have questions or concerns about your rights as a participant or about the way the study is being conducted, you may contact:

> McMaster Research Ethics Board
> Secretariat Telephone: (905) 525-9140
> ext. 23142 Gilmour Hall – Room 305
> (ROADS)
> E-mail: ethicsoffice@mcmaster.ca

Sincerely,

Jules Koncovy

Appendix G—Snowball Email Recruitment Script

Part one of the script:

Dear [insert name here],

My name is Jules Koncovy and I am conducting a research study from McMaster University's School of Social Work about those who identify as d/Deaf, Hard of Hearing, or with having hearing loss, who were also raised outside of, or without access to Deaf community, culture, or connection, within a hearing environment or without access to signed language. I am the student principal investigator on this project, and I am completing this research as a requirement for my Master of Social Work thesis (I also identify as a deaf, cochlear implant user), and is am supervised by Dr. Saara Greene.

Would you be willing to pass along my name and contact information, and the following short description of my study, to your peer, friends, and colleagues? There is no obligation for you to pass along this information, and there will be no consequences if you do not provide this information.

Hope you have a lovely day and thank you for your support.

Take care,

Jules Koncovy

Part two of the script—for laison to pass along.

Hey there! I am passing this information along on behalf Jules Koncovy, a Master of Social Work student at McMaster University, conducting research for their thesis. If you are interested in participating, here is the information below.

Jules Koncovy identifies as a deaf cochlear implant user and is a student principal investigator is conducting a research study from McMaster University's School of Social Work about those who identify as d/Deaf, Hard of Hearing, or with having hearing loss, who were also raised outside of, or without access to Deaf community, culture, or connection, within a hearing environment or without access to signed language. This project is being supervised by Dr. Saara Greene.

The following is a brief description of the study.

There is a great deal of information on the experiences of people who are a part of Deaf culture—this is a broad term, often associated with those with access to signed language and other d/Deaf or Hard of Hearing community members. While these experiences are incredibly important to highlight, the majority of people who are d/Deaf,

Hard of Hearing, or identify as having hearing loss often do not have access to other people with similar experiences, Deaf culture, or access to signed language.

We are interested in exploring what community looks like to you, how your experiences have informed this, and what would better support you in accessing the d/Deaf and Hard of Hearing community.

We will explore these issues using an arts-based approach called PhotoVoice. PhotoVoice is a qualitative research approach that invites participants to use and take photos to record and reflect on their experiences and concerns, to promote discussion about important community issues and to reach healthcare, social service provider, and policymakers who can facilitate change. Each workshop will be approximately 60-90 minutes each, for a total of four meetings.

In order to participate you must:

- Identify as someone who is d/Deaf, Hard of Hearing or someone with hearing loss;
- identify as someone who was raised in a predominately hearing environment/without access to signed language/found Deaf community later in life;
- Over the age of 18 years old;
- be willing and able to participate in a four-day workshop to create a PhotoVoice project.

If you are interested in participating, please contact the Student Principal Investigator, Jules Koncovy, at <u>koncovyj@mcmaster.ca</u>. If you know of someone who might be interested in this study, please pass along this email and the Letter of Information to them.

The research team will not disclose any information about who contacts them, about what was shared in the screening process, or about who participates in the study. Since confidentiality is upheld, taking part or not taking part in this study will not affect any services you receive in any groups or support services. Please see the attached Letter of Information for detailed information on the study, the consent process to participate, and how confidentiality will be protected at every stage of the project.

Closed captioning via Zoom, and ASL interpretation will be made available for each workshop session. If you would like to meet individually and require interpretation or other accommodations, please let me know.

We would like to thank all potential participants who take the time to inquire and screen for this study. We are grateful for your interest. All potential participants who complete the screening will be notified regarding whether or not they have been selected for the study.

This study has been reviewed and cleared by the McMaster Research Ethics Board. If

you have questions or concerns about your rights as a participant or about the way the study is being conducted, you may contact:

McMaster Research Ethics Board
Secretariat Telephone: (905) 525-9140
ext. 23142 Gilmour Hall – Room 305
(ROADS)
E-mail: ethicsoffice@mcmaster.ca

Sincerely,

Jules Koncovy

Appendix H—Social Media Recruitment Script

Hello! My name is Jules Koncovy, and I am a Master of Social Work student from the Critical Analysis as well as a Local Principal Investigator. Under the supervision of Dr. Saara Greene, I am looking for volunteers to take part in a study about the experiences of people who are d/Deaf, Hard of Hearing, or identify with having hearing loss, who were raised outside of Deaf culture or community, within a hearing family or without access to signed language. This study will be using PhotoVoice to explore your experiences of what community means to you and the barriers that come to accessing it. This study will take place virtually on Zoom and will involve approximately four 90-minute sessions of your time. ASL interpretation and English closed captioning will be available. In appreciation for your time, you will receive a $50 Visa e-gift card.

Eligibility to participate:
- identify with experiencing hearing loss;
- raised outside of Deaf culture/community or without access to signed language;
- Over 18 years old;
- Currently reside or were raised in Southern Ontario.

For more information please email me, Jules Koncovy, at koncovyj@mcmaster.ca. You will be presented with a Letter of Information followed by a consent form before the research begins.

It is important to note that there are some risks to the project that you need to be aware of before participating. These include:

- Sensitive questions;
- Limits to confidential participation;
- A data breach could pose a significant risk to one's status at work/within the community.

This study has been reviewed by and received ethics clearance from the McMaster Research Ethics Board (#6563).

Appendix I—Verbal/Visual Consent Script

Introduction:

Hello. I'm Jules Koncovy and I am conducting research about the experiences of people who are d/Deaf, Hard of Hearing, or identify with having hearing loss who were raised without access to the Deaf community and/or signed language. This PhotoVoice Workshop series is part of my Master of Social Work at McMaster University's in Hamilton, Ontario. I'm working under the supervision Dr. Saara Greene of McMaster's department of Social Work.

Thank you for your interest in participating in my research.

Have you had time to read the Letter of Information I sent you?

Great, then I would like to take a moment to review some main points from the Letter of Information before we continue.

Confirm the following to the participant:

- What is your name?
- What is the unique study identification or pseudonym you would like to use?
- Confirm the date.
- Your participation in this study is voluntary.
- If you do not want to answer some of the questions you do not have to, but you can still be in the study.
- Your participation in this study is voluntary. You may decide to stop participating and you have the right to withdraw from the study without consequence at any time. Any information gathered from you during the recruitment process and the research will be destroyed and will not be used in the study. If you choose to withdraw from the study during the workshop, you are free to do so.

- If you do withdraw during the workshop, you will still receive your full honorarium. If you choose to withdraw from the study after you have participated in any or all of the workshops, including the group discussions, we will delete your comments and answers from the group sharing circle transcript to the best of our ability.

- You can ask to remove your data from the study up until approximately **June 10th, 2023.** After the focus group, it may not be possible to pull out your data due to the interconnected nature of this type of data collection.
- Your data is being collected without any identifying information, which means it will not be possible to remove your data from the study after this session. However, if you chose to take a photograph of yourself, or reflect on the photograph through including other aspects of your social location or identity (ethnicity, culture, gender, etc), I will keep this information in with your consent. I will follow up once the transcription is completed.
- The photographs you contribute will be stored on a password-protected electronic MacDrive folder. With your permission, we will also share your images in presentations, at conferences, and at other virtual and in-person events. Your photos will only be shared with

your permission and with a name/label that you choose (e.g. with or without your name, using nickname or pseudonym).
- This study has been reviewed and cleared by the McMaster Research Ethics Board.

Do you have any questions or want me to go over any study details again?

Consent for Participation

6. Do you agree to have the PhotoVoice workshop recorded by a member of the research team, so that it can later be transcribed?

YES   NO

7. Do you agree to maintain the confidentiality of other participants in the PhotoVoice Workshop by not recording our meeting, or sharing any details about other participants?

YES   NO

8. Do you agree for the Photographs (that are not copy written, and that contain no identifiable– such as people, names, etc.) that you share during the PhotoVoice Workshop to be shared in potential publications, and/or presentations (including the art exhibit)

YES   NO

9. Do you permit the use of your direct quotes from this study in written work such as potential publications, and/or presentations?

YES   NO

10. Do you permit the use of this data in future research projects?

11.

If no, "Thank you for your time."

Appendix J—Counselling Services Information Sheet

- Here is a list of services where you can find someone to talk to, if you have something on your mind.
- If you aren't ready to use one of these services, you might want to talk to a trusted family member or friend that you would normally go to when you have something on your mind.

Canadian Hearing Services

Canadian Hearing Services (CHS) offers a wide range of counseling services for Deaf and hard-of-hearing people and their families. Our services are free, confidential, and provided in an accessible environment using American Sign Language (ASL), la langue des signes québécoise (LSQ), real-time captioning, and amplification devices as required. There are often specific branches within major areas, as referenced below.

Email: generalsupportservices@chs.ca
Phone toll free: 1-866-518-0000
TTY toll free: 1-877-215-9530
Link to Canadian Hearing Services Counselling Support

Furthermore, Canadian Hearing Services also has a section on accessible crisis lines. Should you need immediate support please access the link following to Distress Centres and Crisis lines in Ontario. There are text crisis lines, mental health support for youth and children and local distress centers in many major cities within Ontario.

MCMASTER UNIVERSITY:
Student Wellness Centre
MUSC B101 ext. 27700
offers personal counseling among other psychological services.
http://wellness.mcmaster.ca/personal/personal-counselling/about-personal.html

Appendix K—Photovoice Workshop Guide

- First session—Introductions and Explaining PhotoVoice
  - o This session will be an opportunity to meet Jules and the other participants of the project. There will be a chance to do ice-breakers and get to know everyone.
  - o There will also be a chance to go over the prompts for the following weeks, and if the group thinks that these are appropriate questions to respond to.
  - o Finally, there will also be a chance for everyone to share their personal group expectations for how to create an environment that is as safe and comfortable for all participants as possible.
- Second session—Defining Community
  - o This session is an opportunity for you to share your photographs in response to the prompt, "What does community look like to you? How has your personal identity and experiences shaped this understanding?"
    - ▪ Further probing questions could resemble:
      - • In what ways have you felt community within a hearing environment?
      - • What do you know of the d/Deaf and Hard of Hearing community? Have you desired to connect to it before? Why or why not?
      - • Are there aspects of your life that impact your ability to connect to others, in addition to experiencing hearing loss?
  - o Sharing circles will be video and audio-recorded, however, any identifying information that may be shared will be removed during transcription.
- Third session—Supports and Barriers to Community
  - o This session is an opportunity for you to share your photographs in response to the prompt, "What are some things that support your access to community? What are some barriers? If you have not had access to other people who are d/Deaf and Hard of Hearing, why is that?"
    - ▪ Further questions may look like:
      - • Does your experience of hearing loss impact your ability to connect to the people in your everyday community?
        - o If so, how have you received support to better connect with others? What can make connecting difficult?
      - • Are there specific accommodations that other people provide to you in order to make an environment more accessible to you? How does this process make you feel?
      - • Have you ever desired to connect to others in the d/Deaf and Hard of Hearing community?
        - o If you have, what have been barriers to accessing the community? What are some things that would make you feel supported in connecting with others in the d/Deaf and Hard of Hearing community?

- o If not, why is that?
  - o Sharing circles will be video and audio-recorded, however, any identifying information that may be shared will be removed during transcription.
- Fourth session—Debrief and Analysis
  - o This session will occur after the data has been collected and analyzed by Jules after sessions two and three. This should happen roughly around mid-July, and Jules will contact all participants to schedule a group to debrief.
  - o This session will be a space for Jules to share the findings of the community members' data and connect it to broader themes, ideas, and impacts beyond this project.
  - o In this session, you will have a chance to provide feedback and suggestions for what to do with the information moving forward. Furthermore, you will have a chance to share if your information was portrayed accurately or if adjustments should be made.
  - o Should you want to provide more feedback privately, Jules will be happy to book individual Zoom meetings to discuss.