

Voices of Siblings: Shifting the Narrative on Disability, Inclusion and Education

by

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BA., Concordia University, 2019

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We acknowledge and respect the Lək'wəḡən (Songhees and X̱wsep̱səm/Esquimalt) Peoples on whose territory the university stands, and tk'wəḡən and W̱SÁNEĆ Peoples whose historical relationships with the land continue to this day.

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Abstract

Research has long established that siblings influence one another's development. In recent years, it has expanded to examine the unique experience of those who have a disabled sibling. Research on this population exists mainly in the field of psychology, through quantitative methods. In order to have a more wholistic understanding of the sibling experience, research needs to use qualitative methodology that allows for siblings to have control over their own narratives and create space for their voices to expand beyond numbers. The purpose of this study was to give people who have a sibling with a disability the space to share their story and perspectives through a lens that they believe is important to their story. Using a qualitative approach of action-based research, it aimed to uncover ideas that can be used to create change in the field of education. Participants included six participants aged 19-28, who identified as a sibling of someone with a disability. Six themes emerged through the thematic coding analysis of interviews: (1) Advocacy, (2) Barriers, (3) Beliefs, (4) Education, (5) Perspectives, and (6) Relationships. Each theme holds vast knowledge and expertise on inclusion, accessibility and policy that can be used as starting points for more focused qualitative studies. These findings can serve as a foundation for future research to continue to work with siblings as guides to inform inclusive education policies and practices.

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deep commitment to caring for our children and schools. I am so grateful I have had the opportunity to get to know and work with you, thank you for everything.

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made sure you know who you are, who have talked me off the ledge of quitting this thesis countless times and have done everything you can to get me here. Again, this is your moment, too. I wake up every day in awe of the friends and community I have and have been able to learn about love from. I am so, so grateful. I would not be here without you. Thank you.

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Dedication

This thesis is dedicated to all the teachers I've had that have seen my strengths, my passion and have advocated for me. Throughout my life, I have been privileged to have a special few who have truly believed in me, have gone above and beyond, who bent the rules, who were creative and who I could feel really cared about me. From elementary school to grad school, there is always one who gets me to the next step and has fueled to my desire and persistence to be an inclusive educator. I hope to be that one for a student someday.

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Introduction

Historically, the fields of child development and psychology have examined siblings and the impact they can have on one another. From the established understanding that siblings influence one another, research has expanded to examine the unique experience of those who have a disabled sibling. Research on this population exists mainly in the field of psychology, examining the impacts disability has on the non-disabled or typically developing sibling (TDS) including; impacts on self-perception, views of disability, well-being, and family dynamics (Sommantico et al., 2020). It has been well established in the past two decades that growing up with a disabled sibling can positively influence one's view of disability and inclusion, fostering openness, compassion, and social awareness (Findler and Vardi, 2009; Graff et al., 2012; Sharpe and Rossiter, 2002; Sommantico et al., 2020). However, the goal of psychology-oriented research often aims to identify 'difference' in an individual or population, learn about it, and then develop an intervention. This follows a deficit or medical-based model of disability that aims to "fix" problems individuals with disability face or impose on others (Longmore, 1995). Therefore, existing research that primarily focuses on the goal of developing therapeutic support for siblings leaves a holistic approach that centres voices missing. While intervention and therapeutic research seek to explore factors that may designate a sibling as 'high-risk', this invariably highlights and centers negative experiences, deeming this perspective on disability as the most valuable in research (Bachraz & Grace, 2009; Nixon & Cummings, 1999). Positive experiences are seldom highlighted as valuable findings to inform practice across literature and have not been used to inform practice. A dangerous pattern develops when research consistently aims to fix the negative impacts disability can have on those who have a relationship with it. This

approach reinforces a deficit model of disability stemming from the medical model that research has consistently based its work on, framing disability as a deficit requiring intervention focused on the problems disability presents society with and stating the problems are within the disabled individuals themselves (Longmore, 2003).

Amidst the growing field of inclusive education and the shift towards qualitative research that centers individual voices and experiences, educational research has failed to recognize the value of sibling perspectives to inform inclusive educational practices. It is time for research to focus on qualitative research that centers individual knowledge and values all parts of their relationship and experience with disability.

Present Study

This study focuses on the experiences of adults who grew up with a disabled sibling exploring their viewpoints on disability, inclusion, and accessibility. Utilizing qualitative methods, the research questions focus on exploring siblings' experiences in inclusive spaces and relationships with disability, while aiming to identify insights that can be used to inform inclusive educational practices. The following questions are addressed:

- (a) *How can growing up with a disabled sibling influence one's view of inclusive spaces?*
- (b) *What insights can be gained from siblings to inform educational practices?*

Models of Disability

Medical Model

The medical model views disability within the individual as the reason for difficulties they encounter, particularly regarding social integration and access barriers. This model suggests that in order to help the individual, we must seek to treat the condition. Longmore (2003) explains that the medical model views disability as the result of pathological physiological conditions that are responsible for the limitations people face in social, vocational, political, and cultural functioning. This view emphasizes that the restrictions disabled people face to participate in various aspects of life are the consequence of the disability itself. Therefore, the goal to “fix” the disabled person, takes away the responsibility from other members of society to change any external obstacles that may be preventing the participation of disabled people. Despite being named the ‘medical’ model, we must recognize that this perspective is not exclusive to the fields of medicine and rehabilitation. The term is used across educational and social sciences research, as the word ‘medical’ is used to describe the occurrence of disability as a medical condition that needs to be remedied (Kafer, 2013; Longmore, 2003), rather than a natural occurrence in our society. This view not only affects the research lens used to examine and ‘correct’ those with disabilities, it also influences a societal lens that disabled people are defective. Naming this lens the “deficit-based model” reinforces the goals of research to provide individual and family intervention, over intervening in social structures and ideas that limit participation of the disabled (Kafer, 2013). Moreover, referred to as the individual model, the medical model removes responsibility from society to adapt our structures, institutions and social relationships to include disability, as it views the challenges of disability to be only in the disabled individual and their deficits. Even as research begins to critique the medical model,

acknowledging its ableist lens, the main focus of most disability-based research continues to provide remedies for the negative individual experience of having relationship with disability, whether it is for individuals or families, and continues to conclude with recommendations for interventions or rehabilitation. Viewing and researching disability through the medical model and seeking ways to fix it, views disability as a problem rather than viewing disability as part of nature (Four Arrows, 2024). Quantitative data continues to be used to examine the experience of disability dismissing the voices of disabled individuals and what they would actually like to tell us about their experience. Critiques of the medical model and quantitative data approaches emphasize a reductionist approach and “dilutes” the human experience through data, eliminating the ability to see it as a part of what makes the individual whole (Saia et al., 2023). In order to address this colonial approach to psychology and social research, (Four Arrows, 2024) has led to the development of models that shift away from the individual and look toward society- its colonial influences and harmful approaches to engaging with difference. As Kafer (2013) states, “The problem of disability is not solved through medical intervention or surgical normalization but through social change and political transformation.” (p.6).

Social Model

In response to critiques of the medical model, the social model was developed as a way to look at disability as a part of one’s identity and part of society, parallel to class, gender, race or ethnicity (Longmore, 2003). This model claims to view the ways in which society regards and responds to disability and critiques the way that the medical model places responsibility on the disabled to change to participate in society and neglects society’s role to change in order to include disabled people. Unfortunately, the main goal of disability-based research, looking both at the individual experience and the experiences of family members, consistently seeks to offer a

remedy for the negative aspects of this experience and rarely has ever offered action items for policies, educational curriculum or other societal structures, to change. Critiques of the social model from voices in the disabled community claim that it shifts focus to the way society is disabling to individuals, through factors such as physical barriers and perspectives of disability. Therefore, it neglects political, relational aspects of disability and the individual experience of living in disabled bodies.

Through the critique of the medical model and conversation around the views of the social model, the holistic view of how individual identities intersect and impact our experiences in society have brought forward theories such a DisCrit (Disability/Race) theory (Annamma et al., 2013). DisCrit uses critical race theory and disability theories to highlight how multiple parts of our identities impact our experience with each one and influences our positionality in relation to others' who hold those identities. Understanding the experience of someone holding one identity, is not the same experience as someone else who shares that one identity, and criticizes how society separates racism and ablism when in fact, they both stem from the same power system that seeks to uphold the idea of "normal" (Saia et al., 2023). Focusing on marginalized populations, this theory critiques the social theory of disability by ignoring that disability is political and addressing ableism must be anti-capitalist, anti-colonial, a cross-movement solidarity action and recognizes wholeness in disabled individuals (Saia et al., 2023). The social model aims to fix the problems of disability, without recognizing that we still marginalise and oppress the voices of those who have relationship with disability who are trying to tell us what they need us to know about their bodies, their lives, their dreams.

Relational/Political Model

In response to the ableist shortcomings of the medical and social models and the systems they continue to uphold, despite attempting to switch the narrative without the responsibility, Disability advocate Allison Kafer proposed a relational/social model. Kafer's model is focused on giving voices to the disabled, to imagine a future together and recognize the "political experience of disablement" (Kafer, 2013, p.9). This framework rejects institutional classification of who is disabled and who is not, seeking to understand this relationship as part of a holistic blend of individual identities and experiences. The framework rejects definitions, the need for guidelines around access, distinctions and diagnoses, in order to decide who qualifies for what, how much they get and what healthcare and educational institutions they have access to. Kafer (2013) argues that the academic study of disability and social disability movements, medical and social models, all fail to account for the fact that those with mental illness, those with immunodeficiency, those who use wheelchairs, those who are deaf and so on, are all connected. The relational/political model focuses on the framework that disability is an individual experience that should not be a) defined by others and b) a separate identity that is viewed through a generalized lens. It follows a relational framework to theories such as the DisCrit, that emphasizes the structures and political power that is held over individuals, that seeks to uphold an image of "normal" over society, and aims to either "fix", or oppress those that do not fit. This model reinforces the need for disability justice to give platform to those voices, fight for them to be heard, acknowledge the shared experience of disability, and reject categorization that aims to further separate individuals when they share the same sources of oppression.

The present study examines the experience of disability through a relational/political lens. It aims to give voice to those who have familial experience with disability in their family. The

study offers the opportunity to share their relationship with disability/accessibility and learn from their perspectives, what structures in our educational institutions are contributing to the oppression and lack of inclusion of disabled individuals. The questions asked are an opportunity for siblings to reflect on and critique policies and social structures that impact accessibility and inclusion, as well as to share their experience focused on the relationship to both their sibling and these structures. The research framework for the present study was designed based on theory from the relational/political model and self-advocacy pieces, as there were no elements of existing research that could be found that follows this model as revealed in the literature review. Therefore, to the best of my knowledge, beyond publications on theory this is the first research study to address perspectives and experiences of disability using the relational/political model of disability. This research seeks to advocate for change focused on who is making decisions for disabled children and provide opportunity for those who have a holistic relationship with inclusion, adaptability and liberation to be heard, to lead society toward real political, institutional and relational change focused on disability.

Positionality Statement

I have an ongoing reflective practice on my positionality that brings me to this work and the way I move within it. I am a white, third generation settler who was raised on the territory of the Mississaugas of the Credit First Nation, in the suburbs outside of what is known as Toronto, Ontario. There are multiple parts of my identities that make me who I am; some of which are stronger in my position and appearance than others. On reflection, these are often the identities that hold the most privilege; being white, educated and sometimes, appearing as an able-bodied person. I reflect on what it means to be a descendant of European settlers whose privilege was given to me at the consequence of the treatment to the Indigenous peoples of the land I live on. When I reflect on this privilege, I look at the generation in which I was raised in my family lineage on this land. I am aware of the attempts of mass assimilation and violence that continue to this day. I grew up in a time between the arrival of colonists, mass removal of children from their homes and communities and the truths that are finally coming to the surface, the unmarked graves, the stories, the voices of past and present violence and oppression. These voices were not centered or heard in the communities I was raised in as a child. They were kept to communities and silenced in the media. A large part of my privilege is not just the ways I can walk safely in the world and the opportunities I am given because of my skin colour, but that I didn't have to know the pain that was and is here while I was growing up. I navigated childhood ignorant to whose land I was on and what happened before I was there, without parents who had endured the trauma of being taken from their homes and all the things we know to be true now. I reflect now on the pain that carries on in communities and with Indigenous peoples, the silence and oppression that they continue to live with, even as history reveals itself. This ignorance, the

childhood I had that was light, happy and hidden from violent truths, is one of the heaviest parts of my privilege that I do and will always continue to reflect on.

Fuller (2021) speaks about funds of knowledge related to our cultural capital, our experiences and parts of our identities. These funds are comprised of every part of ourself that impacts our knowledge, position, privilege and leadership when we sit at a table with others. There are parts of myself that are not obvious to others in every environment, but that shape my experiences and identity. I believe these identities significantly affect my funds of knowledge as a leader. For example, I identify as having a disability. I grew up with chronic illness that was undiagnosed and untreated until I was 20 years old, as well as a learning disability. I missed large amounts of school from being hospitalized. I missed social events and parties, had to quit multiple sports and faced physical and emotional isolation periodically through my childhood and adolescence. When I would return to school, I struggled to catch-up and learn with my learning needs and have constantly needed to adapt my learning. I was often faced with educators and educational leaders that did not know how to accommodate me or support me with both a physical disability and a learning disability, leaving me to be taken out of mainstream classrooms throughout my education. Persisting with my education while struggling to make and maintain friendships, gave me knowledge of what it's like to feel unequal to your peers.

I come to this proposed research with experience as a person who grew up with a brother who has a disability and therefore underwent ongoing reflexive practices to examine any bias I have throughout all parts of the research process. At home, our mother tried her best to support my brother with his learning and social/emotional needs while caring for me when I was ill, and spent a large amount of her time in our schools advocating for us. In addition to my own needs and challenges faced growing up, I witnessed my brother navigate a school system that harmed

him and I continue to watch this affect him into his 30s. I witnessed him receiving detentions and expulsions regularly, his inattention and creativity being punished as misbehavior, while I received empathy and support when my teachers noticed my struggling grades and hyperactivity. My brother was never presented with university as an option. Labour-based jobs were pushed on him when he struggled to succeed in high school, while I was met with a handful of educators that did whatever they could to ensure I got into the university of my choice. I am reminded daily, that I do not hold the privilege, opportunities and safety that cis-gendered men do and I also carry with me reflection on my position as being female-presenting and how it has privileged me. My brother and I have struggled so similarly and have had extremely different outcomes and treatment that has affected our entire development, self-perception and adult life. This has and continues to influence my role as an educator when I work with children, especially those with disabilities. The inequality of treatment those across different gender identities face in education is important to reflect on regularly as an educator, especially as we create safer spaces for diverse gender identity and trans students. Equity, access and social inclusion, along with breaking down varied treatment across gender identity, are my utmost priorities as a leader and educator.

I come from a position of adversity and privilege which I constantly reflect on as I navigate through life. I identify as queer, gender fluid and disabled. There are times I knowingly and unknowingly faced discrimination. Parts of my identity I can choose whether to disclose to others and other parts, such as my disability, I can't always. For example, when I graduated with my undergraduate degree, I was offered a position in an elementary school. In the first month of this position, I had a flare up that required hospitalization and I had to take 2 weeks off work. I felt a sense of frustration from my boss and pressure to provide an answer on when I would

return to work. I received indirect comments that implied I should not have been offered that role when I would be “unreliable”. I felt ashamed for not disclosing my condition when I was hired; but I knew if I did, I would not be offered the position. I have learned this through observing systemic ableism. When I was offered the position, I had worked hard to achieve my degree, despite my struggles, and I was passionate about working towards schools being more inclusive and safe places for children. On paper, I presented as the perfect candidate; however, the reaction and feeling I was a burden and letting others down when I needed time off, confirmed that I wouldn’t have been offered the position if I had disclosed my disability. As a child who was often sick and struggled to catch up on schoolwork, often while fighting fatigue and pain, when I returned to school it seemed there were limited resources for educators to support this type of need and disability, only learning related disabilities. This part of my identity I believe adds value to my funds of knowledge in my chosen career field, as I have been accommodating and adapting my own education my entire life. I can use my personal and professional experience and tools to support students who have disabilities or face discrimination or adversity, to some degree.

When I say I come from a position of adversity and privilege, I mean every part of me that holds an identity that faces oppression through ableism, sexism or homophobia, will never experience these things the way that people of colour who also hold these identities, experience them. My positionality will always enter a room, an interview, a doctor’s office, etc. with privilege based on my skin colour, the middle-class family I was raised in, as well as being an educated, female-presenting person. I know that I made it to this point in the education system, despite struggling as a learner and having a disability, because of the privilege I hold as a white settler on stolen land, because of having the same first language as my education was received in

and the support I had from my family. It was difficult to get here, in an education system that is not built for exceptionality, but I am not here just because of my hard work, I am here because I hold privilege.

As a leader and educator, all these parts of my identity influence my position when I enter a room. As I continuously reflect on my position in society, I will use my funds of knowledge to support, protect and advocate for equity and inclusion of others. I understand my position when I know my identities may cost me jobs and other opportunities; but I also know many opportunities are given and will be given to me because of my privilege. I believe this influences my role as a leader, to be aware of the rooms I am in and who is in them with me.

Through my own experiences, the experiences of my family and the extensive relationship I have formed with past research and literature, I understand how systems and research can exploit, manipulate and attempt to control others experiences and views of disability. I do not see people as data, and I never intended to do so. I do not wish to be a researcher, but I do wish to be a storyteller, an educator, and a weaver of relational learning. Storytelling continues to prove itself as a transformative gift and tool, and each of these stories will be ingrained in my heart forever.

Literature Review

Background: Foundation of Sibling Research

Early theories such as Bowen's family systems theory (1950s) and Bandura's social learning theory (1977) explored how siblings shape one another's social skills, behavior, and relationships within the family (Titelman, 2014). As siblings often spend most of their significant time together as children, research influenced by Bandura's social learning theory has looked at the influence social interaction, play and companionship between siblings can influence how individuals interact with peers and friends (Tsao, 2019), as well as roles between children and caregivers (Foley et al. 2012; Graff et al. 2012). These early studies have revealed that growing up with siblings, compared to being an only child, leads to differences in family dynamics, cognitive development, emotional behaviours, and how individuals socialize with others. For example, we know that because siblings offer early opportunities to engage in social processes such as play, individuals who have a sibling have a greater likelihood of developing early emotional awareness of other's feelings and other social constructs (Noller, 2005). Despite siblings being one of an individual's earliest relationships, studies of siblings continue to receive considerably less attention compared to other types of relationships such as parent-child, peer, or friendships (Noller, 2005; Bachraz & Grace, 2009; Meadan et al., 2010; Titelman, 2014; Tsao, 2019; Wright et al., 2022). In addition, while family systems theories have been valuable in understanding subsystems and their impact on individuals, most existing studies on sibling relationships are generalized, fail to consider family diversity, and lack insights from individual experiences (Bachraz & Grace, 2009). In response to both shortcomings of early sibling research, some studies have shifted towards investigating a broader range of family dynamics and diversity in sibling experiences. Specifically, findings that observe the influence siblings can

have on social and emotional development have opened up avenues to explore how having a disabled sibling might impact a typically developing sibling (TDS), particularly looking at perceptions of self and their sibling, well-being, and development of social skills (Graff et al. 2012; Corsano et al. 2016; Davys et al, 2016; Tsao 2019; Wright et al. 2022; Beffel et al. 2023).

Research on Siblings and Disability

While research on siblings in relation to disability has gained prominence in the last decade (Beffel et al., 2023), much of it is conducted within the field of psychology. In the following review of available literature, researchers in this domain dominantly employ a medical-based approach to examine the experiences of disabled people and their siblings, seeking to offer insights for clinical intervention support. This research often examines the negative impacts of their sibling's disability on the TDS, aiming to develop effective interventions for them and their families. By focusing solely on how experiencing disability in the family impacts siblings for the purpose of informing therapeutic practice, existing literature consistently aims to understand whether the experience has predominantly negative or positive impacts on siblings (Bachraz & Grace, 2009; Graff et al., 2012; Ling-Ling Tsao, 2020; Meadan et al., 2010). Further, it often uses quantitative methods, rather than looking at the experience through a holistic lens, focusing on what siblings want to share.

Meyers & Vipond (2005) reviewed literature between 1980-2002 examining sibling relationships and influences when one sibling has a disability. Disabilities identified in the review are defined as; Down syndrome, hearing and visual impairment, cognitive, emotional, and language impairments, learning disabilities, physical and orthopedic disabilities, cerebral palsy, ataxia, quadriplegia, autism, spina bifida, Williams syndrome, and brain injury. The aim of their review was to understand the influence having a disabled sibling has on a TDS. It was

published in *Physical & Occupational Therapy in Pediatrics* and concludes with suggestions for the provision of therapeutic and intervention practice by occupational therapists and other family-centered practitioners. From the fourteen studies reviewed, Meyers & Vipond (2005) looked at variables that could influence the effect siblings have on one another and their interactions when one sibling has a developmental disability. Variables examined across studies include; age, design of the study (i.e., experimental, non-experimental, observation, behaviour scales), behaviours studied and other characteristics considered that may impact the sibling relationship (i.e., birth order, gender, type of disability, age interval, diagnosis, absence of a parent, communication status). Across all studies and among all variables listed, the presence of disability in one sibling was reported to be the strongest source of influence on the siblings. Although all variables contribute to unique family dynamics and influence individual development, the extent of all articles reviewed by Meyers & Vipond shows that numerous studies have reported that sibling interaction, family dynamics, and behaviour are all influenced by disability being present in one sibling. Meyers & Vipond (2005) reported this as valuable information for therapists to intervene with the child most effectively.” (p.98-99) Referring to intervention developed for both the sibling with and without disability, as well as for the whole family, the authors list the benefits of reciprocal sibling relationships that could benefit specifically the disabled sibling. Although these findings are valuable, to the field of therapeutic intervention, there is a persistent limitation to this type of research that does not extend beyond the field of intervention and psychology and lacks depth to what the experiences of siblings and families are. This review also illustrates a consistent narrative and research approach towards this population over a period of two decades.

In the past few decades, research has reported positive development of social skills for disabled siblings, attributed to interaction with their TDS (El-Ghoroury & Romanczyk, 1999; Hoffman-Williamson, 1984; Stoneman et al., 1987, 1989). Although reported, the positive impacts of having a disabled sibling on the TDS are not as strongly highlighted or used to further guide research in a new direction as a result of this unique sibling relationship. Citing a study by Lobato and colleagues (1991), Meyers & Vipond (2005) state that studied children who have a disabled sibling displayed more pro-social and nurturing behaviour than their counterparts (i.e., siblings where neither are disabled). Positive reports about TDS are often referred to as valuable findings to inform therapeutic practice, referencing the need for TDS and families to “cope” and be “resilient” with their experience of having a disabled sibling (Bayat, 2007; Graff et al., 2012; Beffel et al. 2023; Wright et al., 2022) and are rarely framed as a standalone positive finding, without referencing suffering of some sort for the family members. This could result from the focus or goal being to develop interventions aimed at supporting siblings and families, with sibling-based disability research being approached from a psychological or medical-based perspective.

Although it is important to include and listen to the voices of those impacted by disability in order to develop a genuine and accurate understanding of their experience to support them effectively, it is equally important to identify and name ableist perspectives in disability research (Meyers & Vipond, 2005; De Caroli & Sagone, 2013; Connell et al., 2016; Sommantico et al., 2020). The table Meyers & Vipond (2005) used to outline all studies reviewed uses the language of “increased” or “decreased” in the results section, describing the impact on social behaviour and development for both siblings. For example: “Increased ability to interpret behavioural cues” or “decreased rates of social adjustment” (Meyers & Vipond, 2005). Seeking to look for patterns

that can influence the development of interventions, using language such as 'increased' or 'decreased' to describe a behavior or psychological effect, is parallel to categorizing this experience as either a 'positive' or 'negative' for the TDS. While reviewing Stoneman et al. (1987), the authors highlighted findings that TDS developed skills such as adaptation, changing their activities to accommodate and include their siblings with disabilities to play together. Almost 40 years later, despite evidence that having a disabled sibling can foster skills like adaptability in play and social contexts, research has yet to acknowledge that TDS possess valuable expertise regarding adaptability and disability based on their own experiences and skill development. Positive findings are not incidental or secondary to reporting a need for TDS support, they should be the pathway to dive into research that frames individuals with disabilities and their family members as valuable in our society. Since, the time of this review, the dominant goal and perspective of disability-related sibling-based research continues to look at the ways we can support families who experience disability, rather than how they can support us in informing inclusive practices.

In the past few decades, research has reported positive development of social skills for disabled siblings, attributed to interaction with their TDS shared experiences. Beffel & Nuttall (2020) examined the relationships between TDS and their autistic sibling, looking specifically at the relationships' influence on the development of pro-social behaviours in the TDS. Their study begins by highlighting the emphasis on the negative lens prior research uses to look at the effects of having a sibling with autism on a TDS. Beffel & Nuttall (2020) suggest the value in exploring the positive effects this experience has on TDS, such as the fostering of a deeper comprehension of the needs and perspectives of disabled individuals overall (Davys et al., 2016). Examining survey results from 108 participants, identified as TDS who have an autistic sibling, the authors

used rating scales as a method to analyze their experiences. Tools used were retrospective questionnaires reflecting on parentification roles in the TDS, scales that examined prosocial and helping behaviour, as well as benefit-finding scales used to measure positive contributions this experience can bring to siblings. Results showed a positive correlation between the development of pro-social behaviour in the TDS and their experience of having an autistic sibling, especially when the siblings are similar in age. These findings are not exclusively reporting positive social behaviour towards their sibling, rather prosocial behaviours in general. The authors emphasize the value that prosocial behaviour can not only bring attention to a positive outcome in the experience of having a disabled sibling in research, but it also brings value to those who benefit from interactions and positive behaviour from TDS in society. The authors discuss that findings from this study can be useful in shifting focus to the benefits of having a family member with Autism Spectrum Disorders (ASD) and interventions targeting families may find this approach useful in developing support and coping tools for stressors that also come with this experience. Although Beffel & Nuttall (2020) identify that there is a negative focus on past research looking at TDS and their experience and outcomes of having an autistic sibling, the conclusion to their findings leaves us short when it comes to looking at this experience through a strength-based lens of disability, and instead focus on how it can further contribute to supporting TDS through difficulties that come from this experience. Although using self-reporting measures can be a useful methodology to analyze connections between experiences and outcomes, this study provided the field with limited details on what the TDS experiences and relationships were with their siblings. Self-reporting pro-social behaviour on a scale also limits our understanding by providing no details of how this behaviour is carried through to all their relationships, what the development of these behaviours are, and leaves little room for us to expand on this as an

outcome in the argument for evidence of positive experiences in inter-ability sibling relationships. A narrative approach or qualitative research would give a voice to TDS to share more personal, detailed, accounts of their experiences and possibly allow for self-reflection of how their experience affected their development, views of disability, and other relationships. Although this reviewed study aims to focus on positive perspectives from this experience, concluding by highlighting positive findings, and then applying them as useful in only therapeutic contexts merely moves us away from the medical model and towards the value of listening to what siblings want to tell us. If we understand from decades of research that siblings have unique experiences and often develop positive understandings of disability, then why are their voices still undervalued in shaping how we understand disability and inclusion? What would it mean to value their insights- not solely to inform intervention, but to accept and celebrate disability as a part of our society?

Recognizing this ongoing pattern and lens through which research has focused on this population, Orm et al. (2022) chose to focus on the strengths that TDS have gained through their experience of having a disabled sibling. The researchers introduced their study as a response to sibling research being the negative impacts this experience on the TDS and their mental health. The authors looked at the development of pro-social behaviour between TDS with autistic siblings, physically disabled siblings, and sibling pairs where disability is not present in either counterpart. Using questionnaires as their methodology, Orm et al. (2022) used a multi-informed approach, having both parents also complete surveys to examine family dynamics and experiences that can support the development of pro-social skills gained by the TDS. Although the authors introduced this study intending to examine the positive outcomes of the inter-ability sibling relationship, the Negative Adjustment Scale (*NAS*; Labato & Kao, 2002) was used as one

of three measurements used to examine how the disabled sibling has affected the TDS. The Strengths and Difficulties Questionnaire (*SDQ*; R.Goodman, 1997) and Parent-Child Communication Scale- Child Report (*PCCS-C*; Conduct Problems Prevention Research Group, 1994) were also used to measure adjustment, degree of openness in parent-child communication, examining internalizing or externalizing difficulties experienced by the TDS and emotional/pro-social development. Results from the scales and questionnaires support the findings that having a disabled sibling may benefit the TDS' development of pro-social skills. It is discussed through parent reports, that the type of disability (i.e., physical or developmental) may impact family communication and mental health in the TDS, concluding that these findings can be useful in supporting intervention targeting communication for the TDS. Orm et al., 2022 follows suit in informing therapeutic practice and intervention supporting TDS, despite the claim to address the problem of emphasizing the negative influences a disabled sibling has on TDS in research. Reporting that this experience can influence the development of pro-social skills in TDS, the authors offer nothing in terms of new knowledge, as this has been well established and reported through the past 3 decades focusing on this population. Looking at family dynamics and communication to support the development of pro-social skills and sibling impact in general is a unique lens, but leaves us short of data that offers a holistic view of family members' relationships and dynamics. Using quantitative data does not focus on the conclusions in previous literature that call for qualitative data to further examine the voices of TDS, as rating scales necessarily limit the ability of siblings' perspectives, voices and stories to be heard. Regarding future implications, Orm et al. (2022) discuss the need to examine pro-social behaviour in longitudinal data to understand the development of this behaviour over time, as well as examination by an observer rather than self-reports or parent reports. The authors conclude

that the findings are an addition to the discussion of the risks TDS are under through the experience of having a disabled sibling, the importance of family communication, and its relationship to the development of pro-social behaviour, leaving us with implications for family targeted intervention for this population. Quantitative data that continues to look at social relationships and development, has research stuck in a pattern where we are establishing and re-establishing the same findings of ‘positive’ and ‘negative’ outcomes of this sibling dynamic and experience. Quantitative data and rating scales limit the ability for research to move forward in the examination of the TDS experience, how they feel their experience and pro-social skills impact their lives, what their story is, as well as the ability to use their voices to advocate.

A study that aims to fill these gaps is a qualitative study by Wright et al. (2022) that aims to understand the sibling perspective and experience of young adults who have an autistic sibling. Highlighting that research focused on TDS who have an autistic sibling is limited, Wright et al. (2022) reference existing research with supporting theories that siblings provide early opportunities for social and emotional development, including communication and perspective taking. The authors bring attention to the gap in the literature that focuses on the perspective of TDS in this dynamic and the influence of their autistic sibling. Calling attention to past research that labels the experience of the TDS as either positive or negative, examining rating scales and traits siblings have developed, Wright et al. (2022) seek to give TDS the opportunity to openly share their siblings and personal experiences and perspectives. Participants were university students aged 18-24 who had an autistic sibling over the age of 18. Using semi-structured interviews, TDS discussed the following topics; shared activities, communication, family impact, benefits, and influence of their sibling relationship. The use of benefits and influence categories removes deficit-based language such as “benefits and challenges” or

“positive and negative influences” used in past research, while still allowing participants to openly share their experiences. Qualitative analyses revealed that all participants reported the autistic sibling influencing the TDS sense of empathy, openness, and understanding toward others. Of 11 participants, 8 reported that their autistic sibling influences their future career choices in areas such as psychology, education, and physical therapy as working with people with autism and other disabilities is something that “comes naturally (to them)”, specifically referring to their autistic sibling as a teacher to them. Participants also reported the desire to advocate for people with disabilities as a result of their experience with their autistic siblings. Wright et al. (2022) conclude that the findings from this study have produced a more holistic and extensive understanding of this sibling relationship, and specifically the TDS experience, than available existing literature. This could largely be due to the nature of qualitative semi-structured interviews that allow TDS to tell their stories and offer details that are not only unique to their experience with their sibling, but the diversity of their own interests, values and desires to pursue futures in disability work and advocacy. By inserting direct quotes from participants, we can hear the voices of the participants, which translates feelings of warmth and positivity towards their autistic siblings and gratitude to have developed these skills and values. In comparison to other studies reviewed, this removes the sterility of the researchers deciding what the experience of the TDS is through numbers and attempting to place it in any sort of category. This study does not aim to determine “what” this experience is, whether good or bad, it aims to allow TDS to talk about their experience and relationship with their sibling and disability in general. Conclusions report these findings and perspectives as important to inform family-centered services for families and autistic individuals. Referring to autistic siblings as “teachers” the authors highlight the expertise TDS have gained from their relationships and experiences with their sibling.

Informing services through these perspectives can give TDS narrative over their own story and what can positively support them and their families. This is a big step towards using a relational and socially based lens of disability and re-writing the TDS story as experts on their experiences and relationship to disability.

The reviewed research supports the present research, inferring that siblings hold value as experts on disability and inclusion from the perspective that they have organically developed skills and knowledge through growing up and developing alongside their disabled sibling. Referring to their siblings as “teachers”, as well as reporting that their sibling has fostered a passion to work with, and advocate for, people with disabilities in general, calls for more opportunities to center their voices and encourage their participation when decisions are being made about accommodation and inclusion. This study also allows siblings to voice that, despite the ways their experience may be labeled in past research, they have a desire to share their story and advocate for those with disabilities- which invites future studies, such as the proposed research, to begin conversations in research that value sibling voices as valuable informants in the world of disability change, policy and justice.

Since the time of the foregoing reviews, there has been little research that attempts to shift toward qualitative work and focus on a narrative approach to what we can learn from siblings. Although still limited to the focus on therapeutic practice, it is important to emphasize that TDS voices can inform social policy and relational practices that don't need to be exclusive to interventional therapy. Connel et al., (2014) write a sister's story of her experience with an autistic brother, emphasizing that listening to sibling experiences and using their narrative to inform policy and practice is essential to any change in disability justice work. In line with the foregoing reviewed literature, Connel et al. (2014) begin by highlighting that historically, authors

who investigate this experience attempted to focus on labeling it as either positive or negative for the TDS. As a reader and a researcher, this lens takes the narrative of TDS' own experience away from them, in order to come to some sort of conclusion about it. This article is a narrative constructed from conversations between Connel, a TDS (sister of an autistic sibling), and a home-support respite nurse manager, who have had a long-standing relationship of 12 years. Connel emphasizes that literature written by siblings (and family members) needs to be prioritized, naming that researchers historically claim their interpretation of what the experience of those who experience disability is, which reproduces the cycle of ineffective inclusive policy and practice. The purpose of this article and Connel's desire to share her experience and personal journey is described as her need to "claim ownership" over her story. This article and perspective are paramount to advocating that researchers should not get to create narratives about disability or inform practice based on those conclusions, especially when those conclusions are based on quantitative data that eliminates the voice of those whose experience it is. Connel et al. (2014) offers her story, stating what she feels she has learned from her autistic sibling and positive memories of her experience, as well as reflections on services, family pressures, and difficulties. Connel emphasizes the need for a holistic view of this experience for families, that do not seek to offer interpretations or conclusions about it. Connel speaks of positive social skills such as empathy and patience, which she attributes to her autistic sibling, as well as the importance of supporting one another within the family and having a positive social network of community. When speaking about hardships TDS may experience, such as pressure or worry for the care of their sibling, the authors call attention to listening directly to the voices of siblings and asking them directly about their experiences and needs. While acknowledging the difficulty that can come with having an autistic sibling, Connel describes what her brother has taught her, and the

ways this experience has shaped her life and perspectives. Painting a holistic picture of her experience, Connel consistently advocates for ownership over TDS experiences, that it can't be generalized, and for researchers to stop trying to define this experience for them. This research advocates that listening to the voices of disabled people and their families and centering them in disability research, with power over their own narratives, is the only way change will happen in policy and society. Not only does this article place value on giving power and space to TDS voices in research, it's call for change in policy and societal views connects it to Kafer's (2013) relational/political model and is the first among reviewed literature to address this experience through this perspective. In the current review of available literature, this is immensely difficult to find as a lens used in any type of research or study and is limited to self-advocacy publications, such as Connel et al., (2014). Connel et al., (2014) were the first to highlight TDS voices in a way that not only speaks to exclusively informing therapeutic practice but also to policy and break cycles of ableism in research that continues to harm the disability community. By emphasizing TDS's power to inform policy documents, practices, and systems, the authors challenge the reproductive cycle of those who do not have experience with disability making assumptions and choices for systems that impact this population. This article is published in *The British Journal of Learning Disabilities* (Connel et al., 2014), and is the first among reviewed literature that is published in a journal related to educational practice, rather than therapeutic, psychology, and even nursing journals. Although it does not discuss educational policy in any significant reflection, this perspective sets a precedent for the importance of listening to TDS voices as experts on their experience and views of disability as an approach to research and policy, supporting the importance of the present study.

It is important to notice that across the literature reviewed, the focus on the experience of inter-ability sibling relationships is almost exclusively focused on demographics of TDS where one sibling is autistic. Autism continues to be an emerging focus of research, with a recent rise in self-advocacy publications. In this literature review, research that looks at this dynamic focused on a broad definition of disability or focused exclusively on other populations of disabled siblings, it is very limited and often used in comparison to other disabilities, and through a medical model lens. It is important to look at all definitions and experiences of diverse populations of disability to understand the uniqueness of each experience, as well as understanding commonalities in shared experiences. Looking at disability on a broad spectrum and understanding it as a diverse community, can help self and family advocates come together in the broader advocacy for disability activism and justice. The more research focused on other and broader experiences of disability, the more space there is to identify common experiences and expertise on inclusive practices, which also contributes to identifying and combating ableism on a larger scale.

Ableism

Ableism is a form of discrimination embedded on individual, cultural, institutional, and systemic levels that oppress those with disabilities, grounded in ideologies about health, productivity, beauty, and the value of human life (Rauscher & McClintock, 1996; Hehir, 2002; Storey, 2007). Derived from colonial views, ableism has normalized the way we are socialized to react to “otherness” in the human body and mind, intending to “fix” people to fit the dominant group (Story, 2007; Annamma et al., 2013). Because our ableist perspectives and actions are embedded on a systemic and cultural level, how we define and validate disability can vary across different cultures and social contexts (Annamma et al., 2013). The foregoing reviewed literature

reveals limited research focused on siblings examining their experience of a TDS with a disabled sibling, that is not in the context of informing therapeutic practice and viewed through a medical-based model of disability. This focus in research reinforces the sibling experience through an ableist perspective, as it only contributes to the narrative that the experience of disability equals the need for intervention, and discredits positive findings. Although the social model claims to look at disability as less of a problem in the individual, it continues to reinforce ableist perspectives as it still frames disability as a defect that needs to be remedied. To address ableism at its root, we must look at the social contexts in which we view and interact with disability, politically and relationally, and what systems, ideologies and structures contribute to the cycle of ableism in society (Longmore, 2003).

In the context of education and child development, ableism is deeply rooted in the ways we approach special education and therapeutic practices with children who have disabilities. Hehir (2002) emphasizes that we must recognize the ways in which our education systems play a role in the reinforced cycle of ableism, stressing that classrooms and educators must guide students through a lens that integrates disability as a natural part of life. To do so, the field must address the attitudes of educators towards disability. Through framings of disability that reduce it to intervention practices and quantifiable data, educators without personal experience of disability, are left relying on deficit-based studies and frameworks to shape their views. Not only do these views focus on deficits, they also alienate those with disabilities and focus on “othering” children with different needs, over viewing them as whole humans. There is a missing piece in research, and in practice, that centers the relational knowledge of those who have lived alongside disability as something they’ve organically adapted and accommodated for. Families have co-created inclusion with their loved one in everyday life, without needing to change the disabled

person. This is why the voices of family members and siblings should be informing practice, to embrace disability as part of the natural fabric of our diverse society. We cannot attempt to address ableist perspectives in schools and in educators until we re-frame how we view and interact with disability in research and society.

Hehir (2007) states that the aim of special educators is often to approach “inclusive” education in a way that aims for disabled children to befriend nondisabled students over disabled students. This approach represents a visual of children with all abilities being in the same space and orchestrates special education with the goal for disabled students to “do the same things in the same manner as non-disabled kids” (Hehir, 2007, p.3). This concept of “inclusion” negates the experience of the disabled individual and centers an ideal that appears to be doing the “right thing”. Rather than focusing on the child and what may make them feel included in a space, these goals of special education often position them to be harmed and forced to conform, rather than supporting friendships or belonging with peers in their disabled community. When children with disabilities are not able to conform and perform the same way as nondisabled children, it can create a hostile environment that reinforces ableist ideas that those with disabilities are “less than others”, leading to different treatment, attitudes, and segregation of children with disabilities (Storey, 2007). When students without disabilities witness these attitudes from their educators toward their disabled peers, they are drawn into the socialization processes that reinforces the cycle of ableist beliefs in society. These types of goals in special education also overlook the value of inter-ability friendships and the ways disabled can children positively influence their non-disabled peers, by exposing them to different ways of being and doing things, rather than trying to make disabled students do things the same way as non-disabled peers. Peer relationships are the primary relationships we observe in research when looking at the sense of

“belonging” (Foley et al., 2012). Foley et al., (2012) uses focus groups to look at the voices of people with a wide-range of disabilities, focusing specifically on belonging, highlighting the importance of good friends, ability to participate and school performance. We know from this research that we cannot simply put someone in a group with their peers and tell them they are “included”, rather it is a combination of feelings regarding self-perception, participation, friends, personal growth, well-being and perceptions of others (Foley et al., 2012). This focus on belonging over inclusion, gives power to the individual experience over an image of inclusion that educators and systems seek to impose on their classrooms and teach to other children.

There is limited research that uses a narrative approach to examine the experience of disability through a strength-based lens. Further, it is crucial to identify that there are no established frameworks to approach research through a relational/social lens. This lens exists exclusive to theory and self-advocacy publications, reinforcing the contribution research has on policies, colonial perspectives and systemic structures, through using medical/social models as their framework. In order to address ableism and oppression in society, the lens in which we approach and report research through must change. By not addressing these crucial aspects towards disability justice, research removes its responsibility to create actual disruption in how we view, treat and interact with those with disabilities. It is important to focus on theory that frames disability through a decolonized lens that calls for qualitative and story-telling opportunities to guide research. Research that continues to inform medical or therapeutic practices, aims to solve the problem(s) of disability and correct the experience of individuals to fit the norm. This contributes to ableist perspectives and allows able-bodied people to come to conclusions about disability and inform practice. Neither of these models speaks to how policies make decisions about how people with disabilities deserve to live, the opportunities they are

given, and how much funding they receive to live, go to school, access equipment, or be cared for. Ableism as a form of oppression reinforced by those who do not have a personal relationship with disability and leaves the disabled population with limited allyship outside its community. Ableism is not just direct discrimination. It is related to systems views and opinions. It is also related to the invisible, the sick, and the voiceless who cannot disrupt and advocate for change. The field needs to change the ways research is approached and the models through which disability is examined. We also need to disrupt. Oppression is systemic and oppression is political. Continuing to use evidence-based models to inform educational policy that does not include, or value, the voices and experiences of those who have a relationship with disability, promotes regeneration of ableism through our educational institutions, and by default, our future generations. This pattern spans from preschool through to post-secondary education and extends into academic research, policy, and practice- reinforcing the cycle back into our classrooms. This is why ableism must be addressed on individual, cultural, institutional, and systemic levels (Castaneda & Peters, 2000).

The present study does not seek to offer a remedy or prescription for the experience of having a disabled sibling. Rather, this study offers siblings the opportunity to describe their relationship and experience with their siblings who have a disability, in a way that feels foundational to them. Understanding that schools and institutions reinforce ableist perspectives in our youngest generations, is crucial to highlight in any inclusive education research if we truly want it to dismantle ableist perspectives and create environments and practices where disabled people genuinely feel included, respected and valued. The present study was designed to address two research questions: (a) *How can growing up with a disabled sibling influence one's view of inclusive spaces?* (b) *What insights can be gained from siblings to inform educational*

practices? Grounded in the reviewed literature, identified gaps and self-advocate calls for research to approach sibling perspectives through strength-based, qualitative approaches, these research questions aim to approach their experiences with curiosity. Through open-ended inquiry, these questions seek to provide the opportunity for siblings to have control over their narratives and share what they can potentially teach us about disability and inclusion.

Methodology

Research Design

This qualitative research study is part of an ongoing research initiative in Dr. Rose Vukovic, Principal Investigator's lab. Dr. Vukovic's lab focuses on inclusive educational spaces, with the primary goal of listening to the voices of individuals who have direct experience with disability. The interview guide (Appendix B) was created by myself, the student investigator, finalized through feedback and input from two other members of Dr. Vukovic's lab, both graduate students. Myself, my lab team members, and Dr. Vukovic worked together to ensure the interview guide was asking open-ended questions that focused on their views and experiences, without leading them in any particular direction that would enforce pre-existing narratives or biases of the research team. After revising multiple rounds of the interview guide, critically reviewing questions with my lab team and reflecting on my own bias towards my beliefs and hopes for this project through journal reflections, I finalized the research guide. It was approved by the Research and Ethics Board at the University of Victoria on July 17th, 2023. The guide lead the interviews and focuses on the participant's experiences, personal definitions, and views related to disability, such as inclusion, accessibility, and feedback on their experience and observations of the school systems. This study aimed to give siblings a space to share their story and perspective on their experience with disability through a lens that they believe is important to their story. The interview guide followed a narrative design, based on a definition of narrative research by Brantlinger et al. (2005) that recognizes that "people are storytellers who lead storied lives". This study also looks through the qualitative lens of action-based research, as it hopes to uncover ideas that can be used to create change in the field (Brantlinger et al., 2005) using thematic analysis. The purpose of thematic analysis in this study highlights categories of shared

importance across participant narratives. It does not aim to come to conclusions about individual experience, rather to document shared voices that wish to advocate for change. This qualitative approach was chosen in response to self-advocacy literature such as Connel et al., (2014) that bring attention to the sparsity of research that focuses on the voices of siblings in disability advocacy work. As well as literature such as Four Arrows (2024) that emphasize how quantitative data in psychology or related social research can contribute to the colonial agenda by trying to “control, manipulate and manage the human experience” through data and empirical numbers. Brantlinger et al. (2005) explains that qualitative methods used when working with disabled individuals and their families makes room for descriptive information and fills the gaps of understanding that are presently left empty through rating scales results and other quantitative data. This study aims to begin to fill those gaps.

Using semi-structured interviews, I, as the student researcher, provided participants with the opportunity to reflect on their own experiences as a sibling, their views of inclusion and accessibility, and knowledge that can inform educational practice. Data was examined and used to understand the knowledge that siblings have relative to their experience of disability, to give value to their storytelling, and provide opportunity for their voices to guide change.

Participants

Participants interviewed consisted of six adults, who identify as having a sibling with a disability. Adults are defined as those 19 years of age or over. The participant demographics collected include; age, gender identity, race, ethnicity, Indigenous status, nationality and highest level of education collected. Information collected consists of the following; six adults who identified as female aged 19- 28, with the mean age of 24.83. The majority (n=5) identified as white, Canadian, from European descent and one (n=1) identified as Indigenous. Highest levels

of education completed were, high school (n=3), undergraduate degree (n=1) and master's degree (n=2). The participants may or may not have a disability themselves.

Recruitment was conducted using flyers and emails through the Society for Students with Disabilities (SSD) and the Centre for Accessible Learning (CAL), at the University of Victoria. Flyers and recruitment materials were created by the research team, explaining the research project, its purpose, participant involvement, and compensation in the form of a \$20.00 gift card (See Appendix A). Those interested in participating were asked to contact the research team via email. Participants were selected given they fit the criteria listed above, have received information on the project, the data collection process, and purpose, have expressed interest, and have given consent to participate. Participants were informed of their right to withdraw from participation at any point in the project. This project, all recruitment materials and processes were approved by the Research and Ethics Board at the University of Victoria on July 17th, 2023.

Data Collection

Consent forms were sent to participants before the interview and reviewed between participant and researcher before beginning the interview (see Appendix C).

Data was collected through semi-structured, individual interviews between participants and myself. One interview was conducted by another graduate student who is a member of the same research lab (Vukovic Research Lab), due to a pre-existing relationship between myself and the participant. Another lab team member was asked to conduct this interview to attempt to remove researcher bias, to follow anonymity procedures and allow the participant- researcher relationship to stay professional and ethically in line with other participant experiences. This student researcher completed a positionality and bias questionnaire I developed beforehand as part of the training process to assist in my research. This questionnaire prompted the assistant to

engage in their own reflective practice to recognize and account for any bias they held going into this project and position themselves, and their experience, to the work in this study. Questions answered were the following:

- What is your positionality to this project? (Educator? Family member? Disabled?)
- What are your current views on inclusive practices in our schools, if any?
- What do you know about policy and advocacy in disability and inclusion practices in our schools? What is your opinion on them?
- Are you aware of any bias you have coming into this process?

The assistant student researcher held a Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2: CORE) certification.

- Five interviews were held over Zoom and one in person at the University of Victoria. The researcher and participants reviewed the signed consent form together before interviews began. Participants were reminded of their right to withdraw at any point, or choose not to answer any question asked. A list of resources was also provided, should any emotional or mental health needs arise as a result of the interview. Audio recordings were transcribed verbatim into text using Microsoft Word Online, under the University of Victoria server, which was then uploaded to qualitative software, *HyperRESEARCH* (Version 4.5.7; ResearchWare, Inc., 2024) for coding. All transcriptions were checked by myself through listening to the audio recording and ensuring the transcribed texts were accurate. This also helped with the first step of my analysis: familiarizing myself with the data. All data and recordings were deleted from all personal devices, immediately upon transcription and uploaded to the University of Victoria server.

Approach to Qualitative Analysis

Interviews were audio recorded, transcribed verbatim into text and coded using thematic analysis. Transcriptions were done using computer software through Microsoft Word and reviewed by myself, the student investigator, to ensure precision and exact phrasing of recordings. From there, transcriptions were uploaded to computer software, HyperRESEARCH, to begin analysis. Scharp & Sanders (2018) describe thematic analysis as a way to find themes within a story in order to understand it as information in research. Braun & Clarke's (2006) six-step guideline of thematic analysis guided my approach to coding and analyzing my data. The guide follows the following steps: (1) familiarizing yourself with your data, (2) generating initial codes, (3) identifying for themes, (4) reviewing themes, (5) defining and naming themes and (6) producing the report (Braun & Clarke, 2006). Williams & Moser's (2019) guide to qualitative coding guided my coding process which follows the process: Open Coding, Axial (Category) Coding, then Selective (Theme) Coding. These guides allowed me to organize data in a way that reveals relationships between codes and explore greater categories that lead to theme development and eventually a broader theoretical framework through which I could tell participant stories.

Participants are anonymous in this study and were assigned a number (001-006) to represent each interview. All rounds of thematic coding were conducted using qualitative computer software, HyperRESEARCH by myself. One round of secondary coding, using Axial codes was performed by an undergraduate research assistant (RA), to account for researcher bias and check for validity and trustworthiness in my interpretation of the data (Hays & Singh, 2011). The undergraduate research assistant (RA) underwent the same reflective practice as the Master's degree level (MA) student assistant by answering the questionnaire on their own views

of accessibility and inclusive practices in schools, before and during the analytic process, as recommended by Braun & Clarke (2006). The undergraduate RA did not have access to participant information and held a Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2: CORE) certification.

Another way to approach reliability in the data, and my interpretation of it, was through member checking. Member checking, as recommended by Braun & Clarke (2013) is useful in qualitative research that aims to “give a voice” to participants. Member checking adds a layer of trustworthiness in researcher interpretation of the data and provides participants with the opportunity to verify their own shared understandings and approach to telling their story (Braun & Clarke, 2013). Member checking was completed by myself, as the student researcher, through sending participants full transcripts and quotes identified as important or unique to each theme. Participants were offered to confirm, change, add or remove anything from the interview, confirm that it is true to their story, and give consent whether the direct quotes could be inserted into the final thesis. All participants confirmed the transcripts felt true to what they want to say and gave consent for quotes to be used.

First Round Coding Methods

I began the coding process by re-reading each transcribed interview, to familiarize myself with the data as recommended by Braun & Clarke (2013) and begin to think about what types of similarities or open codes may be present in the data and how they might relate to my research questions. First round open coding is a coding process that identifies specific statements that stand out to the reader and can possibly later lead to emergent themes or sub-codes (Williams & Moser, 2019). The method used for this process was “line by line” coding, as Williams & Moser (2019) explain, it keeps the researcher “closer to the data”, can help “identify nuance and remove

bias” (p.51). Because I have already identified my bias and relationship to the topic, a process of coding the data line by line, using a first round, specific coding method, allowed me to see what statements and commonalities emerge, rather than imposing my own view of the narrative. This was also the reason I chose to go through a thematic analysis process, and not solely with a narrative approach. Undergoing multiple rounds of line-by-line coding allowed me to contribute emergent themes directly to the words the participants said and arch a bridge between the story telling narratives and themes in the results section. I engaged in a constant, reflexive journaling process before, during and after the coding process to understand my own views, thoughts and biases about the data. This process allowed me to understand that although I began to see similarities amongst the participant answers, each participant held a unique set of open codes, that were specific to their unique experience, without thinking about whether they would fall into larger themes later created. I originally reflected on what I anticipated coming from the coding process, due to my previous review and familiarization process with the data, before beginning the analysis process. During this reflexive process, I ensured to reflect on these pre-conceived ideas and ensure I was not looking to tell specific stories with the data with this initial round, rather to identify specific codes, or experiences, and not to come to conclusions about them. Journaling done during coding attempted to be objective about what I was feeling and notice differences between what I was expecting to see in terms of themes and what revealed itself during analysis. Using the HyperRESEARCH qualitative coding software, 225 open codes were created and applied between the 6 interviews. Williams & Moser (2019) explain that open coding generates preliminary, specific concepts that can then serve as building blocks for identifying categories, then themes. Therefore, after the first round, open coding, the framework for second round coding was established to begin to identify any relationships between codes.

Second Round Coding Methods

Second round coding began by looking at the list of open codes and identifying the most commonly used codes, to begin to understand similarities between participants and what was important for them to talk about, I used the HyperRESEARCH code mapping tool. The mapping tool produced a visual organization of the codes which facilitated understanding how they organize themselves in relationship to each other on a map. Naeem et al., (2023) states that visual tools such as maps in the coding process can help the researcher begin to see connections in codes as they go from specific to general categories, which is the goal of the next step: Axial Coding. As I began to drag the open codes into the blank canvas of the code mapping tool, it enabled the visualization of overarching themes, as dragging just one code over, then seeing which other codes from the list were related to that concept, created a web. Codes that did not have a direct relationship to one another began to be connected to shared, broader codes, that revealed themes, such as advocacy. Codes from the open code list that did not relate to codes or categories in the map, started a new map, following the same process, which led to the creation of 6 maps (See Figures 1-6) that identified and named categories (sub-themes) and themes.

Third Round Coding Methods

The categories and themes established from code mapping were put into a new code list in HyperRESEARCH, called 'Axial Codes'. An undergraduate student was recruited as a research assistant (RA) to engage in a round of line-by-line coding on all 6 participant interviews, using only this new code list. She did not have access to code maps, or first round coding data. The research assistant was given instructions to assign codes from this list to sentences, words or full paragraphs in the transcripts that they believed were relevant or fell under the category of that code. I underwent same process of line-by-line coding on all 6

interviews, using this new code list. The purpose of this last round of coding was to establish trustworthiness in my interpretation of the data and to test reliability in ensuring the Axial Codes derived from open codes remained consistent and a reliable representation of the voices of the participants. Both the research assistant and I used all codes when coding the interviews, overlapping in where we assigned them, as well as determining that multiple codes could be assigned the same statements, further showing a strong relationship between determined themes and how they represent the stories participants are telling. Ongoing reflexive practice through analysis and interpretation included journaling my thoughts, beliefs and own positionality towards topics that arose through analysis. I also completed journaling between the RA's coding and my last round of coding, to understand where our views and interpretations of the data were similar, where they were different, and what could account for the differences. I reviewed these differences with my supervisor and reflected on the interpretation and trustworthiness of my analysis. To finish the coding process and as a final bias check towards my interpretation of the data, I reviewed all rounds of coding with both members of my committee, who agreed in the development of themes and sub themes, and that they are well supported by the extensive coding process, undertaken by myself and the research assistant.

Results

This research project aimed to give a voice to people who grew up with a sibling with a disability, addressing a historical gap in research and a call in past literature from self-advocates to focus on siblings through a qualitative, non-medical lens. The study was approached through research questions that did not seek to determine the sibling experience but rather approach these storytellers with curiosity of what knowledge they may hold to help guide us into creating more inclusive spaces. It also addresses the importance of changing the narrative that focuses on disability as a harmful experience and provides the opportunity for siblings to be viewed as strong, as knowledge keepers and experts on their experience. The research guide (Appendix B) asked open-ended questions that focused on prompting participants to share their views of inclusion and accessibility practices, their experience with their sibling and feedback they may have for schools and community practices. Through extensive qualitative coding using a thematic approach, six themes emerged as a result of relational mapping through specific sub-theme identification revealing commonalities among all participant stories. The six themes are as follows: (1) Advocacy, (2) Barriers, (3) Beliefs, (4) Education, (5) Perspectives, and (6) Relationships. The following section will explore the major themes that emerged from the analysis and coding process. How these findings answer the initial research questions of this study, will be addressed in the Discussion section.

Advocacy

All participants reported an active role in advocacy work, with unique experiences in relationship to their sibling, to their community, in their careers, and everyday lives. Statements shared about advocacy were weaved into stories about how participants see their role in their

relationship with their sibling, as well as their role in society. Advocacy was a theme established as an umbrella that encapsulates findings in relation to participant stories forming sub-themes through the code mapping process. The code map for advocacy is represented in Figure 1.

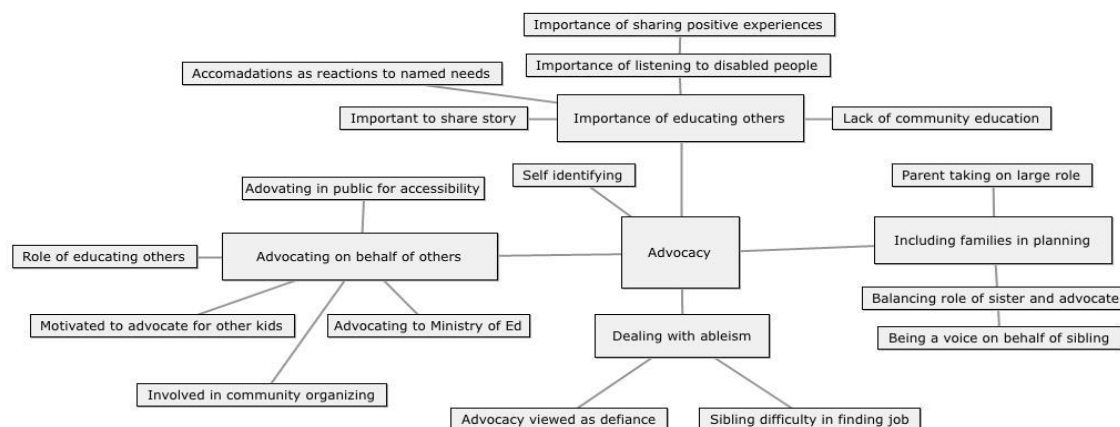


Figure 1. Code map for Advocacy displaying relationships to sub-themes and specific codes.

Each sub-theme is explored below, to demonstrate the unique details and stories shared in relation to advocacy. Sub themes, as illustrated in the code map are; Advocating on behalf of others, dealing with ableism, including families in planning and importance of educating others.

Advocating on behalf of others

All six participants spoke to the role of advocating on behalf of others, including their siblings, as well as general advocacy for access and inclusion. Experiences around advocacy were not exclusive to answers regarding one question from the research guide, rather as an ongoing theme that appeared through sharing beliefs, impacts and experiences. All participants shared that their experience with their sibling brought a larger awareness of other disabilities and needs, as well as barriers in society. Some of these examples are in day to day conversations from noticing barriers in society, such as mentioning to a public pool that their lift is broken upon noticing. Some are more organized forms of advocacy, such as having a meeting with the

Minister of Education on inclusive practices and mental health support in schools. Advocating on behalf of others is woven into many parts of stories told in this study and it is clear that it is a shared value and skill learned through their experience.

...our pool had an issue with like the chair lift kind of thing for a while and I was like oh just so you know, like it's not working properly and hasn't been for a while. Just like just so you know and that's like yes that's for my job. But it's also like I know these kids probably want to go to the pool with their family when they're not at camp and it's like I don't want to put that on like the parent who's chasing around their other kid and their child with a disability around the pool, trying to take care of everything at once when, like, I have many hands on deck. I can have the little bit of a hard conversation to be like, hey, can you fix this or do this? Just make it a little better. -001

Dealing with Ableism

Based on my review of literature and definitions of ableism, along with my personal understanding of ableism as a form of discrimination and oppression, ableism was a sub-theme identified through stories that were interpreted by myself as a form of ableism, where a participant advocated against discrimination on behalf of their sibling, or witnessed others advocate on behalf of them. Ableism can be present in the failure to accommodate and notice barriers; although it is more recognized as a direct action toward someone. These types of direct ableist experiences were referenced in parts of conversations in the interviews that were related to playing the role of an advocate. In one story, a participant noticed that a couple of young children stood up to their teacher on behalf of their sibling with a disability, then were punished and sent to the principal's office. This passage was coded as "Advocacy viewed as defiance" under the sub-category "Dealing with Ableism".

Seeing these kids who were like 8 or nine years old like also advocating for my brother...it was really interesting seeing like these kids when I was like in middle school... they had this like, particularly awful like grade 4 teacher, where she was like, very much the kind of person who was of the mind that like everybody had to be like prim and proper... She constantly was sending my brother into the hallway to, like, go and be loud and not be in her classroom, which like it was... it was so bad... it was not at all, inclusive education, like the antithesis of it, honestly. And these kids, they were siblings, it was like a grade four or five split class and both of them were in the class and they got sent to the principal's office for advocating for my brother. And I just like, I just, I feel like, I hope for a system of education where like ... teachers, would understand how... how vile that is.... – 002

This story shows how deep ableism can run in societal structures, such as schools; where discrimination happened in the first place, and then was viewed as a misbehaviour to speak out against. The second participant (005) shared a story of her sibling having difficulty finding a job due to ableist perspectives and skepticism from employers on whether they could perform the tasks needed, despite having already completed a practicum doing the same work.

... they've seen my brother do work because he did a stage (practicum) at a work place...but when we tried to get him hired, they kind of were like well... I don't know. ...Can he do that? And I'm like he's been doing it for weeks. And now like, what changed now versus giving him a paycheck for it? Hmm, like instead of him just helping out? And actually, hiring him. That's why I was like... I've like shifted my perspective and like, hey, this place is probably not the best for him because they value him as someone who's

helping them out, but not as a worker and not respecting him by giving him that rightful title and employment. -005

She explained this experience as “speaking on behalf of” her sibling and standing up for him, then removing him from that environment, as part of a decision they made together.

Including families in planning

The importance of including families in planning, more specifically shared under educational planning, was highlighted throughout participant stories. Under Advocacy, it served as a sub-theme found in stories that included sibling advocacy, as well as parent involvement. Two of six participants directly mentioned their parent involvement in their sibling's care, education and community often advocating in planning processes regarding their care. One participant spoke to how important it is to include parents in planning for their sibling, especially in school settings, in order to best support where their abilities are and eliminate the possibility of harm.

The one time they tried to get my brother to write his name for 30 minutes straight and when they told my mom they were surprised that she was like, do you hate him? He can't. He doesn't know how to hold a pencil properly. He can't write his name. Let alone do anything for 30 minutes. So, it's stuff where it's like, yes, another kid might be able to do that and sitting them there for 30 minutes would be great. But for him, that's not going to work. – 001

Throughout unique experiences of each participant, the importance of listening to families and theme of families knowing their sibling the best was a reoccurring theme. One participant shared that because their sibling dynamic is different from other family member dynamics and is closer to a friend, they were able to understand their sibling and their needs

well. The closeness of their sibling dynamic helped build a relationship of trust and care that helped her advocate for and learn from her sibling and was recognized by other members of the family.

My family growing up often referred to me as [sibling's name] Whisperer. Like I was the one that was able to, like, really understand what he needed and to be able to like, take care of him in ways that sometimes my parents couldn't. And he like trusted me in ways that sometimes he rejected from my parents, like they were more of like an authority over him or whatever. But I was like his friend and his support. -003

Importance of educating others

The last sub-theme under advocacy is the importance of educating others. This references examples given of advocacy as a source of education, as well as advocating for more sources of education on disability and accessibility for others. Examples provided across all interviews included; emphasis on sharing stories to advocate and raise awareness to others, importance of sharing positive stories to advocate against ableist views of disability, as well as advocating for more community education, such as self-advocate presentations and workshops.

I always kind of see myself as an advocate because there's always a teachable moment when you know when you interact with others or businesses organizations... So, I always find myself switching between just like the sister and the advocate, because again, there's so many different chances to give information and to give whatever knowledge I do know to others, so they better understand so the next time they interact with someone... They're at least just a little bit better prepared than before to respond appropriately or to kind of have a better understanding of how to interact with someone. – 005

Barriers

The second theme identified through my analysis of the data was barriers. This theme appeared primarily through the first two questions in the research guide, addressing the participants views of accessibility and inclusion. Figure 2 illustrates the development of sub-themes and diversity of responses regarding barriers distinguishing the six sub-themes.

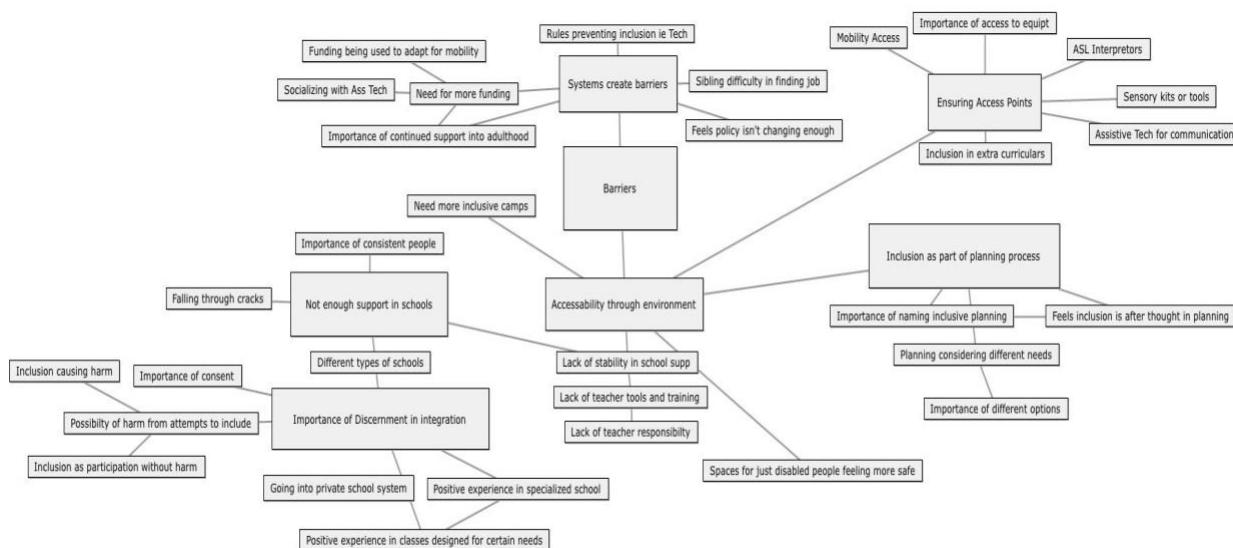


Figure 2. Code map for Barriers displaying relationships to sub-themes and specific codes.

Accessibility through environment

Accessibility was a sub-theme that emerged through the word-mapping coding round and provided an umbrella for many specific statements given in participant stories such as, accessibility related to school environment and recreational environments (i.e. summer camps). Environments specifically created for people with disabilities mentioned as a “safe space” were mentioned across three out of six interviews, leading to the sub theme of Importance of Importance of discernment in integration. Three out of six participants shared stories of classes or schools specifically for disabilities being a positive experience for their sibling, with the

opportunities to integrate with peers, stating that trying to include their sibling in classes above their ability level or that cannot meet their needs was harmful for them. This is where environment can be a barrier to successful inclusion and is explored more in the next sub-theme.

My brother also went to [school name for children with disabilities] for a bit during like his later, schooling experience, which like... Oh my God so amazing. Amazing staff, amazing teachers, amazing playground once again!... Like genuinely I think like my main take away from like having just, like, experiences that like, were very much tailored to my brother being like, I mean, special needs, like, growing up was like... How... awkward it was to try and include him in some of like the more regimented like regular curriculum schooling and then how awesome it was when he was able to be part of like different youth programs that were like specifically for like people with like different or like more intensive needs. And so like going to pick them up at school was like always such a highlight because like the hallways are like, full of artwork, there's like... Kids hanging out like wherever doing their thing like it was just like chaotic at times, but like generally like such an interesting and like happy space and like I don't know, just like really, really cool to, like, get to see... -002

Importance of discernment in integration

Inclusion causing harm, possibility of harm from attempts to include and inclusion defined as participation without harm was consistent in participant definitions and views of inclusion. These stories state how “inclusion” should not be deducted to putting everyone in the same environment and that using discernment, especially in educational decisions, is important. Participants explained how ability level, as well as peer and social factors can cause harm when

trying to put students in classes that is above their current ability. An example from a story is below:

... being in an environment where he's expected to sit there and listen to a teacher explain math that he probably doesn't understand where he can't really stim or let out his emotions or like move around probably is actually harming him in a way like that's making him feel a little restrained rather than like... I know he loves being in his, we still call it a resource room at his school and not sure if that's what it's still called properly. But he loves all of his friends in his class. He loves his teachers... Like my brother goes to gym class with all of his peers where I know that they've talked about moving more towards people with disabilities, being fully integrated in classrooms which ... wouldn't like... I don't think that'd be super inclusive for him because he wouldn't benefit - like it actually probably harm him more than benefit him. -001

It was also mentioned throughout participant stories that environments specifically for people with disabilities can be a safe space to just be themselves and should not be conceived as exclusive from definitions of inclusive spaces. These views and stories revealed that integration without using discernment and seeking consent from people with a disability relative to their participation and environments can be a barrier to feeling included and possibly cause harm.

Inclusion as part of planning process

Inclusion as part of the planning process was coded multiple times across every single interview. This included ensuring access points, providing a variety of options to participate in and removing barriers while considering different needs. One participant's definition of accessibility really highlighted how important the planning process is to be doing the work in creating truly accessible spaces and ensuring as few barriers as possible.

It (accessibility) is the work that you do ahead of time to sort of anticipate the needs of people in space and plan for how you're going to include them. So, accessibility is kind of like the removal of systemic barriers or practice barriers... And accessibility practice means the facilitator of the space or the planner of the environment takes responsibility proactively before any people arrive to set it up. And so yeah, things like... anticipating the physical needs, the cognitive needs and the social, emotional needs of people and having options... – 003

When someone is being included, I would say that there are as few barriers as possible from for them to participate in whatever is going on. Whether that's like a conversation like physical activity, a space, I think a lot of that can come from like the pre planning of a space or an event kind of using like those universal design principles and assuming that people with a variety of different access needs will be... -006

Ensuring access points

Ensuring access points was also an over-arching sub-theme when barriers were mentioned, again, primarily in relation to the guide prompt on definitions and views of accessibility. American Sign Language interpreters and wheelchair access ramps or physical barriers were both mentioned in five out of six responses when discussing access points and removing barriers.

When someone is being included, I would say that there are as few barriers as possible from for them to participate in whatever is going on. Whether that's like a conversation like physical activity, a space, I think a lot of that can come from like the pre planning of a space or an event kind of using like those universal design principles and assuming that

people with a variety of different access needs will be, like attending an event or participating in an activity and that when that person, if that person who wants to attend, like if they want to attend - that they're able to attend with as little or ideally no barriers as possible. -006

...making sure that everything has an access point. Even it might not be the exact same way or the exact same thing. Making sure that like...that's happening. I think of wheelchair ramps a lot and how like even sometimes like they'll have a wheelchair ramp, but it's like a super long roundabout way of getting there and it's like they're on the like road to like being good and where they should be. But also, like making it easier would still be good. -001

One participant (006) shared how at the post-secondary level, their sibling had an experience with a co-op program that was specific for people who identified as having a disability. She shared how this experience removed barriers that the traditional program presented for her sibling, and created an access point where she could succeed.

When she got older, like more of the post-secondary age, there's now more programs like there's a co-op program at Uvic specific for students who self-identify as having a disability. And I know that was really helpful for her in terms of accessing professional... Like employment opportunities while she was in her undergrad, and I think lots of the accommodations that were being built into the program at that time are what really supported her. And had she gone the more like traditional Co-op route, I don't think she would have been as successful. But clearly, she was like, capable of doing the thing because then she went on to do these terms. -006

It is in these intersections of barriers, access points and accessibility that the relationships between planning and environment become clear as an important part of inclusion and we can begin to see the areas of knowledge and awareness that siblings hold.

Systems create barriers

In discussing views of accessibility and inclusion, all participants shared thoughts on barriers that are put in place, or upheld through systems.

...a lot of our systems have created artificial barriers based on like what is seen as like a normal way to do a thing versus a disabled way of doing a thing. And so I think for the most part, I definitely think that is just like part of my understanding is that there are acceptable ways of showing learning or like producing work, and there are ways that are seen as like less valuable or less important or less like competent even, and so I definitely think that's true. I also think for the record that like sometimes disability can result in like a more difficult life or ability to participate in general, but especially for my brother and my friend, the more important piece to me was about just like, normalizing that people can do things differently or show up differently in the world. -003

Some shared stories mentioned barriers that I interpreted as systemic, such as rules in extra-curriculars that prevent devices such as iPads and phones, creating communication and access barriers for their sibling.

For example, my brother uses an AC device to communicate. So... Him having that at school and like there's rules at like summer camps, for example, and sometimes even schools where like electronics, you're not supposed to have them. Like it's not OK you

can't use them, but like taking into account the. Like. He for him to be like, excessively hitting the points that you want him to be, like benefiting from in school. He's going to have to have his iPad. -001

Some were more direct regarding systemic barriers such as the lack of government funding in schools and community resources, along with strong beliefs around policy from one participant stating that there is not enough movement towards change happening in educational policy. This will be explored further under the theme “Education.”

... more funding for people to be able to be in the classroom helping to do one-on-one support because it's not fair on a teacher to be like you know in charge of 30 kids and maybe five to ten of them really require like at least some extra support than just one teacher in the classroom. And so, I think that was one thing that like as a kid, I was like, why don't they just add more adults helping? Why can't they be the same adult helping? Who is this new adult helping? -002

Not enough support in schools

A common shared barrier for inclusion amongst participants was the lack of adequate school support, predominantly in sharing what they would like us to know to better support inclusive environments. The lack of school support and consistency in people working with their sibling was shared by three participants in what they feel were barriers to their sibling having a positive school experience, as well as why they feel students with disabilities “fall through the cracks”. Lack of support in relation to barriers in school can also be seen as relational to using discernment in integration, with two participants stating how many barriers were removed when

their siblings moved to schools for people with disabilities or private schools, sharing how there were more resources and less barriers to participation for their sibling than in a public school.

I was, you know, constantly having to come in, and my mom would have to come in and somebody would have to come in to, like, try and help my brother get to know the people that were supposed to be supporting him. And then they would change like the next day or the next week or, like, there wouldn't be capacity. And he would have to go home because he really can't be in the classroom without one-on-one support and I think that it just like having more stability in those roles. -002

...there is not enough support in a lot of schools and a lot of kids in our school system fall through the cracks and they're not able to be supported. And so, they either have a couple options so you know, if you are lucky and privileged enough like my family, you can take your kid out and put them in private school and hope that that solves things. -004

Beliefs

The theme of sibling beliefs was explored in relation to the research guide prompt “Where do you believe these definitions and/or beliefs came from?”, following discussion of their views and definitions around accessibility and inclusion. This theme also encompasses sub-themes that emerged as siblings shared their feelings or beliefs around these topics and societies’ response to disability. The following section will explore commonly shared experiences focused on beliefs. The code map demonstrating commonly explored categories on beliefs is illustrated in Figure 3.

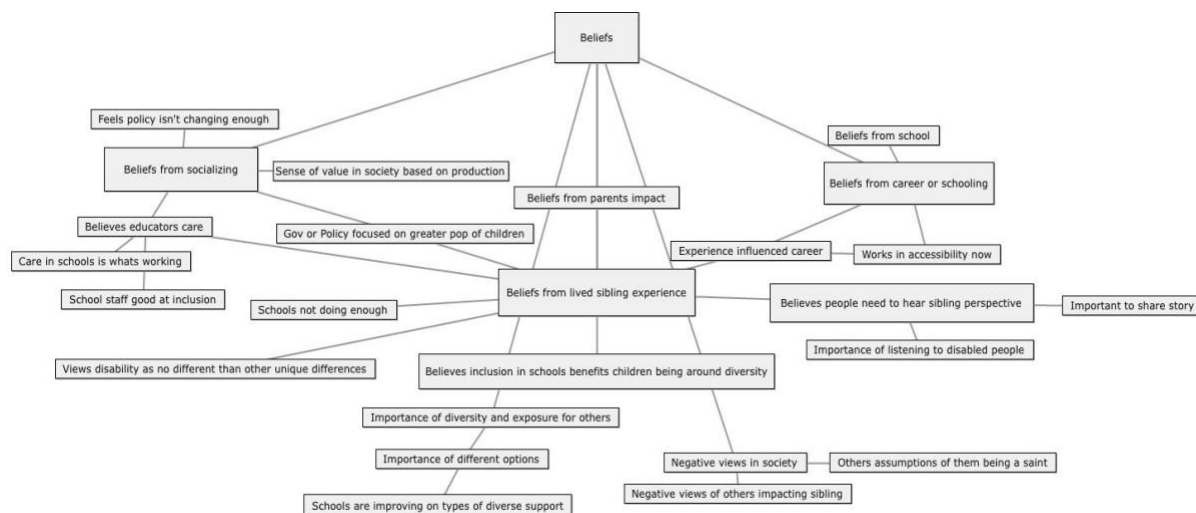


Figure 3. Code map for Beliefs displaying relationships to sub-themes and specific codes.

Beliefs from career or schooling

When responding to the prompt surrounding where participants felt their beliefs came from, the theme of a career, or schooling contribution was common among participants. Five of six participants reported working or attending a post-secondary program related to social fields, with three being exclusive to accessibility and disability work. Fields of work included: Speech language pathology (n=1), accessibility consulting (n=2) and teaching (n=1). Post-secondary programs included education (n=1) and special care counseling (n=1). Participants shared how their views and experience with their sibling impacts their work or career choice, and also how their experience in their work continues to contribute to their involvement in their community.

Believes people need to hear sibling perspectives

One of the shared beliefs that was prominent through participant stories, was that they feel it is important for other people to hear sibling voices. Sibling stories all referenced gratitude for their siblings, the perspectives they have brought them and the desire to have their experiences told. All participants shared stories and reflections on how as an adult, they can

better understand how their experience as a sibling with a disability is unique and beliefs around why it should be shared.

When I was in high school, a lot of kids... they...well, some of them, I guess they didn't understand as much because they didn't grow up with a sibling ...and I feel like I'm really thankful to have like this different view and perspective because I think a lot of people need to hear that kind of perspective. - 004

When I grew up and was learning about the rest of the world, I realized that other people did not have the same experience and understanding of disability as I did. And I was like, oh, I think people are thinking about this wrong, they don't really have that lived experience or there are barriers in society that don't need to be there. And so yeah, I just wanted to share my perspective about disability, accessibility and like how my brother really shaped that for me. - 003

This was a strong belief across participants and it should be highlighted how all participants uniquely shared their own statements of why it is important to them. Some shared the drive and desire to advocate for change, some sharing beliefs focused on the importance of having a place where their story is documented. All expressing that they have never been asked to tell their story before and/or have not seen perspectives that are positively highlighted before. More statements that stood out include:

I've played a role in like his support and education and like a very unofficial role that like I often stepped into as a child without really knowing that I was part of a support system...And I was like, oh yeah, like none of that is documented anywhere...So it was with genuine interest... I was like, oh, that would be nice to actually share for the purpose of this research, my own experience. -002

... Kind of have that connection of, you know, being a sibling and helping provide a voice for my brother and I do think ... it's not really talked about as often and not really focused on. So, I thought it'd be a good way to kind of shine light a little bit. At least give my side of my perspective of how it was growing up and where we are now and some difficulties as a family and stuff my brother has faced, you know, being a human with the disability and society and how he navigates that and how society works with him as well. So, kind of just help give my perspective from my experience. ...I tend to always be a little bit emotional when I do talk about, you know, my brother and my experiences because... it's not really focused on siblings sometimes. So, talking about my experiences sometimes get me emotional because it's like, oh, someone's asking how I'm doing, not how my brother is doing. - 005

Believes inclusion in schools benefits other children

The next sub-theme revealed a shared belief that other children benefit from being around peers with disabilities and different needs. Part of this belief emerged from participants sharing how they were positively impacted by their sibling and the awareness brought from the views and skills they have learned from them. Discussed in the next sub-theme below, it was shared commonly through stories that participants feel the development of beliefs comes from the experience of socializing.

I think yeah, like especially in educational settings like early exposure to inclusion and diversity leads to better outcomes for everybody, like the earlier people experience inclusion, the more they go on to expect that in future systems and also champion it and also, yeah, just demand it. And so, I think that like awareness among teachers and just facilitators and spaces of about, like, naming that disabilities are welcome and different

contributions are going to be valued is, I think, really important for like developing inclusion. - 003

As demonstrated in the previously quoted statements, it is commonly shared among siblings that their experience with their sibling impacted their beliefs and views on disability, which can be attributed to the shared belief that inclusive spaces and socializing with diverse needs can be positive for other children too. In relation to Education, this is expanded in the next sub-theme.

Beliefs from socializing

This sub-theme emerged from beliefs that participants shared based on their observations and experiences relative to societies' responses to disability. Some shared beliefs were in conversation in relation to observing their siblings' experience, and some in relation to their own observations. The beliefs included; feeling as though educational policies are not changing enough, believing that educators care and that is something that is working in schools, as well as beliefs that schools are not doing enough. An observation shared by one participant was the belief that our society attributes individual worth to their production, which leads to ableist perspectives around work, which I thought was worth noting as a societal belief.

I think a lot of our systems have created artificial barriers based on like what is seen as like a normal way to do a thing versus a disabled way of doing a thing. And so I think for the most part, I definitely think that is just like part of my understanding is that there are acceptable ways of showing learning or like producing work, and there are ways that are seen as like less valuable or less important or less like competent even, and so I definitely think that's true... what is a valuable contribution, what is not a valuable contribution?

I'm thinking, like why? And is that true? And can we find space for different people's contributions in different environments? I think especially education- there is so much expectation that things are going to look similar and that you're going to be able to compare like an assignment product across like the whole class like everybody submits the same thing. And like why? We don't expect every graduate from high school to go on to do the same job. And so like, we should like, let people contribute in different ways so that we're preparing more better people to go do the different things they're going to do in life. -003

Education

Thoughts shared that focused on education were a prominent theme that emerged from the participants' stories. This is demonstrated through the code map Education (figure 4.). This theme of education is not exclusive to our education system and expands on the importance of educating others, the impact of society; beliefs within it and sources of education within it as well. Sub-themes that emerged were Society, Educating children at an early age, Educating teachers, Importance of educating others and Importance of a strength-based mindset.

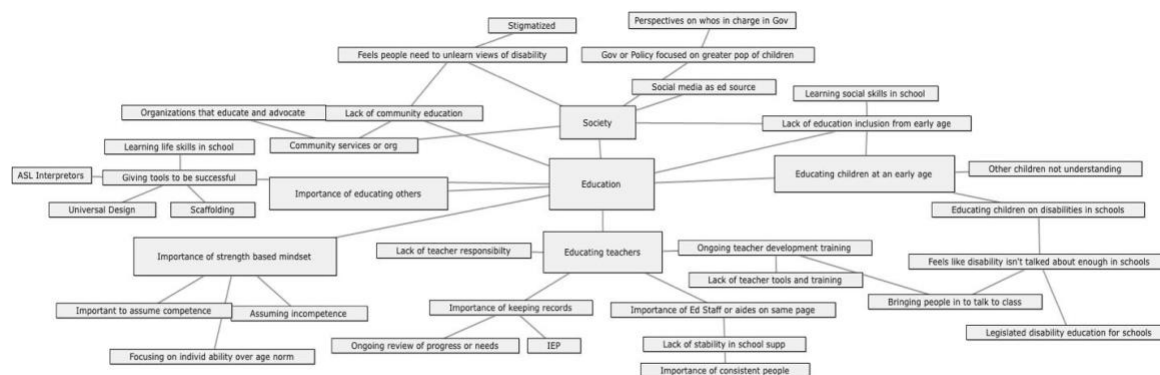


Figure 4. Code map for Education displaying relationships to sub-themes and specific codes.

Society

Connecting to the importance of educating others, participants reflected on views of disability they have observed surrounding disability commenting on stigmatized beliefs and the need for people to un-learn their views of disability and diversity in general. Speaking to the education system as a systemic influence on society, one participant shared her experience with the opportunity to speak with the Ministry of Education, as part of a youth leadership program focused on advocacy.

Yeah, it definitely gave me a perspective of what it was like to talk to people that are in charge of our policies and our government and it kind of gave me a window into why things are the way they are with our school systems in BC... I feel like they were thinking of a small demographic when we were talking to them and I feel like that makes sense in that there is not enough support in a lot of schools and a lot of kids in our school system fall through the cracks and they're not able to be supported. It felt a little bit discouraging, but at the same time I felt motivated to do more and make sure that these kids have better experiences than my brother. - 004

Two participants shared a positive perspective on the relationship between society and education, in relation to disability. These participants shared the positive impact social media has had on the ability to share and receive information, as well as the platform it can give to voices of disabled self-advocates. Both participants shared that social media has been another source of their disability related education.

...Also, through lots self... kind of learning through influencers online, people who are sharing their lived experience whether they identify as like an advocate or not. But people are just sharing resources, sharing kind of their own lived experience. And then through

kind of a combination of, I guess, like the education and my professional experience and also just engaging with people online. -006

Especially with like social media, I feel like more people with disabilities are getting platforms to speak and like share their life experiences which opens other people's minds to see different people with disabilities and how they navigate the world and so I feel like social media did play a big part, especially now with it being so... I guess popular and you know, you see it with younger kids. It gives them more of an opportunity to interact or hear first-hand from people with disabilities. And I feel like that's good because, you know, you can only see so much in the real world, so to have access to it on your phone to see and ask questions to actual content creators who have disabilities... -005

Importance of educating others and Importance of a strength-based mindset

These two sub-themes are closely inter-woven, as they both encapsule the lack of information in society, outdated ableist views, and lack of value in voices of advocates in mainstream systems. The theme of educating others emerged across all participants, expressed in unique ways that demonstrated the diversity in what felt important for each story-teller.

Educating others was framed as the means to teach others tools and skills to support the inclusion and success of disabled people, as well as foster a strength-based mindset and un-learn deficit-based views. Assuming competence over incompetence was a consistent theme throughout the stories of two participants. These stories highlighted the lack of education people have relative to different abilities, and how that leads to assumptions that just because someone can't do one thing means that they are incompetent in other areas.

... the whole, like assuming competence over incompetent like, I know a lot of people probably look at my brother and be like, oh, he can't vocally talk out loud... So, there's like, I doubt that he can read like, stuff like that where you're assuming the incompetence behind it when really, it's like, he can't talk, so I assume. How do you know he can't read? Like I think maybe he can read that book. He just can't say it out loud. And it's not like that. Also, it's a lot easier for me to like recognize that and be like that's not probably how it works. -001

...And especially when I'm with my brother at the same time, because again, people tend to talk to me instead of him, and I do have to correct people like "no talk to him, he can understand you, he understands everything you're saying it just he might not be able to respond the way you expect him to". -005

In particular, one participant's story strongly illustrated the importance of educating others. She shared the lack of exposure and education to diverse needs and how that can impact the safety of her sibling, who uses an alternative communication device to communicate.

For instance, if you're hurt, I taught him how to call... which I do want to reach out to the first responders to kind of educate them as well on, you know, not every phone call you're going to get is going to be a person's voice on the other end. And to still take it seriously and... Because I know there is probably some instances where they hear like a robot talking, and they're probably like, oh, this is like a prank call or not to take it seriously. But they're certain people like, that's their only way to voice when they need help and... So, I do want to contact my communities first responding team to be like, look if this ever happens, like it might be my brother on the other end and it's his last resort. If

I don't answer the phone, he's going to call you guys and I hope that they honor, you know, that they don't like, react poorly or inappropriately where they're just like it's probably a prank call. – 005

Educating children at an early age

Stating that our early social skills are built in school, one participant emphasized the role that it plays in the views and behaviours we adopt through teachers, other children and what is directly taught to us. All participants shared the importance of educating children on disability and inclusion at a young age. One participant shared her beliefs that early exposure to topics like disability is beneficial to everyone as it sets a precedent to include people in different spaces as they move through life. Across participants, shared suggestions to educate children at an early age, included; a legislated curriculum on disability in schools, bringing in self-advocates to do presentations, as well as learning pro-social skills in general.

I think education is huge that's kind of where I think it needs to change. There needs to be more education starting as early as elementary school. I think it should be inputted in at a provincial level where there's some sort of legislation where both kids and teachers have to continually learn about this kind of thing... -004

Perspectives of Sibling Experience

Perspectives of sibling experiences was another very broad theme. Sub-themes also held multitudes of storytelling and revealing perspectives. This theme includes the feelings participants expressed about their experience, their perspectives on family dynamics, reflections on their values as well as what they want people to know about their experience. Sub-themes

explored are Support or Caretaking, Family experience, “Glass child” experience, Skills gained from sibling, and Values influenced by the sibling as illustrated in Figure 5.



Figure 5. Code map for Perspectives of Sibling Experience displaying relationships to sub-themes and specific codes.

Support or Caretaking

All participants named taking on the role of caretaking or being a support to their sibling. This included taking on a support role at school, noticing the lack of support for their sibling, supporting their sibling in decision making and identifying career options as well as caretaking as part of the family dynamic. Participants reflected that as an adult, they realize that they took on caretaking roles as a young child, but didn't really realize it at the time, as it was just a part of their sibling dynamic. Two participants said that they didn't notice or feel affected by these roles until they were a teenager.

And then as we kind of left our adolescents and teenage hood and we became closer to adulthood, I definitely more formally took on the role of kind of watching out for her and helping coordinate things for her, looking for resources on my own time and bringing them to her or like supporting her through things like looking for employment, applying for school, managing her like post-secondary schedule and making sure she was on top of like assignments and stuff, and then she... Sometimes would resent me for that because she's like, you're not my parent. But yeah, I guess, like throughout my whole life, like I've kind of been like watching out for her in a way. But also, part of that is just like I'm the older sibling. So, it's kind of hard at times to disentangle how much of it is just our sibling dynamic and how much of it is just our personalities -006

Although sharing that at times as a teenager, this role impacted their social lives, participants shared that they do not hold any resentment or regret about that role and that they want to support their sibling, with one participant offering that it's just a matter of finding balance as an adult.

I had to explain to people a lot and kind of defend him there and then getting older as a teenager, that's why I feel like it impacted me more just because... I did feel a huge need to protect him and help him out, which did affect my social life. I didn't have many friends because they didn't really understand that I'm like, well after school I have to go home and help my brother with his homework and I'd make him his dinner and so I wasn't really out and about more as a teen. Which I don't regret at all because I would help him all over again and be there for him. But I didn't know that now as an adult where I'm like, oh, OK yeah...I didn't really do much of what typical teens did and I had a

different mindset than others where they were more worried about socializing, I was more worried about family and kind of making sure my family was safe and had everything they needed...until he's able to be 100% independent like I'm going to take care of him, I'm going to be there for him. So for when it comes to like my life and dating, it's kind of... OK I have to let them know like this is a huge part of my life, it's not going to change for anybody and you have to accept that about me in order to kind of be with me in a sense. I guess as an adult, it's kind of navigating again my independence and where I want to be with also that balance of family and finding ways to prioritize myself as well as my family. And there's always that like small voice in the back of head being like, oh, I should be doing more. But also remembering like I am... I have to take care of myself as well in order to get take care of others. -005

Family experience

Family dynamics were shared through stories related to how growing up with a sibling impacted participants and from where they believe their views arose. All participants expressed deep love and care towards their sibling, often sharing that they have a close relationship. A common theme among the stories was that, despite taking on roles that would be considered caretaking, participants did not notice that there was something 'different' about their sibling from a young age and did not feel that parents were placing these roles upon them.

Honestly [I] did not notice it that much. I was just kind of always like, yeah, like this is, this is what we're doing. This child is chasing me in an electric wheelchair right now and that is fine. I definitely like, looking back like I know like my parents were definitely like hyper aware... I think the biggest way that it's affected me is like seeing the ways that like

my parents tried to never like... just like try and like delegate any kind of tasks or responsibilities to me. -002

I feel like when I was young, I didn't really notice as a young child would say like 5-6, that my brother was different in any way. In my mind as a child, he just needed extra help from my mom and my mom was always with him. So, I didn't really notice anything right away. And then as I got a little bit older... to more like preteen, that's when I started to realize more how society looks at him and reacts to him because there was a lot of small instances where I would have to either defend him or kind of explain to people like, well, he, he's on the autism spectrum and that's why he's doing like, you know, stimming... - 005

In regards to discussing family dynamics and their relationship with their sibling, four participants also shared that they want people to know that just because their sibling has a disability doesn't mean they still don't have a 'normal sibling' relationship. Examples include; when they get annoyed at their sibling, people are surprised as if a younger brother annoying his older sister is unusual, as well as people treating them like a saint for having a close relationship with their sibling and spending time with them.

... because as much as he is the cutest man in the world, he, he is a teenage boy. He he's still a teenager and. That's another thing is like people watching the way I interact with him and be like why'd you tell him to go away? As if he's not still my little brother. Who...? I don't view as this like object where I can never tell "No you have to be kind to him all the time"... as much as like, like watching people and see our interactions and think that it's weird when it's really just like take out the fact that he has autism and it's

exactly the way a brother and a sister would probably act towards each other if one of them wasn't autistic. -001

“Glass child” experience

The “glass child” metaphor refers to the experience in which people who grow up with a sibling with a disability feels that their needs are not seen, often due to the demands of their siblings needs, leading to the feeling up being “invisible” or “looked through” (Hanvey et al., 2022). Three out of six participants reported having this experience, two of them naming the term “glass child” specifically. While two others said they did not feel they had this experience, with one participant using this term specifically.

I am one of the people that I think I had a very positive experience having a sibling with a disability...I think it's important for like somebody who has had a very good experience to be involved in a way. Like I don't there was ever any like favoring of him in my family so. I see a lot about siblings who are like, oh my parents coddled my sibling with a disability- so now I'm more of like a ‘glass child’ who's not always paid attention to as much... But like, I never had any of that. Like, my mom was very good at that separation. -001

I think the biggest way that it's affected me is like seeing the ways that like my parents tried to never like... just like try and like delegate any kind of tasks or responsibilities to me and I think tried to like overcompensate for being like “Well, you know, like we have to take him to like 5 appointments this week, so like we should probably make like some kind of like space for like me to like also get to do a bunch of activities.” And...I think that like looking back like once I like kind of gained more consciousness of that I'd be

like, mom, you don't have to, like, give me a ride to this ... I can go and do things by myself because, like, I just have that capacity and like that is fine. And so, I think, like the big... kind of impact that I wish that I could change was just like how much my parents were focused on being like ...we have to make this seem like, 'normal'" with huge air quotes. Like that there was some kind of like typical like you know like 50% of our parental energy will go towards one child and 50% towards the other child... they definitely stress themselves out like more than they needed to trying to create like balance in that kind of way... I think that in that way it made me wish that there was like... You know, like more kind of people in their lives being able to say "hey, like, you're actually doing such a good job -002

Two participants that shared having this experience shared a gained sense of independence due to this experience as well as a learned skill of caring for their own needs at a young age. Participants who named having this experience organically shared that despite this experience, they do not feel resentment towards their sibling. They were not prompted to comment on how it made them feel.

But then as we got closer to more of our adolescence age, I feel like we adopted more of that kind of the like 'glass child', other sibling dynamic where she required a lot more support and attention from our parents. And so, I was kind of like, well, you know, I'm good on my own. I can kind of do all the things I need to do on my own and that's OK. - 006

I think on the other hand, it did...I'm sure you're aware it's like the idea of like the 'glass child complex' ... the idea of like a sibling with, or a person who has a sibling with a disability is sometimes looked through, like their needs are not met because the other

sibling has so much more need. And I definitely relate to that experience...my brother would receive care and attention much more quickly. And so, I definitely learned to take care of myself a lot more and umm, not really accept care or help from other people. -003

Skills gained from sibling

Skills gained from sibling is a sub-theme that was created as a place to hold all the abilities the participants shared; they feel have been influenced by their sibling. These include; ability to be flexible and adapt easily to change in the moment, gained sense of comfort around different disabilities, patience, as well as the ability to critique perspectives in society such as one size fits all accommodations.

Values influenced by sibling

This sub-theme refers to the perspectives and values the participants feel they have gained from their sibling. Gained awareness for difference in general emerged across all participant stories and was evidenced through many different experiences, once again illustrating how despite these themes that seem to generalize experience, each story was unique. Some examples of this are; the desire to normalize difference, desire to celebrate difference, embracing difference, and a gained sense of normalcy around all different types of behaviours. A notable value shared by a participant in speaking to how their sibling helped them view disability as 'normal' was a personal story of coming to terms with their own disabilities as an adult, sharing that their experience with their sibling, and being around people other people with different disabilities, made them less "scared" of disability, and easier to accept their own.

... I already don't think disability is scary... And then when I acquired vision loss, it was the same thing, like it was more like a gentle cushion into a disability identity because it was already something that I was like, familiar with and comfortable with and I didn't see

it as scary or bad. So, I think that was another positive impact of having a sibling with a disability. -003

Positively impacted by experience

This sub-theme holds many of the findings mentioned previously and through the code map, the relationship between them is apparent. Other findings that siblings reported as a positive influence of their sibling were the impacts their sibling had on their career choice, shared by five out of six participants. Also shared was the impact siblings had on participant involvement in their community and volunteer work. All participants attributed their experience with their sibling as a positive impact on them.

I work in accessibility now. I've spent my whole career working as an accessibility professional and I credit a lot of that to growing up with a sibling with a disability and that really like started my... I guess my interest in accessibility, but also just it shaped the way I think about disability... I think it has made me a really caring person to the people around me and really like community focused, I really want to make sure that everybody is like included and able to participate and feel like...like celebrated for who they are... I do feel like the caring-ness like benefits me a lot. Again, it's part of what I do in my work like it really ...it motivates my professional career. -003

And special education is something that's really close to my heart, I've always been really passionate about it, I've done lots of research and advocacy projects. I've helped set up programs at my brother's previous private schools... He has autism...so support all the kids with autism, but also just generally neurodivergent kids and groups that help them to

connect. So, I've done volunteering with the hockey team, which is an all abilities hockey team that he plays for ... and other programs I've helped with...- 004

Worries

Some worries were noted in speaking about relationships to siblings and ways it has impacted participants. Two out of six participants directly mentioned the possibility of their sibling needing to live with them as an adult, or worries about their living situation as an adult.

I think something that I've considered for my brother is when my parents aren't able to support him anymore, like what kind of support is he going to receive when he becomes an adult too? So that's still something I'm looking at is... I can't afford a house on my own, but I also need to make sure that he has a place to live too, and I've long since thought if I could afford a house, I would get something at the basement suite so I could support him. I don't know if he'll be able to hold a job or even if he gets a job, you know, I don't know if it will be enough to live off of, so that's always been something in my mind. -004

Worries about their sibling being able to communicate when something is wrong was expressed by three participants. Worrying about bullying was shared by three participants.

I was super passionate about inclusion from a really young age and making my brother feel like he belonged. I saw first-hand in elementary school kids that would bully him and that was really hard for me... I felt like I couldn't do anything and everything I tried... It didn't really work and I even saw, like, my parents working really hard, going above to superintendents and I think that's really shaped my opinion of it. -004

...especially cause he's non vocal, so I always had to worry of, like, if somebody was being really mean to him at school... He can't exactly tell us that ... we always had that issue...I was more worried about school exactly cause like I'm from a small town where people were not the best... On the best of days, so it was like. when he went to high school, I worried and I watched out and ... we were lucky that everybody ended up loving him. He's very he's a very lovable little boy. So, he never had issues. But that was like the main issue was like worrying that there'd be issues or people just not getting it rather than having an issue with it. -001

Relationships

This theme comprises stories that are not exclusive to the participants' relationships with their siblings, rather than stories shared around relational aspects of their perspectives and experiences.

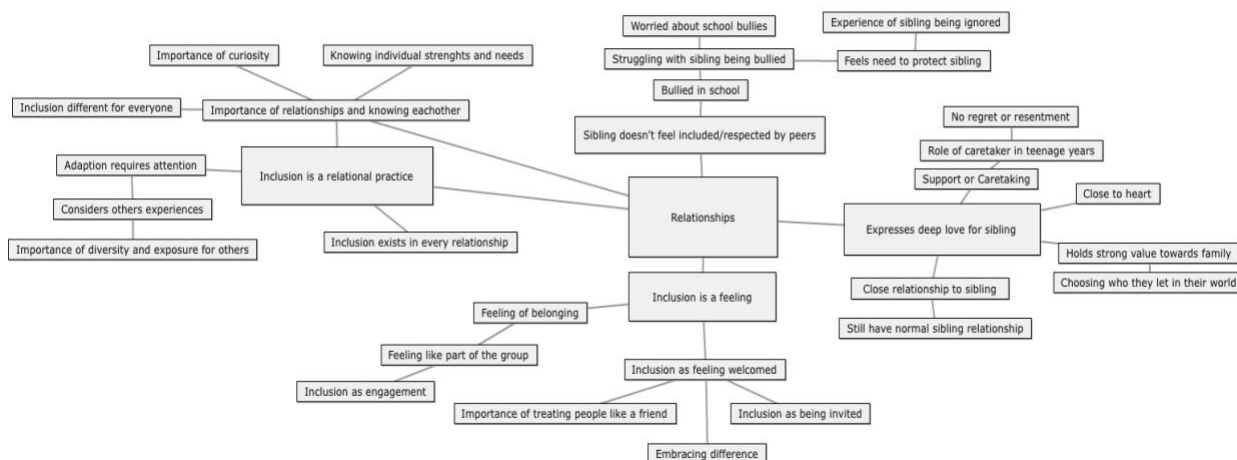


Figure 6. Code map for Relationships displaying relationships to sub-themes and specific codes.

Sibling doesn't feel included/accepted by peers

A feeling that their sibling didn't feel included or respected by peer relationships was shared by two participants, as well shared concerns about bullying. Three participants shared that in terms of relationships with others, bullying, acceptance and lack of inclusion were worries they held for their sibling. Another participant (005) shared that her family are cautious about who they "let into" their world.

...having other people understand the one how to interact with him with him being nonverbal, people tend to assume he either doesn't understand or you know, like they kind of shy away from interacting with him to begin with, and they tend to talk to just me. And they go well, "Can you tell your brother this?" And I'm like he can hear you like he's right here. Like, talk to him. He can hear you...So it's kind of starts with educating them on how to interact and have a conversation with my brother. Then once that's good... It's kind of having open communication with others and whoever, you know, we choose to let into our world. -005

...lots of people don't really take my brother as seriously because he has autism and he often presents younger than his age. He was severely bullied in school. And so yeah, a lot of kids, they kind of dismiss his ideas or they'll ignore him when he's talking to them. And even if they let him tag along and play, he doesn't feel really included and he doesn't feel respected as another peer. So that's definitely something like by connection of a personal experience that impacts my definition of inclusion. -004

Inclusion is a feeling

Feelings of being included, celebrated and welcome were mentioned across definitions of inclusion from four participants, with one participant exclusively naming her definition of inclusion as a feeling.

I really do resonate with the piece about it being like a feeling is that you can't tell someone "yes, you're being included." Like they either feel like they're included or they don't. And part of that is like, do they feel like it's a safe space? Do they feel like they are free to be themselves in a way that like resonates to them? So, it's like, yeah, it's more like on them. Do they feel like they're being included? -006

This definition really stood out to me and for it, I created the code "inclusion is a feeling". Through my second round of coding, I found that others definitions of inclusion also resonated with this sentiment, finding that it was applied across four different participant stories, by both my secondary coder and myself. Other participant definitions of inclusion related to it being a feeling such as inclusion is; feeling like part of the group, feeling welcome, feeling of belonging, being invited/feeling like other people want you there.

Inclusion is a relational practice

Related to the previous sub theme is the shared belief that inclusion is a relational practice. Under this sub theme, participant stories spoke to the importance of relationship in inclusion through sentiments such as; sharing the importance of knowing each other, including strengths and needs and how adaptation requires attention. The importance of curiosity was mentioned by one participant who shared that she wants people to know it's okay for people to ask her questions about her sibling; that curiosity is essential to getting to know one another and our

needs. One participant shared their perspective on inclusion and how they view all their relationships as holding different needs and that disability is no different, which felt impactful under the sentiment of relational practice.

You know, like they have different things you need to accommodate but in both scenarios like you get to know that person and you're like oh, you know like [sibling name] loves buses and probably will be stuck at the bus stop for like an hour before he will be willing to move anywhere and he will have a tantrum if you try and move him within that hour and someone else will die if you bring peanuts into the room like those are both things that like an inclusive framework for that person will accommodate. They're different, but it's like nobody is like with or without things you have to be mindful of when you're including them in something. It's just like it's different from person to person and like the consequences may be different. But like in any like relationship with another person you need to be taking steps to include them and their uniqueness. And I think that that's kind of like a beautiful thing to be able to honor, you know, is like that... Yeah, the relationship is at like the center of it. Inclusion is, I mean at its core, the creativity and knowledge of that person... it exists in every single relationship. And then like that kind of network of inclusion would look different depending on who you bring into that space that you're including people. -002

Expresses deep love for sibling

The last sub theme under Relationships is related to how participants spoke about their relationship with their sibling. All participants explained their relationship with their sibling as close, with three stories speaking to a close family dynamic and strong values towards family.

Very positively... like my brother is a very calm... He's kind like he's super happy all the time... I say he's the light of my life because he is. I love him more than anything in my life and he just made everything just a little bit more fun...like I said before, like my mom never put him over me or put me over him like we were all just kind of equal level playing field. Yeah, he was just a ball of energy and light. He's, he's been great to grow up with. -001

... my family is always coming first, not just my brother, my sister and my dad. Like, that's my mindset, where it's like family is everything. We were so close growing up so like they have my back, I have theirs always. And everything else comes second. – 005

Discussion

Throughout the analysis and reporting processes, within the themes and sub-themes that emerged, all stories speak to both the unique parts of their sibling experiences, as well as their interconnected commonalities. As discussed in the literature review, siblings are our first peer relationships, play partners and source of social development (Tsao., 2019). Over a 2-year period I extensively reviewed literature dating back to the 1950s, looking at early findings of social influences that siblings have on one another. This search included Bowen's family systems theory (1950s) and Bandura's social learning theory (1977). As early as 1987, research started reporting that siblings of people with disabilities developed positive views of disability and skills such as adaption, i.e., changing their activities to accommodate and include their siblings in play, openness, compassion, empathy and other pro-social skills (Stoneman et al., 1987; Findler and Vardi, 2009; Graff et al., 2012; Sharpe and Rossiter, 2002; Sommantico et al., 2020). Yet, despite increasing research focussed on this population in the four decades since, offering these siblings the space to share their stories, and likely, many other valuable teachings, through qualitative work, has not been prioritized in research. As mentioned in the literature review, this can likely be attributed to that fact that most research focused on this population is in psychology and intervention-based fields. As a result of observing this pattern in research, along with my value in giving platform to minority experiences and commitment to decolonizing my practice, it was important to me to create an opportunity for humans to holistically share their experience and knowledge, through whichever stories they feel are important to them. Four Arrows (2024) speaks to how psychology has "lost sight of the mystery and paradox inherit in human life" speaking to how psychology and related research follows the colonial agenda of de-humanizing people by deducing their experiences to numbers and contributing to power dynamics that rank

humans over other humans, and allows stories of people's lives to be told through whichever agenda the researcher wants to manipulate it.

This study was diligent in addressing researcher bias and did not ask questions that would prompt or guide participants to speak about their experiences in a positive way. Rather, this thesis asked open-ended questions specifically on the participant's views, their perspectives of their sibling's impact and simply what they would like us to know. The aim of this study was to make space for participants to answer in ways that allowed for their human voices to come through, to prompt reflections on their experience and not confine it to rating scales or surveys that remove their voice and opportunity to expand on their story. For example, if this study was quantitative and asked participants through a questionnaire if they felt they had a "glass-child" experience, at least the three participants who reported so would answer yes, possibly more when prompted. This would continue past narratives of the experience in research, as it is asking a question about something that is interpreted as a negative experience in this sibling dynamic, without room for a fuller story to emerge. This study did not ask about the "glass-child" experience in particular, these experiences organically emerged when asked how participants feel their experience impacted them. Although it is important to report this experience, it is equally important to share the expansion on their story and note that participants shared a gained sense of independence due to this experience. Participants additionally said they did not feel resentment or negative feelings towards their sibling because of it. There is an importance and a humanization that siblings brought to this study through being open about their feelings that cannot be evidenced in quantitative work.

Over-arching themes on the importance of relationships, normalizing disability and the desire to educate others were woven throughout all stories and emerging themes. Although

participants shared that they have developed beliefs and have been impacted by their sibling's disability, a normalcy in being siblings is shared across participants that is important to highlight. In regards to what they want us to know, four out of six participants reported that it was important to them that other people know they still have a normal sibling relationship. Additionally, stories shared that participants did not notice their sibling's disability as a young child, rather it was society's reactions that brought notice to them being "different". These are stories that can invite research to look further at ableism as a systemic/societal issue and is a theme worth investigating further through a social/relational lens.

A relational approach to inclusion is a strong theme in these stories and it is essential to emphasize that most emerged themes are woven into the importance of getting to know and build relationships with one another. The emergent values of assuming competence over incompetence and unlearning harmful views around disability demonstrate participants understanding of the role that education plays in others' responses and actions. The relationship that families hold to one another, and the level of noticing and knowing that it holds, is demonstrative of how important it is for educators to listen to them and work with them.

Past research has established that as the first, and likely most enduring peer relationship in one's life, siblings influence one another through early years in play, development of social skills and other unique experiences (Noller, 2005; Bachraz & Grace, 2009; Tsao, 2019; Wright et al., 2022). Past research aims to categorize the sibling experience into measurable outcomes regarding skills, impacts and deficits, then compare these categories to the experiences of other populations. The current study demonstrates how the stories behind the labelling of experiences, are the true teachers of what it means to think about the ways our relationships impact us, our views and our values. With unique experiences in advocacy and teaching others, it can be

concluded that these siblings all have unique experiences that should be brought forward and valued in how we are planning our spaces, our classrooms and navigating our lives in society. There is a human-ness to these stories, that speak to how disability is no different than any other need. Through storytelling, it is brought into perspective how everyone has differences that need to be accommodated, in any relationship. The stigmatization of disability in society as bad and scary highlights how our narratives have contributed not only to ableism, but to alienation of disabled people. Participants in this study challenged and critiqued these experiences, sharing their desire to advocate for and teach others.

Through their stories, participants emphasized the importance of educating children about disability at an early age. By acknowledging that adaptation and inclusion were skills that were organically part of their early development, they noted that these skills were a natural part of their sibling dynamic and didn't notice it as "different" until other social environments taught them so. All participants asserted that education plays a vital role in building communities that include and celebrate people with disabilities. The sentiment that our schools are not doing enough towards achieving inclusive environments was common among participant responses. Lack of funding, teacher education, student education, and inclusive policy were all concerns shared amongst participants. Stories such as participant 004, who had the opportunity to advocate in conversation with the Minister of Education, brings to light how these systemic cycles are reinforced, sharing that their attitudes were focused more on the "general population" of children. This particular story highlights how ableism can exist at any level of leadership and is relative to previous literature that ableism is present at all levels of the educational system (Castaneda & Peters, 2000; Hehir, 2002; Hehir, 2007; Storey, 2007; Foley et al., (2012). Participant suggestions to address systemic change in our schools were; legislated curriculum on

disability for students as early as elementary school, that the Ministry of Education considers minority populations in decision making and that voices of families and self-advocates are valued. Due to the stories shared in this study, further research looking at all systems of the education system, and how people with disabilities are heard within them, is recommended.

Summary of Responses to Research Questions

This research project aimed to address the following questions: (a) *How can growing up with a disabled sibling influence one's view of inclusive spaces?* (b) *What insights can be gained from siblings to inform educational practices?* Through the analysis and coding process, many insights and perspectives emerged that can be viewed as valuable to inform educational practice, educate others views on disabilities and further understand the experience of someone who grew up with a sibling with a disability.

The first question, *How can growing up with a disabled sibling influence one's view of inclusive spaces?* can be addressed through the ways participants shared their passion for inclusion, their motivation to educate others and make change, and opinions on inclusive spaces. One of the ongoing emerging themes was how important relationships and knowing the person you are accommodating is, in order to facilitate spaces that will feel inclusive to them. Another consistent finding was the general awareness for different needs participants shared, impacting their career choices, the way they see themselves as advocates and the way they understand the ways environments can create barriers. What is shown through these stories is that the sibling experience is unique as it offers insight to the many aspects of their sibling's life such as, school, work, social, housing and family dynamics. These stories offered insights of what it means to participants to include their sibling in their schools, in their communities and in their own lives as they become adults. Examples are demonstrated in the perspectives shared around awareness

for planning processes, in consulting with people with disabilities to ensure environments are appropriate for their strengths and needs, and in the continued message that what's inclusive for someone, may not be for everyone- emphasizing the importance of relationship and educating others. Through the ongoing attribution to their siblings as teachers to them, participants shared that this unique sibling dynamic can shape the ways one sees environments, responds to societal structures and behaviours and motivates them to advocate for change. Due to their experience with their siblings and witnessing their relationships with different systems and environments, siblings in this study have shared that their experience with their sibling has impacted many aspects of their own lives, views and have helped them offer a unique perspective of difference in general.

The second research question, *What insights can be gained from siblings to inform educational practices?* can be considered through participant stories and themes that emerged across responses. Specifically, in regards to education, the most common and emphasized insights shared were the importance of discernment in environment and the need for change at a systemic level. Due to the involvement some participants shared in having in their siblings' educational journey, as well as through witnessing their sibling's experience, insights shared highlighted the lack of funding, teacher and student education and support in schools. Due to the unique relationship of being a sibling, experiences shared ranged from observing their sibling and the ways they were treated in schools, to being influenced by their sibling to taking on leadership roles in advocacy and addressing their concerns at a systemic level. Participants across this study consistently expressed the desire to advocate for their siblings, and people with disabilities in general, and their desire to teach others. Responses addressed educational practices across all interviews, not exclusively in response to questions about schools, rather across

definitions of inclusion, accessibility, ways participants believe their sibling and experience have impacted them, and what they would like people to know. Insights shared through participant stories and experiences are unique as they come from a perspective that acknowledges both how the shortcomings of school systems affect practice, as well as how they affect the individuals with disabilities. Each story shares a different perspective from policy, to environment, to legislated curriculum and teacher education from elementary through to post-secondary support. This study demonstrates the vast and valuable insights siblings can bring to inform educational practices, and should be valued, recognized as expertise and continued to be explored in educational research.

Limitations

The limitations of this study include a small sample size, the broad scope of questions in the research guide and time restrictions. Due to this project being a Master's thesis, lack of funding and time were factors that contributed to the ability to expand on the population size of participants and recruitment. Because there are six participants in this study, conclusions about their experiences cannot be made or shared as generalized findings to directly inform practice. The purpose of this study was to allow the space for different experiences to come through. Although it is positive that participants had the openness to share their stories and weren't restricted to questionnaires or other potentially limiting methods, the diversity and broad range of knowledge revealed makes it difficult to focus on and engage with each theme in the depth that it warrants. With the many themes and sub-themes that emerged from open-ended questions, this study opens up future pathways in research to further explore specific sub-themes that revealed rich and expansive knowledge. Lastly, it is important to mention that the siblings of the participants experienced different types of disability, which contribute to the challenge in making generalized statements.

Implications

Through the extensive analysis process of this study, I have discussed six themes that are each rich in stories, experiences and information. Findings from this study can make implications to inform both educational practice and policy, as well as recommendations for future research. It is important to note that in order to implement any of the following recommendations, researchers, educational institutions and educators must work toward addressing and understanding ableist perspectives in society and within our school systems.

Recommendations for Research

With this study, I have developed the framework to approach this experience through a relational/political lens in research. This framework approaches storytelling through a lens that does not seek to come to a conclusion about others experience, gives space for individual voice to be heard and understands systemic and political structures that reinforce ableism. These understandings, paired with narrative and qualitative methods, allows participants to have control over their own narratives, using their own experiences to critique the structures and views in society that impact our systems, classrooms and relationships to one another.

This study revealed 6 themes and 28 sub-themes that can be further explored in more focused studies. Each theme and sub-theme revealed knowledge that when possibly explored as a more concentrated study, could explore further into the specifics and implications for that theme. For example, stories under the theme of Education ranged from speaking about educating the broader community, to teacher education, to school funding, to curriculum. The depth and richness that was explored through each theme in just one-hour interviews with only six participants, demonstrates the vast knowledge that this population holds and how much

educators, policy makers and researchers can learn from siblings. It is recommended that future researchers offer a place to hear stories under more focused topics, to dig deeper into the implications and changes that can be informed by siblings. This study offers this framework and these themes as a starting point for that work.

Lastly, all participants reported having never been asked about their experience or about themselves, in regards to their experience with their sibling. One participant who works in education reported having never seen research focused on siblings like her in the field and felt it was important when she heard of the opportunity to do so. Another participant became emotional, expressing she has never been asked about herself. All participants acknowledged that they hold valuable knowledge and perspective that others without this experience or relationship to disability, don't have. Participants reported a desire to share their stories, to advocate, to educate others and held the shared belief that others can benefit from these teachings. The historical gap in research on sharing sibling voices, along with these findings that confirm they do in fact want the opportunity to do so, implicates that research needs to continue to centre and value these perspectives.

Recommendations for Educational Practice

Findings that highlight the importance of family knowledge and expertise on their children, implicates that educators and schools should consult and include family members in all planning and decision-making processes for children with disabilities in schools. Building relationships, knowing your students and working as a team with families are all recommendations participants had for teachers in the field. Participant stories in this study stress this recommendation is not only to help include children in the classroom, but to limit harm done to children due to systems that make decisions for them. In order to ensure that decisions and

planning for students are appropriate for their ability level, don't assume level of competence and are centered to the child's best interest, educators should include and consult family members as the experts on their child, or sibling. It is also recommended that educators use discernment, and re-evaluate their own ideas around inclusion and concepts of physically including students in the same room vs. the feeling of inclusion. This study revealed numerous stories of harm caused by educators due to lack of family involvement and consultation, assumptions made about ability level and ableist beliefs and attitudes of teachers. In order to reduce harm caused to children with disabilities, looking toward the student with the disability, and their families as experts on their abilities and needs, as well as thinking critically about the systems educators work within, is recommended to teachers. This study offered knowledge that is beyond what teachers learn in their education, and can even contradict what Universities and textbooks say is best for children. It is recommended that teachers approach their classrooms humbly and question the systems that they work within. We will never have the answer for inclusion in our classrooms, because it is different for everyone. Until we ask children what they feel they need to belong, are willing to learn from their families and examine our own ableist perspectives and assumptions about disability, we cannot begin to imagine the future of true inclusion.

Recommendations for Educational Policy

Several recommendations to educational policy came through participant stories. The recommendation for exposure to disabilities, in order to de-alienate those with disabilities and normalize difference from an early age, was recommended through legislated curriculum, as well as bringing in self-advocates into classrooms. Mandated education on different types of disabilities and on ableism, as a form of discrimination, starting as early as pre-school was

recommended by participants, and follows literature that addressing how schools can reinforce ableist perspectives. Intervening with education to others and normalizing difference, for both teachers and students, can help address ableist perspectives and attitudes in schools. Recognizing and removing barriers in schools is another recommendation in policy, as it speaks not only to physical barriers in the environment, but in policy due to lack of funding around technology and other barriers that limit the participation and ability for children with disabilities to feel included. Increased funding towards inclusive education, not only to support children with disabilities and equipment needed, but also towards the salary of special educators, can address barriers in education as well. Participants frequently reported the lack of stability, support and funding for special education staff in schools, impacting their sibling's ability to thrive, as well as family ability to build relationships with staff, due to frequent position turnover. Policy must address barriers on every level, including staff, environment, funding, professional and student education and representation in schools, to begin to address the other recommendations offered. If children cannot access the school, learning programs, or have access to technology to communicate or do their work, then we cannot implement the other recommendations made. If staff turnover isn't addressed through proper compensation, professional development and support, then families cannot build relationships with them and begin to work as a team. If teachers are not undergoing on-going professional development, informed by disabled self-advocates, then they cannot begin to look within their own ableist attitudes and begin to break the cycle of reinforcing those attitudes on their students. We need changes in policy, to begin to ensure education on disability is coming from a non-ableist source, to provide funding that removes barriers for students and educators and to mandate curriculum to de-alienate and humanize disability as a natural part of life, in order to begin to move in the direction of addressing other movements towards an

inclusive classroom, or society. This is where disability is political and relational. This study highlights many implications for teachers and classrooms, but it also highlights the barriers in policy, curriculum and funding that prevent us from putting them to action. There is a web that needs to be untangled, and it starts with understanding it needs to be addressed on every level.

Conclusion

Despite being established as one of our most foundational and most enduring relationships (Noller, 2005; Bachraz & Grace, 2009; Tsao, 2019; Wright et al., 2022), siblings continue to be examined predominantly through quantitative research methods. This is in spite of decades of calls to explore qualitative studies that bring their voices beyond numbers to their experiences. Sibling dynamics in which one sibling has a disability continues to be explored through psychology and intervention-based research that seeks to identify defects in experiences, to create intervention and supports for siblings.

The current study aimed to fill the gap between numbers and voices and respond to the ableist perspectives identified in research (Meyers & Vipond, 2005; De Caroli & Sagone, 2013; Connell et al., 2016; Sommantico et al., 2020). It also sought to answer the calls from self-advocates who have been asking for qualitative work that centers the voices of siblings providing an opportunity to tell their stories the way they'd like to (Connell et al., 2016). Through semi-structured interviews, this study asked open-ended questions of people who have a sibling with a disability and; provided an opportunity to respond to questions on their views, perspectives and experience through stories they believed were important to them. Six themes emerged from the analyses: (1) Advocacy, (2) Barriers, (3) Beliefs, (4) Education, (5) Perspectives, and (6) Relationships. The findings demonstrate both the unique experiences of individuals and their stories, as well as shared values, messages and teachings that need to be explored. It is evident from this study that siblings hold vast knowledge of their experience and that they have a desire to share, teach and advocate. This should serve as part of a shift in the way we study the experience of disability and particularly, through the lens in which we view sibling experiences.

There is a lesson in this study that holds heavily the un-learning of institutional knowledge and brings forward relational knowledge. Following the framework of the relational/political model, this study organically emphasized how important relational expertise is in regards to making change. When I say I do not wish to be a researcher, I mean that I do not wish to extract data to make reports and decisions about others' lives. I wish there was a way for me to have told these stories that did not need a university seal of approval as "research data" for institutions and educators to recognize them as real knowledge that can inform practice. These sibling stories of being disregarded by leaders in education, then opening up in this study on the expansive, important perspectives and teachings they hold, must be a call to examine what constitutes who can teach and what is needed for us to value knowledge. There are knowledge keepers in all of our communities that have learned powerful skills and teachings through their relationships and experiences, some of which cannot, or do not wish to, partake in the academic system. There are stories here of siblings, and their family members, advocating in schools and communities for people with disabilities in ways that can promote celebration, acceptance and belonging, as well as to prevent harm. This is a call to educators and schools to consider all parts of knowledge and information when approaching practice, to carefully observe where it is coming from, who is sharing it, and whose voices are missing.

These stories tell us that siblings have a unique and valuable perspective on disability and inclusive practices. They tell us how important it is to build relationships, to view people as whole and that disability is no different than any other difference. They tell stories of how important it is to learn about one another, to not make assumptions or judgements, and to listen. They tell us how important it is to educate one another and value how each unique life brings

unique lessons to be learned. They tell us that disability isn't a deficit that makes life harder for people, rather that can be disability a beautiful teacher, and so can siblings.

This study concludes with an invitation to continue this work, not just in research, but in the way we value and uphold the voices of humans who have personal experience with disability in our communities. There are many more stories to be told and I hope this work can provide a starting point to continue to tell them.

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Appendices

Appendix A

Recruitment flyer

Project Title, Purpose, and Objective: You are invited to participate in a project entitled “Experiences of Disability across Learners, Families and Community”, that explores disability and inclusion, especially in siblings and peers. The objective of this project is to learn the experiences of those who grew up with a sibling who has a disability. What we learn can be used to inform the development of inclusive and accessible practices for students. This project is being conducted by student researcher, Julia Speirs, under the lab of Principal Investigator, Dr. Rose Vukovic, Professor, University of Victoria Educational Psychology & Leadership Studies. Several graduate students may also be involved in this research as part of the requirements for a degree in Educational Psychology & Leadership Studies. You may contact Professor Vukovic, Principal Investigator (PI) at 250-721-7760 or rvukovic@uvic.ca.

Importance of Research. The perspectives of individuals with disabilities are rarely centered in education research. Listening to the lived experiences of students with disabilities and their families is crucial for informing research and practice relating to inclusive education.

Participants Selection. You are being asked to participate in this project because you are a sibling of someone who has a disability. Your participation in this project is entirely voluntary.

What is Involved. If you consent to take part in this project, your participation will include:

- **Procedures:** Individual interviews
- **Methods:** Audio tapes and hand-written notes will be taken. A transcription will be made of the audio recordings.
- **Duration:** 45 minutes – 1 hour
- **Location:** University of Victoria campus or Zoom call or other private space.

Inconvenience. Participation in this project may cause some inconveniences to you including the time devoted to completing the interview.

Risks. There are some potential risks to you by participating in this project and they include discomfort, embarrassment, and/or stress when answering questions or sharing your experiences. To minimize these risks the following steps have been taken

- Interview protocols and interview questions have been reviewed by an advisory board.
- Support resources that are available on campus and/or locally will be provided to you.
- You may choose not to answer any question(s) during the interview.
- You may choose to end the interview at any point.

Benefits. There are no direct benefits to participating in this project. What we learn from you can be used to inform policy, practice and advocacy in inclusive education.

Compensation. As a way to compensate you for any inconvenience related to your participation, you will be given a gift card with the value of \$20.

Voluntary Participation. Your participation in this project must be completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation, including after you sign this consent form. You have the right to skip questions you'd prefer not to answer. Refusing to participate will not affect your education in any way. If you do withdraw from the study:

- You can decide whether to include or exclude your data from the analyses.
- You will still receive compensation listed above as an appreciation for any time given.

Anonymity. To protect your anonymity, your name will be changed within data analysis and any report of the results. This unique identifier will be linked to your name in a separate file should you wish to be contacted for follow-up interviews. Only the principal investigator (PI) will have access to the file that links participant names with unique identifiers. Your identifying details (name, job, appearance, etc.) will not be stated in any literature.

Confidentiality. Your confidentiality and the confidentiality of the data will be secured on a password-protected computer accessible only by The University of Victoria's secure storage network.

Future Use of Data. Once your participation in this study is complete, your secured and de-identified data will be stored by the PI. If you consent, we may use your anonymized data for future projects that address the same research purpose. If you are interested in participating in follow-up interviews or related projects, you may provide your consent below for the research team to contact you.

Dissemination of Results. The results of this study may be shared with others in the following ways: theses, dissertations, articles, chapters, books, presentations at scholarly meetings, policy documents directed towards service providers or others involved in the education of students with disabilities, etc.

Disposal of Data. Any paper files will be shredded and destroyed after data analysis and entry. Archived data will remain encrypted on a password-protected computer accessed by the PI as described above.

Questions or Concerns. If you have any questions or concerns at any point before, during or after your participation, you may contact:

- Professor Rose Vukovic by phone at 250-721-7760 or by Email at rvukovic@uvic.ca
- You may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office, University of Victoria, (250) 472-4545 ethics@uvic.ca

Consent. Your signature below indicates that you are ~~18~~ 19 or above, you understand the above conditions of participation in this study, that you have had the opportunity to have your questions answered by the researchers, and that you consent to participate in this research project.

Name of Participant *Signature* *Date*

Future Use of Data

I consent/do not consent (circle one) to the use of my data in future research: _____
(Participant to provide initials)

I consent/do not consent (circle one) to be contacted in the event my data is requested for future research: _____ (Participant to provide initials) If you consent, please provide a contact email _____

A copy of this consent will be left with you, and a copy will be taken by the researcher.

Appendix B

Interview guide

Guiding research question

What impacts people's experiences in inclusive spaces?

What can we learn from siblings and families to inform educational experiences?

a. Consent reminder

Review the consent form, remind participants of the option to withdraw and ask for clarity on any questions/parts of the consent form. Go over reminder and consent for audio recording. Give space to ask questions.

b. Intro

Thank you for speaking with me today ...

Introduce myself, how I identify and my plans for this project

Offer time for participation introduction, space to identify

c. Questions

1. What drew you to participating in this study?
2. What does it look like when someone is being included?
 - a. In your experience, what does inclusion look like in practice?
 - b. What would you say your personal definition of inclusion is?
3. When you think of accessibility, what comes to mind?
 - a. How would you define accessibility?
 - b. What does this look like to you in practice?
 - c. Any examples?
4. Where do you believe these definitions and/or beliefs came from?
 - a. From home/family? From school? From experience as an adult (workplace, etc.)

5. How did growing up with a sibling with a disability impact you?
 - a. Are there experiences or things you feel continue to impact you as an adult?
 - b. Can you think of an example?

6. Drawing on your experience with your sibling, what do you feel needs to be done to better support inclusive and accessible environments?
 - a. What are we doing right?

7. Is there anything you would like people to know or say that I haven't asked you?

Check in/wrap up

Ask participants one last time if they wanted to add anything. Review answers with participants and ensure they feel their thoughts are clear and true to their experience. Check in on how they are feeling emotionally and remind them of access to any support. Thank participants for their time.

d. Demographics

1. Age
 - a. _____
 - b. Prefer not to answer

2. What is your gender identity?
 - a. _____
 - b. Prefer not to answer

3. Race
 - a. _____
 - b. Prefer not to answer

4. Ethnicity
 - a. _____
 - b. Prefer not to answer

5. Indigenous status
 - a.
 - b. Prefer not to answer
6. Nationality
 - a.
 - b. Prefer not to answer
7. What is the highest level of education you have completed?
 - a. Elementary school
 - b. High school
 - c. Undergraduate degree
 - d. Trade or College degree
 - e. Master's degree
 - f. Prefer not to answer

Available resources

- On campus
 - SSD
 - CAL
 - STEPS Forward
- Community
 - Victoria Disability Resource Center
 - Pathways Victoria

Appendix C

Consent form



**University
of Victoria**

Project Title, Purpose, and Objective: You are invited to participate in a research study that explores social development around disability and inclusion, especially in siblings and peers. This information may be used to inform the development of inclusive and accessible practices for students with disabilities across educational contexts, as well as to advocate for the positive outcomes of inclusivity and diversity in childhood settings. This study is being conducted by Professor Rose Vukovic, Professor, University of Victoria Educational Psychology & Leadership Studies. Several graduate students will also be involved in this research as part of the requirements for a degree in Educational Psychology & Leadership Studies. You may contact Professor Vukovic, Principal Investigator (PI) at 250-721-7760 or rvukovic@uvic.ca.

Purpose and Objectives of the Research: This study will look at experiences of those who grew up with a sibling who has a disability and their views of inclusion and accessibility as an adult. This research aims to advocate for inclusive and accessible learning experiences for all children.

This Research is Important because: Perspectives of individuals with disabilities are not often included in educational research. Only in recent years have the voices of students with disabilities begun to be listened to in the context of educational research. Historically, research has been done *on* individuals with disabilities rather than research being done in collaboration with disability communities. This research is important as it aims to understand the social experience of inclusive spaces for people of all abilities and provide important insight that can be used to inform practice and contribute a new perspective to existing literature.

Participants Selection You are being asked to participate in this study because participants informing our research belong to an underrepresented population in research. Participation in this project is entirely voluntary.

What is Involved

If you consent to voluntarily participate in this research, your participation will include:

- ● **Procedures:** One on one interview
- ● **Methods:** We will audio record interviews. Audio-tapes and written notes will be taken. A transcription will be made. If interview is done over zoom, only audio files will be recorded.
- ● **Duration:** 45 minutes – 1 hour
- ● **Location:** University of Victoria campus, remote

Inconvenience: Participation may cause some inconveniences to you including the time devoted to interviews.

Risks: There are some potential risks to you by participating in this research and they include discomfort, embarrassment, and/or stress when sharing your experiences. To prevent or to deal with these risks the following steps will be taken:

- • Research protocols and interview questions will be reviewed by an advisory board.
- • Support resources that are available on campus and/or locally will be provided to participants.

Benefits: Potential benefits of this research include informing practice in inclusive education. What we learn from you can be used to create safe and accessible learning spaces for individuals with disabilities, and provide educators and other support systems (e.g., families, peers) with perspective to navigate accessible spaces. This study also aims to provide information that can be used to advocate for the benefits of inclusive classrooms and environments for all.

Compensation: As a way to compensate you for any inconvenience related to your participation, you will be given a gift card for the value of \$20.

Voluntary Participation: Your participation in this research must be completely voluntary. If you do decide to participate, you may withdraw at any time without any consequences or any explanation, including after you sign this consent form. You have the right to skip questions you'd prefer to not answer. If you do withdraw from the study:

Participant Consent Form

- • You will be asked if you want your data to be included or excluded from the analysis. If included, it will be used in summarized form with no identifying information.
- • You will still receive compensation listed above as an appreciation for any time given.

Anonymity: In terms of protecting your anonymity, your name will be changed within data analysis and any report of the results. This unique identifier will be linked to your name in a separate file should you wish to be contacted for follow up interviews. Only the principal investigator (PI) will have access to the file that links participant names with unique identifiers. Your identifying details (name, job, etc.) will not be stated in any literature.

Confidentiality: Your confidentiality and the confidentiality of the data will be protected by password protected computer accessible only by The University of Victoria's secure storage network.

On-going Consent: To make sure that you continue to consent to participate in this research, you will be asked for your permission to participate if we conduct follow-up interviews. Once your participation is complete, your secured and de-identified data will be kept for future projects that address the same research purpose. Only the PI and/or research assistants have access to this data. If you agree below, you consent to your anonymized data potentially being used for future projects.

Dissemination of Result: It is anticipated that the results of this study may be shared with others in the following ways: thesis, dissertations, articles, chapters, books, presentations at scholarly meetings, policy documents directed towards service providers or others involved in the education of students with disabilities, etc.

Disposal of Data: Any paper files will be shredded and destroyed after data analysis and entry. Archived data kept will remain encrypted and in a locked folder accessed by the PI as described above.

Questions or Concerns: If you have any questions or concerns at any point before, during or after your participation, you may contact:

- • Professor Rose Vukovic by phone at 250-721-7760 or by Email at rvukovic@uvic.ca
- • You may verify the ethical approval of this study, or raise any concerns you might have, by contacting the Human Research Ethics Office, University of Victoria, (250) 472-4545 ethics@uvic.ca

Consent: Your signature below indicates that you understand the above conditions of participation in this study and that you have had the opportunity to have your questions answered by the researchers, and that you consent to participate in this research project.

Name of Participant Signature Date

Future Use of Data *PLEASE SELECT STATEMENT*

I consent to the use of my data in future research: _____ (Participant to provide initials)

I **do not** consent to the use of my data in future research: _____ (Participant to provide initials)

I consent to be contacted in the event my data is requested for future research: _____ (Participant to provide initials)

Results

I would like to be contacted to receive the results of this study _____ (Participant to provide initials)

A copy of this consent will be left with you, and a copy will be taken by the researcher.