A Sibling's Sense of Self


by


Danielle Russell


Submitted to OCAD University in partial fulfillment of

the requirements for the Master of Design in Inclusive Design


Toronto, Ontario, Canada, 2023

# ABSTRACT

**Background:** It is commonly viewed that siblings of those with disabilities are positioned as caregivers and tasked to support their sibling with a disability. Family members of those with disabilities are particularly viewed as impacted heavily by the burden of care placed on them. However, truth be told, there are many influential and positive attributes that are acquired by one's upbringing and living with a family member who has a disability. Typically overlooked by researchers in the field, there are dismissed perceptions of family members that should be accounted for. Further, individuals who have grown up alongside of members of their family with a disability have unique perceptions that influence their self-perceptions and ways of living. This study found that an individual with a sibling with a disability has experienced in childhood up to current time circumstantial practices relative to their family position which influence the way they currently carry and perceive themselves. Further indicated in this study is the importance of family relationships, dynamics and stability in support of the care to the sibling with a disability. Particular qualities and characteristics are highlighted in this study to showcase the intricate yet complex lives of individuals with siblings who have disabilities. Proven is the need for augmented initiatives and enhanced supports to address gaps and needs among individual family members who are related to someone with a disability.

**Specific Aim:** The objective of this study was to gain a deeper understanding of how individuals perceive themselves based on their experiences growing up with a family

member who identifies as having a disability. The aim was to investigate the perceived experiences of these individuals and their reflections on their personal identities and sense of perception.

**Method:** A total of 10 individuals over the age of 18 who have siblings with disabilities from across Ontario, Canada completed virtual or in-person interviews.

**Findings:** To reflect participants' upbringing, current experiences, and anticipated future roles within their families, themes naturally surfaced and were identified as means to represent consistent data responses. In general, the findings revealed a range of experiences that impact their sense of self and family responsibilities. Many unique and positive perceptions of self were conveyed by participants in reference to their lived experiences.

**Discussion:** This study fills gaps in disability studies by highlighting the positive outcomes of sibling relationships and the unique lived experiences of individuals who have siblings with disabilities. It emphasizes the importance of recognizing an individuals' experiences and stories relative to having a sibling with a disability.

## ACKNOWLEDGEMENTS

## DEDICATIONS

I dedicate this research to all the individuals out there who have siblings with disabilities. To the individuals who opened up to me and let me hear your experiences, stories and opinions, you have my endless love and support.

Lastly, to my brother Jean-Luc for teaching me that love always wins. If you love yourself and others around you then all will be good. Thank you for inspiring me to always make this world a better place.

# TABLE OF CONTENTS

**LIST OF FIGURES**

# 1. INTRODUCTION & DEFINITIONS

Siblings of those with disabilities play an important role in the lives of all their family members. At a young age, many siblings take on a primary caregiver role with inherited increasing responsibilities to support of their family as individuals age into adulthood (Avieli et al., 2019). Increasing attention needs to be paid to the significant roles that siblings have when supporting their familes (Sommantico et al., 2020), with a particular emphasis on understanding the impact of their unique experiences. Existing evidence suggest that in cases where families have a member with a disability impacts the siblings' perceptions and ultimately impact their future field of employment (Chambers, 2007). It is important to recognize that the experiences of siblings in families with disabilities can have significant influences on family members, including their personal understanding, sense of self and how they conduct themselves in other areas of their life.

The present research project seeks to make a significant contribution to the field of disability studies by specifically examining the perspectives of siblings in families with members who have disabilities. The study aims to address the lack of diversity in existing research, which often focuses solely on families raising a child with a disability and neglects the experiences of other family members with diverse backgrounds. Moreover, previous studies have primarily focused on the negative aspects of having a family member with a disability, while ignoring potential positive outcomes. Using interview data collected from individuals about their childhood experiences and current

perspectives, this study provides critical and longitudinal data that is often absent in disability-sibling research. By shifting the focus beyond just the child with the disability to include other family members, this research provides clarity on the lived experiences of other family members. Ultimately, this study contributes to a deeper understanding of the dynamics of relationships in families with members who have disabilities, emphasizing the importance of recognizing the unique lived experiences and perspectives of siblings and family members. The findings of this study offer a more positive perspective on families with members who have disabilities, which deviates from the traditional focus on negative aspects of disability studies.

The following terms are used throughout this MRP as a means to support readers. Please refer to the following definitions used consistently throughout this study.

**Disability** - for the purpose of this study, someone who may experience but are not limited to physical, intellectual, learning, psychiatric, hearing, visual and other personally experienced limitations.

**Non-Disabled -** Individual who does not identify as having a disability.

**Neurotypical** - Individuals with average neurological development and cognitive functions.

**Sibship** – Relationship between siblings.

## 2. RESEARCH PROBLEM

Siblings of individuals with disabilities often undertake a crucial role in providing care and support to their loved ones, which presents both challenges and opportunities for personal growth and development. Despite the significance of their contributions, research tends to overlook the unique perspectives these siblings have acquired from their life experiences. Siblings of those with disabilities have experienced a unique set of circumstances and have important family relationships in their life that influence their sense of self and continue to support their identity and how they carry themselves. Consequently, there is a pressing need to place greater emphasis on these members of the family and to explore the challenges and opportunities they encounter when accounting to care for their sibling with a disability. By understanding the scope of their lived experiences, we can gain a deeper understanding of the ways they perceive themselves and how their lives have been influenced from their sibling with a disability.

# 3. Theoretical Frameworks

## 3.1 Background

To understand the ways in which an individual interprets themselves in relation to their sibling with a disability, it is valuable to view theories across disciplines that identify reasoning for emotional and behavioural development in a family setting. With a focus on a neurotypical sibling's experience within a family who has someone with a disability, I examined Bronfenbrenner's Ecological System Model (1979) and Bowen's Family Systems Theory (1966) to provide a theoretical backdrop for my analysis. Both theories bring clarity and understanding to the importance of a person's nuclear family and how one can rationalize their development and sense of self through the re-interpretation of early childhood experiences. In other words, these theories help us understand why an individual with a sibling who has a disability might inherently have a different sense of self than families with a non-disabled child.

## 3.2 Bowen Family Systems Theory

To understand one's sense of self, one can refer to Bowen's Family Systems Theory published in 1966 to understand learning, developmental, and behavioural impacts on specific members of the family. Although the original theory traditionally defined by observing the nuclear family was used to study traditional family settings, the theory can work symbiotically for any family member in any family setting. For this particular research study, I focused my investigation on the sibling of someone with a disability.

Dr. Murray Bowen, a psychiatrist, originated his theory with its eight interlocking concepts. He formulated the theory by using systems thinking, a way to understand

future outcomes by integrating the human evolution knowledge with family research knowledge. Bowen's Family Systems Theory is a theory of human behaviour that views the family as an emotional unit and uses systems thinking to describe the unit's complex interactions (The Bowen Center for the Study of The Family, 2021). Relationships and systems observed in families share commonalities with relationships observed in the natural world and outside of the family (Crossno, 2011). The theory radically departs from precedent theories of human behaviour by conceptualizing the family as an emotional unit. Individuals are more strongly regulated by the unit than being autonomous psychological entities (Bowen Theory Academy, 2022). Families are profoundly affected by their member's thoughts, feelings, and actions that it often seems as if people are living under the same "emotional skin." Family members are uniquely connected and solicit each other's attention, approval, support and needs, which makes the family interdependent. A change in one person's functioning is predictably followed by reciprocal changes in the functions of other family members (The Bowen Center for the Study of The Family, 2021). Reflecting on a neurodiverse family it can be argued that the presence of an individual with a disability or disabilities will reciprocate effects to other family members. In turn, the family as a whole will have unique experiences that will impact their way of natural living outside of their nuclear family.

In Bowen's first interlocking concept, the Differentiation of Self (DoS) was developed. DoS is the development of one's ability to balance their own emotional and logical process while remaining part of the family (Lampis et al., 2019). Bowen theorized that the emotional experiences and the emotional dynamic of the family of origin are central in determining an individual's DoS (Calatrava, María, et al., 2022). The DoS accounts for an individual's ability to freely choose their own intellectual and emotional systems and develop independently while staying connected to others (Bowen, 1978). Bowen also ascertained that an individual's degree of DoS becomes stable at the beginning of emerging adulthood (Calatrava, María, et al., 2022). Bowen used a theoretical scale to

| Lower Differentiated People | Higher Differentiated People |
| --- | --- |
| Unable to separate feeling from thinking | Able to access thinking, even when in high anxiety |
| Reactive—emotionally driven | Responsive—capable of thoughtful consideration |
| Stuck with or cut off from families and significant others | Connected with significant others while maintaining separate self |
| Conform to a situation or rebel | Self-defined, self-validating |
| Need to control functioning of others | Focused on control of self-functioning |
| Less flexible, less adaptable, more emotionally dependent | More flexible, more adaptable, more emotionally independent |
| Easily stressed into dysfunction, has difficulty recovering from dysfunction | Can cope with life stresses and recover rapidly from stress-induced dysfunction |
| Inherit a high percentage of all human problems | Remarkably free of human problems, life is more orderly and successful |
| Life course determined by what feels right | Life course based on principled beliefs |

*Figure 1: Bowen Murray. Family Therapy in Clinical Practice. Jason Aronson 1978.*

range humans from 0, being the lowest functioning DoS to 100, the highest level of DoS). The theoretical scale applies to all humans and transcends categories including social class, genius or cultural-ethnic differences (Crossno, 2011). In the table below, the pseudo-self and solid self can further explain the differences between individuals

who present low to high DoS. In regards to individuals who have siblings with a disability, to better understand their sense of self, it would be worthy to understand their DoS.

The schema from Figure 1 portray results from a study Bowen himself conducted with participants. Similar to the criteria for participants in this study, Bowen studied individuals aged 16 and over to target emerging adults. Relative to this particular study, the aim of researching young adults allows a deeper reflection to understand individuals and their degree of DoS in a family with someone who has a disability.

## 3.3 Ecological Systems Theory

Urie Bronfenbrenner was an American psychologist and is one of the leading authorities in the field of development psychology. Bronfenbrenner´s Ecological System's Theory (1979) dwells on human development and views one´s growth as an important attribute to become a fully competent member of society (Härkönen, 2001). Ecological Systems Theory looks at a child's development within the context of the system of relationships that form his or her environment. Bronfenbrenner's theory defines complex "layers" of environment, each having an effect on a child's development (Ryan, 2001). The Ecological Systems Theory defines four concentric systems; the micro-, the meso-, the exo- and the macrosystems. Later on in life, Bronfenvrenner added a fifth related system called the chronosystem (Härkönen, 2001).

The *microsystem* is the most influential level of Ecological Systems Theory. This is the most immediate environmental settings containing the developing child, such as family

and school (Guy-Evans, 2020). At this level, relationships have an impact in two directions, stemming from the child and from others to the child. Bronfenbrenner calls these bi-directional influences, and he shows how they occur among all levels of environment. The interaction of structures within a layer and interactions of structures between layers are key to this theory Ryan, 2001).

The *mesosystem*, which is the next ecological context, consists of a network of microsystems (Bronfenbrenner, 1977). In this layer, connections between systems are shaped. Social and environmental influences within the microsystem interact with and influence each other in the *mesosystem*, and these *mesosystem* interactions are further situated within an *exosystem* of formal and informal social structures (Paat, 2013).

Following the *mesosystem* is the *exosystem*. This layer defines the larger social system in which the child does not function directly (Ryan, 2001). The *exosystem*, encompasses the bindings and processes between two or more settings. Particularly, one of these settings does not ordinarily contain the developing person, but in which events occur that influence processes within the immediate settings that do contain that person (Härkönen, 2001). At this stage, individuals may not be directly involved, but they do feel the positive or negative force involved with the interaction with their own system (Ryan, 2001). For example, neighbourhoods represent an *exosystem* that provides the context in which schooling and socialization takes place (Paat, 2013).

The *macrosystem* consists of the overarching pattern of micro-, meso-, and exosystems and can be thought of as a societal blueprint for a particular culture, subculture, or other broader social context (Härkönen, 2001). The *macrosystem* is a component of Bronfenbrenner's ecological systems theory that focuses on how cultural elements affect a child's development, such as socioeconomic status, wealth, poverty, and ethnicity (Guy-Evans, 2020). This, in turn, affects the structures in which the parents and families function (Ryan, 2001).

The fifth and final level of Bronfenbrenner's ecological systems theory is known as the *chronosystem*. The *chronosystem* is a description of the evolution, development or stream of
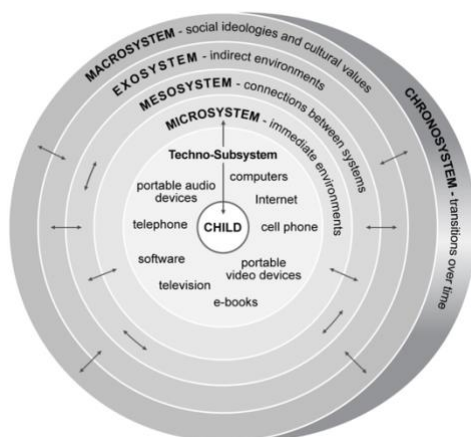


*Figure 2: Ecological Systems Theory. Source Johnson et al., 2008*

development of the external systems in time (Härkönen, 2001). This system consists of all of the environmental changes that occur over the lifetime which influence development, including major life transitions, and historical events (Guy-Evans, 2020). As children get older, they may react differently to environmental changes and may be more able to determine more how that change will influence them (Ryan, 2001).

Understanding Bronfenbrenner's Ecological Systems Theory can help researchers and readers to better understand an individual's life experiences. Markedly, Ecological Systems Theory can reason the individual's unique sense of self when having grown up in a family with someone who identifies as having a disability. As Bronfenbrenner has stated, the microsystem is the most influential level of the Ecological System Theory.

This research intends to highlight the vast differences in a microsystem of a sibling who has a disability and how that can have profound effects on one's sense of self.

## 3.4 Tying into Family Theories

Identifying outcomes for children who have a sibling with a disability in existing research is both inconsistent and contradictory which complicates finding answers and solutions (Hayden et al., 2019) that could be implemented to support the development of these individuals.

In using family systems theory as a framework, it can be understood that interdependent family members are embedded in the larger family subsystem. Previous study's suggest that sibling relationships differ in families raising children with different types of disabilities and that family functioning is associated with sibling relationships (Roper et al., 2014). Influences can stem from the child with a disability towards their parents and shape the parent's beliefs and behaviours. Bronfenbrenner calls this bi-directional influence as relationships exist on the levels of all environments (Paquette & Ryan, 2001). Alternatively impactful, depending on how the parents accept and perceive their child's disability will further impact the views of the non-disabled child. Parents need to establish harmonious family values to allow their non-disabled children to develop interpersonal perspectives and ultimately, inherit prosocial views towards their sibling with a disability (Kramer, 2010; Yeh-Chen, 2000). A family systems perspective with positive outcomes for their children with a disability is likely to affect the non-disabled child's psychological perspectives and perceptions throughout life (Hayden et al., 2019). Referring to family frameworks, non-disabled sibling involvement in families

draws from the qualities and strengths between other family relationships and elder family members. Interestingly, the association between family environmental characteristics views towards their sibling with a disability are noted to extend into later life roles of non-disabled children by predicting their quality of life in their younger years (Bigby, 1998). Through filial family relationships, the personalization of individuals develops and therefore, individual identity always involves being part of one's family, even when individuals choose to disassociate from it (Scabini & Manzi, 2011). Shared history, intimate knowledge and relationship to one's sibling with a disability support individual's to carry out unique identities for themselves. Typically, identities are shaped by individual perceptions along with their sibling with a disability's attributes and qualities (Hayden et al., 2019).

There are habitual theory gaps in disability studies when involving a sibling or a family member of someone with a disability. Many studies conducted showcase a lack of diversity as there are heavy tendencies to focus on families "raising" a child with a disability. In doing so, research potentially neglects the experiences of other family members with diverse backgrounds such as cultural beliefs and family structures. There seems to be an overgeneralization about families raising children with disabilities and the negative impacts on the siblings when there could be variable and diverse experiences within these families that existing research is failing to include. Secondly, existing sibling-disability research lacks focus on the positive outcomes of sibling relationships and how that can independently affect each party of the relationship.

In addition, numerous former and contemporary studies emphasize the impact of the child with a disability on their family and siblings while neglecting the impact that the family and the siblings can have on the child with a disability. This one-directional focus in disability-sibling research presents consequential gaps as resources are favourable and biased to showcase the impacts that disabled people have on others and not enough focus on how others impact people with disabilities. Further, the majority of studies in sibling and disability research have limited critical perspectives and longitudinal data. Existing case studies rely on cross-sectional study findings and lack information relevant to a family's long-term experience. To understand the potential changes in family and sibling dynamics, it is important to account for precedent and current time experiences that have shaped family members over time to be who they are at present.

Outside of the nuclear family, there are exterior factors that are additionally dismissed when trying to understand sibling relationships and disability research. Many theories primarily focus on the internal family dynamics and can neglect external environmental factors that may impact the family relationships, such as cultural norms, policies, and services. As previously noted and relevant to this point, viewing theory frameworks can be an asset tool when trying to understand factors within families that may be influenced by their surroundings and outer functions.

Overall, there is a need for more theoretically-driven research that seeks to capture and account for the interaction between variables; greater diversity in study participants; the use of population-wide data to better understand the factors that impact on sibling

relationships; and greater involvement of individuals with developmental disabilities themselves. (Cebula & Kovshoff, 2020). Because strong sibling relationships offer many long-term benefits to individuals, and with the paucity of research, examining connections and positive sibling relationships is important to understanding unique individual outcomes and how one view's themselves (Taylor et al., 2022).

## 4. RELEVANT LITERATURE

### 4.1 Disability Research

Sibling disability research is the study of siblings where at least one has a disability. Precedent studies have traditionally solely focused on the negative experiences of the sibling of the person with a disability (Meltzer, 2018). Additionally, few studies have investigated positive aspects of family functioning such as family cohesion and its relationship to positive sibling relationships (Taylor et al., 2022). Sibling disability studies have predominantly focused on the problems that disability may cause for non-disabled siblings (Meltzer & Kramer 2016). The psychological focus of sibling-disability research can be understood as rooted in histories of institutionalization and de-institutionalization (Meltzer & Kramer 2016). The shift and emphasis away from solely negative family outcomes in disability research is important. More sophisticated family disability research should try to understand the factors that contribute to families adapting themselves rather than listing the unfortunate consequences or tragedies (Ferguson, 2001). Limited positive documented research findings of growing up with a sibling with a disability can be connected to researchers' interest in medical disciplines and diagnostics (Yonat et al., 2022). Arguably, study contribution in this direction is an

important matter that should be accounted for more throughout sibling-disability research.

Commonly reported in sibling disability research is the lack of parental involvement and time spent with their non-disabled children, driven by the demands of caring for their disabled children (Dew et al., 2004), and negatively impairs the perspectives that family members have towards their siblings with disabilities. Undoubtedly, in other studies and on the other end of the spectrum, attitudes and growth of typically developing individuals towards their other sibling with a disability are generally positive (Harty et al., 2016). The psychological growth among siblings of children with developmental disabilities compared to siblings of typically developing children has been proven to be significantly higher (Hayden et al., 2019). With a range of existing data and knowledge to argue either end of neuro-typical sibling perceptions based on their experiences growing up, it can be helpful to review theoretical frameworks.

## 4.2 Understanding Disability Dynamics in Households

Families of young children with disabilities are often impacted by ongoing challenges that influence various aspects of the family dynamic (Davis & Gavidia-Payne, 2009). With sibling relationships being the longest-family relationship, the sibship subsystem within a family is becoming increasingly more important in contemporary modern life (Yeh-Chen, 2000). In a family unit, where the presence of a sibling with a disability exists, special relationship bonds are formed and can be emotionally characterized as positive or negatively impacting (De Caroli & Sagone, 2013). Relationships between

siblings play a unique role throughout life development stages and can offer reciprocal opportunities for learning, overcoming challenges, joy and support throughout the lifespan (Cebula & Kovshoff, 2020).

Growing bodies of literature are beginning to reveal that an individual's experiences in their families and relative to their experience in having a sibling with a disability are important for adolescent development (Caspi, 2010). It can be argued by researchers that individuals with special needs can induce positive and negative effects on their non-disabled sibling (Alsop, 2001). With siblings acting as surrogate parents, informal teachers and friends, the sibling relationship to someone with a disability can represent one of the most powerful bonds in human interactions (Friedman & Aleksa. L., 2017). Providing care for a sibling with a disability can bring many positives. If their personal needs are met, individuals can feel special too and gain just as much from being actively involved with their sibling with a disability. If caregiving is balanced and valued by the family and not take not taken for granted, caring for a sibling with disability can add to an individual's self-esteem and sense of accomplishment (Strohm, 2014). Siblings do not just share genetic inheritance, they also share narrow sets of interactions and transactions which are fundamental to the development of social skills. Neurotypical children in unique family environments may begin to experience the ability to negotiate, cooperate and compete well which can ultimately set them up for future success in academic and social inclusion (Cuzzocrea et al., 2014). In response to their family roles, siblings to those with disabilities commonly show a number of strengths and larger degrees of maturity. Many siblings of those with disabilities are often deemed unselfish as they frequently care for their sibling and don't expect anything back (Meyer

& F. Vadasy, 2014). Siblings of people with disabilities often grow up to be more compassionate, caring and tolerant of differences. They display maturity beyond their age and a perspective on life that allows them to have a deep appreciation for their blessings. Additionally, they can distinguish what are important issues and worth the time and effort to engage in (Strohm, 2014). The unique experiences of having a sibling with a disability very well contribute to an individual's particular and positively developed characteristics and qualities. Furthermore, acquired positive traits form one's identity and how one acts outside of their family (Vella et al., 2021). This can carry over to a broader consciousness of others' needs and many siblings go on to be advocates, not only for their brother or sister but for people with disabilities in general (Strohm, 2014).

## 5. METHODS

The purpose of this study is to focus on the exploration of social attitudes and a sense of self that an individual may experience who has grown up in a household including a sibling with a disability. 10 qualitative interviews were conducted with non-disabled individuals who have siblings that do identify as having a disability.

A Phenomological approach was specifically used in this research to explore the complexities of the lived experiences of individuals with family who have a disability. By focusing on the subjective experiences and meanings of individuals, researchers can gain a deeper understanding of the social and economic constraints that shape these experiences (Corby et al., 2015). In using Phenomenology approach, highlighted was the importance of exploring the unique perspectives of individuals, and their experiences can inform the development of solutions to the challenges they face (Langdridge, 2007). This approach prioritizes the voices of siblings directly impacted by their lifestyle involving their sibling with a disability, which can lead to a more nuanced and comprehensive understanding of relationships, personal development and an individual's sense of self. Therefore, employing a phenomenological approach, valuable insight was gained into the lived experiences of individuals with disabilities and their families, leading to more in-depth understanding of the relationships and experiences questioned.

Ultimately, the research hypothesizes that siblings of those with disabilities often experience uncommon roles within their families at a young age which leads them to inherit a unique sense of self as they age throughout their lifetime. Secondly, it is understood based on existing disability research studies and bodies of knowledge, a heavy tendency to focus on family obligations and physical care of the individual with a disability by their siblings. In addition, this study explores the dynamics of sibling relationships that involve a disabled person and uncovers that there are more valuable lessons to be learned beyond simply feeling obliged to support one's family and physically care for the sibling.

## 5.1 Determining the Participants

Participants recruited for the study were individuals over the age of 18 living in Ontario, Canada and have siblings who identify as having a disability. A total of 10 participants were recruited for the study. Participants ranged from the ages of 21 to 43. If potential participants wished to part-take in the study virtually, additional requirements for the study were to have basic knowledge of virtual meeting softwares including but not limited to Teams, Zoom, and Google Meets.

## 5.2 Finding & Recruiting Participants

The participants of the study were first recruited via word of mouth, through social media and by email connections. A social media poster was used to post a recruitment advertisement on Facebook, Twitter and Instagram. Further, an email template was used to reach out to colleagues and acquaintances that were known to be a good

potential fit for the study. Individuals who were interested in the study following via

social media were then contacted through email with an invitation letter. The invitation

letter gave the interested potential candidates more information about the study and

helped identify more specifically if they were indeed eligible to participate. Following

confirmation of participation eligibility, individuals were then sent via email both consent

and assent forms to sign.

The participants of the study were determined by following the sampling criteria in

accordance with the proposed study. Participants were deemed eligible if they suited

the criteria below:

- Be over the age of 18

- Have a sibling who has as a disability*

- Lives in Ontario

*Refer to the definitions section of this research study.

## 5.3 Data Collection

Semi-structured interviews were conducted for this research study because it provided

a way of gathering in-depth, comparable data across the board from all participants, still

leaving the option for participants to tailor their own answers. Semi-structured interviews

are a favored approach to data collection when the researcher's aim is to gain insights

into the participant's individual perspective, rather than a broad or generalized

understanding of a particular phenomenon (Adeoye-Olatunde et al., 2021). In using

semi-structured interview questions, this research was able to capture the voices and experiences of participants that would not have been possible to capture from a structured interview questionnaire.

At the time of this research, the pandemic effects were residual and thus, interviews were held in-person or virtually depending on the participants' comfortability with meeting. Research interviews were recorded by hand-written notes. Interviews ranged from 40 minutes to 1 hour long and covered perspectives on:

• Relationships with siblings who identify as having a disability;

• Experiences growing up in households including, an understanding of the family dynamic;

• Experiences in the current time and relative to family dynamics;

• Understanding how individuals currently perceive themselves.

Sibling participants answered very few questions that included self-identifying proponents that would, later on, be removed for anonymity in this research. The interview questionnaire had a total of 42 semi-structured questions. The formatting of the interview script and questions had a phenomenological approach of qualitative enquiry to best understand the experienced lives of the participants. Formal questions sought direct responses and informal questions gave participants the opportunity to express their personal experiences and thoughts.

The interview script questionnaire consisted of five parts. The first section was an introduction to the study which described the following questionnaire that participants were about to be asked. Additionally, at this time, participants were reiterated their rights on omitting any questions and if they wish to withdraw from the study. Section two of the interview script initiated the questionnaire portion of the study. In this section, participants were asked opening questions about themselves and their family backgrounds. Additionally, in this section, the interview script questionnaire was geared to inquire about participants' personal lived experiences in relation to their sibling who identifies as having a disability.

Section three of the interview questionnaire focused on questioning the participant about their experience and family dynamics when growing up in a household with a sibling that has a disability. In this section of the interview questionnaire, the focus was to understand the participant's past childhood experiences and how they interpreted their childhood themselves. Section four of the interview script was near identical to section three of the interview script. The difference however in this section was to question the participants' on their present-time understanding and experiences relative to their family.

Lastly, section five of the interview script questionnaire focused on questioning the participant about their sense of self. In this final section, participants are prompted and questioned to reflect on their own lived experiences from childhood into adulthood and how they currently interpret themselves at the current stage in time. The goal of this

section is to understand how the participant feels about themselves as independents from their family in addition to understanding if their unique lived experiences as someone who has a sibling with a disability has in any way shaped them to be who they are today.

## 5.4 Data Analysis Process

Considering the exploratory aim of the research to uncover and understand the perspectives of individuals who've grown up in a household with a sibling who identifies as having a disability, inductive narrative analysis and data driven coding were used to analyze and organize the collected data. The purpose for this method of analysis was to allow research findings to emerge from the frequent, dominant or significant themes inherent in the raw data (Thomas, 2003).

The initial step in the research analysis process included familiarizing myself directly with the data. Through immersion, key notes and ideas were made which then shaped the understanding of the themes in the data. The second step in the analysis process included the identification of concepts and ideas within these themes. Themes were organized and grouped based on reoccurring consistency. Once frequent themes were identified, categories were formed, ordering the surfaced concepts within these categories to summarize and convey the data. When ordering consistently surfaced concepts within themes, key learnings were combined and collapsed the study information and data (Goldsmith, 2021; Thomas, 2003). In flowing through this research

analysis process, a storytelling process was used to structure the patterned collective information from all participants.

When coding the data sections two to five of the interview script (4 total sections total) were analyzed find common themes among all participants. This research specifically used a data driven coding assessment to formulate themes from the data gathered across all participants. This approach is occasionally called open coding. Rather than starting with a list pre-organized themes for the data to be coded into, the researcher starts with nothing (Gibbs, 2018). Qualitative content analysis in this research was flexible and coding frames accurately matched the materials collected (Flick, 2013). In this research, the data honestly reflected responses from participants as categories naturally surfaced and weren't forcefully preset prior to coding. Themes formed based on reoccurring data-driven information surfaced among participant interviews. Finding categories derived from themes reviewed in this research are the guiding sections in the following findings chapter:

1. Independence and Family Interdependence

2. Future Realities

3. Care Dependability

4. Understanding, Maturity & Relationships

5. Identity and Independent Views

# 6. FINDINGS

Findings and themes uncovered from the analyzed data are detailed below. The findings re-iterate common reiterated information collected among all participants. The following sections; Independence and Family Interdependence, Future Realities, Care Dependability, Understanding Maturity and Relationships and lastly, Identity and Independent Views rationalize the experienced lives and sense of self of an individual with a sibling with a diagnosed or identified disability(ies).

The interview data encompasses experiences from individuals from youth and childhood into adulthood. Categorized sections below begin at looking at the individuals' secluded experiences from their families in addition to relationships and relative interdependence with their family. Subsequently, the research goes into relaying future realities that should be accounted for when seeking to understand an individual's experience relative to having a sibling with a disability. Following, the findings move into informing on care dependability that is accounted on individuals with siblings with disabilities. This chapter particularly focus' on the perspectives of participants and how they interpret their siblings care and how they see their role based on their needs to support their families. The following category is understanding, maturity and relationships where commonalities between participant data inform on qualities and personal characteristics that surfaced consistently among participants in this study. Lastly, Identity and Independent views examines how participants perceive themselves

in addition to the multifaceted and important views that these individuals comprehend when being part of a family where they have a sibling with a disability.

## 6.1 Independence and Family Interdependence

There was a substantial collective response among participants when asked about their childhood. Having grown up in a family with unique circumstances and rare family upbringings, all participants relayed difficult and facile experiences. Nevertheless, every participant in the study conveyed that they enjoyed their childhood and the family position they held. Notably, all participants relayed that their families were never financially impacted by the care required to support their siblings with a disability to the point that it would limit their family's life opportunities. In addition, when asking participants if they were personally affected financially to the point of life alteration due to the need to support their siblings with a disability, all participants responded no.

Six participants noted that they were raised close to their sibling with a disability. Three of five participants who were one of two children in their family indicated that growing up with their sibling who has a disability, there was confusion as to why their sibling had a disability yet, that's all they knew growing up and, therefore, never questioned it otherwise. Among the five participants who were one of three children in their family, three participants experienced similar confusion when trying to rationalize and understand their sibling and their disability in youth. Interestingly, regardless of having another neurotypical sibling, the majority of participants had difficulties rationalizing the concept of a disability and why their sibling was different from them in their youth. The general consensus among participants who were one of three children in their family

25

mentioned that having another non-disabled sibling experience a similar lifestyle to them helped clarify their understanding. When confused about their emotions and experiences, it was helpful to leverage their other sibling without a disability's emotions. Among all participants, trying to understand their family dynamic growing up was challenging. However, the majority of the participants said that was all they knew and thus never questioned it or sought to rationalize it otherwise. Based on the consistent responses from all participants, regardless of how many other siblings they have in their family, the concept of a disability can be hard to understand at a young age.

> *As a sibling, especially when you are young, it's hard to understand the concept of disability. – Participant Sibling 6*

> *It really depends on the family dynamic. Having another sibling to share all the emotions together helped me. You are able to feel guilt, love, happiness together. – Participant Sibling 2*

In younger age years, two participants expressed that their inability to understand the concept of a disability made them feel confused and distanced growing up. In addition to being unable to understand their sibling and their disability growing up, when parents directed unalike care to their sibling, two participants expressed emotions such as resentment and envy when they were younger. Circumstantially, frustrated feelings arose as a reflection of their parent's unique attention towards their sibling and not them. Alternatively, one participant noted that because their sibling was receiving more

focus, they focused more on themselves and became a stereotypically "good child" in school.

> *A lot of attention on my sibling made me a stereotypically good kid. – Participant*
> *Sibling 10*

Reiteratively, most participants in the study consistently noted that growing up with someone who has a disability was all that they knew. Thus, when describing how they viewed and treated their sibling with a disability, it was notable that participants viewed them as ordinary people and did their best to treat them as someone who did not have a disability. Furthermore, participants identified wanting to treat their relationship with their disabled sibling similarly to any standard sibship relationship. Lastly, the majority of participants referenced how people with disabilities should be treated similarly to non-disabled people. Few participants expressed that when removing the care that their sibling with a disability requires out of the picture, at the end of the day, they are similar to the mundane person and apprehend that their sibling should be treated equally to all.

> *To me, that's all I knew. They were just a regular sibling and so I treated them*
> *like a traditional sibling. – Participant Sibling 4*

> *I think life would be more complex if I didn't properly take care of myself. For*
> *example, going to the gym. When I take care of myself mentally and physically, I*
> *am then able to better care for my sibling. – Participant Sibling 7*

All participants identified leaving their family home to live on their own when they were young adults. Nine of the ten participants still live independently from their families and sibling with a disability. Currently, one participant in the study identified that they left their family home in their younger adult years to live on their own but have recently over the past year purchased a home with their newly formed family and have their sibling with a disability living with them. It was evident among all participants that living independently from their families was momentous to them. When the time came to leave their family home and live independently, the majority of participants identified that they felt grown up. One participant expressed the relief of pressure with now being able to focus on their own needs and less on their families. Interestingly, almost all participants were looking forward to gaining independence. However, five participants expressed symbiotic emotions of guilt and excitement when leaving their family homes. Even though participants wanted to live independently, participants worried when transitioning out of their family home that their involvement with their family was going to be less consistent and they would no longer be able to support their loved ones in the same capacity as when they lived with them. Three participants noted when leaving the family home to go live on their own that they felt bad because they would no longer be able to keep the peace between their family. Not being able to play the peacekeeper role that they had assumed growing up made them worry for their family when they left their family homes. Uniquely, the single participant who currently lives with their husband, children and sibling with a disability identified that it was important for them to move out of their family home in their younger adult years. Living on their own allowed

them to focus on themselves. Interestingly, this participant recognized that even though they enjoy currently living with their sibling with a disability again, the separation from their family in their younger adult years was arguably important for their personal development.

Being independent of families was important for participants. Two participants expressed that being a sibling to someone with a disability can be overwhelming, and one's self-identity can easily become entangled with the identity of their sibling with a disability. When someone's life is entangled frequently with another person, building one's individuality can be difficult. Nonetheless, this principle goes both ways. Of these two participants, it was further noted that when siblings with disabilities depend heavily on members of the family, it is also necessary to make sure they develop independence from their family members.

Seven participants noted that their independence was important not just to them but also to their parents. Participants frequently mentioned that their parents were always supportive and encouraging of their children to seek independence and move out from the family home. Four participants noted that since moving out of their family home, they frequently gravitate or actively involve themselves with their families. Involvement practices range among participants. Common family engagements include consistent virtual communication and routinely spending time with loved ones. Three participants who mentioned being drawn to their families noted that it's because they simply are always in connection and routinely see their families so there is no sense of feeling

gravitated to them. Furthermore, two participants mentioned that they do not gravitate to their families. Lastly, one participant mentioned that they don't gravitate to their family members because their sibling with a disability lives with them and their newly made family at this time.

Throughout the study, even though there were no questions directed toward understanding how participants viewed their parents, there were substantial reflections and discussions among all participants about how they felt about their parents. Interestingly, nine participants recognized that while parents had more onus to support their child with a disability which was often more demanding than their non-disabled child, parents were competent to support and tend to all their children's needs separately. The majority of participants expressed gratefulness for their experienced childhoods and how much of that is owed to their parents. In youthhood and in current times, many participants recognized the hard work that many of their parents endured when having to care for their sibling with a disability, all while being able to create a sustainable lifestyle for the family. Participants additionally expressed personal good fortune in having caring and supportive parents that did much of the heavy lifting when it came to supporting their sibling with a disability. It was evident that the majority of participants acknowledged their parent's active and adequate involvement to ensure everyone in their family's needs were tended to which enabled a healthy and successful family living dynamic.

*No one puts in as much effort as my parents. – Participant Sibling 1*

*I'm proud of my parents for putting such hard work to have a sustainable lifestyle so that we (sibling and I) can have good lives. I admire their hard work. – Participant Sibling 7*

*I have amazing parents and role models. I am fortunate that they were able to give my sibling the things they needed. – Participant Sibling 6*

Five participants expressed that their parents acted as role models to them growing up and still continue to be role models for them. Watching their parents take care of their sibling with a disability growing up shaped how they themselves cared for and continued to support their sibling. Many participants learnt to care for their sibling with a disability by their parents' leading example. One situation commonly expressed by participants in younger years was not knowing at times how to specifically care for their sibling with a disability. Watching how their parents interacted and dealt with their sibling with a disability gave them insight and understanding as to how they could then support their sibling. Good leadership in parents regarding supporting an individual with a disability is notably important for other children in the family. As evidenced by the many participants who continue to look up to their parents as models for how they want to carry themselves, being a good leader as a parent and providing support to a child with a disability not only benefits that individual but can also have a positive impact on their siblings and family dynamic as a whole.

## 6.2 Future Realities

The priority of the study was to focus on understanding how unique childhood and growing-up experiences leading up to the current time can impact someone's sense of self. Even though the study had no formal intended questions directed at understanding an individual's future, all participants who took part in the study were consciously planning or accounting for the future. It was interesting to see among participants the importance of planning and trying to comprehend their future lives. The intersection of a person's life with that of their sibling with a disability makes it challenging for participants to understand their future comprehensively.

Numerous participants naturally amalgamated their future prospects with their siblings, forming a comprehensive and interconnected plan. Interestingly the organic conversation typically initiated with the discussion about the participant's sibling with a disability's future life care plans. Over half of the participants mentioned having frequent talks with their parents about their sibling with a disability's future care plans. Three participants voiced the subject of "the talk" with their parents regarding creating a will for their sibling with a disability and went through it with them at least once to discuss future guardian care plans. Participants conveyed the importance of discussing contingency plans with their parents to support their sibling with a disability in case the parents could no longer provide adequate care. Five participants disclosed that they had reached an agreement with their families and had been appointed a legal guardian after their parents, ensuring successful continued care for their sibling. One participant noted, that they lived separately from their sibling with a disability for some time in their younger

adult years but have since created a family of their own and currently cohabitate with their sibling with a disability and newly made family. This participant identified recently purchasing a home where her husband and children could live alongside their sibling with a disability. Notably, even as a primary caregiver and currently residing with their sibling with a disability, this participant expressed that there are still many unknowns when understanding what the future entails and how to best support their sibling with a disability.

*It is an anxiety in the future. I worry when my parents aren't there. It's scary to think about in every way shape and form. How will they fit into my future. – Participant Sibling 6*

The majority of participants who discussed their sibling's future life care subsequently put into question their future realities. Few participants were contemplative of how one could live independently from their sibling and further manage to support their sibling with a disability to live independently when their parents are no longer around. It was evident that participants consciously thought about the future beyond conversations with their parents. Fear and stress of the unknown were reoccurring themes among participants. Two participants relayed that they contemplated how to incorporate and manage their future families alongside their sibling with a disability.

*I'm planning to support my future family. – Participant Sibling 5*

*Emotionally, I can't abandon them. – Participant Sibling 9*

As much as discussions with parents are helpful, it can be challenging for individuals to picture a different life when parents are no longer around. How can individuals successfully support themselves independently from their sibling with a disability? Many pressures surfaced in participant interviews throughout the study. Two participants identified internal pressures to be the best version of themselves and succeed in employment to support their families and sibling with a disability's future care. One participant particularly noted how they currently strive to have financial and workplace stability so that they may be able to support their families and sibling at a greater capacity in the future. Additionally, the over half of participants identified the natural pressures of simply having to take over their sibling with a disability's care when their parents are no longer around. Currently, families who have members with disabilities have limited options when it comes to deciding their loved one's future governing body of care. When guardians and parents pass away, the responsibility commonly falls on to the next of kin. As a result, there are limited options when deciding on whom to succeed their child with a disability's care when parents are no longer around. With minimal routes for future care support, the responsibility commonly lands on the shoulders of non-disabled children and other siblings within the family. It is evident that without alternative care options outside of their families, internal pressures develop for these individuals as their sibling's provision of future life care lands on their shoulders.

*My parents tell me not to feel the need to plan for my sibling's future and support them however, I feel responsible in many ways. I feel the need to set my sibling up in the future. – Participant Sibling 5*

*More pressure to succeed for the sake of my other sibling. To make my family proud. – Participant Sibling 8*

A total of eight participants were noted as forward-thinking as they accounted for present and future realities for themselves and their sibling with a disability. However, many of these participants expressed stress in recognizing that they are likely to assume the role of their sibling's primary guardian or caregiver in the future. It is evident that plans, particularly when considering their sibling with a disability, were a personal and conscious concern for many participants. Irrespective of the level of care or guardianship participants would need to provide and support their sibling's future lifestyle needs, commonly mentioned emotions among participants included anxiety, stress, worry and scared of the unknown.

As previously mentioned, among the ten participants in the study, five were one of two children in their family, and five were one of three children. Three participants who were one of three children in their families mentioned how they interpreted their future differently when accounting for their other non-disabled sibling being in the picture. Three sibling participants additionally conveyed how it can be difficult to coordinate with their other non-disabled sibling when focusing on their sibling with a disability's future

needs. Ultimately, not having the same understanding would lead to one sibling feeling

that they had to take on more responsibility than their other non-disabled sibling in the

future. It was noted by four three-sibling participants that they were additionally aware of

the capacity that they offered to their sibling with a disability in comparison to their other

non-disabled sibling. Regardless of the participant's capacity of care that they felt was

required to support their sibling with a disability, it was noted that having another non-

disabled sibling helped alleviate the general individual pressures when it came to future

planning. Understandably, when there are more than two non-disabled children involved

in discussing and planning for their other sibling's future care plans, emotions and

understanding are shared and individuals can better rationalize. Three participants

identified that having another sibling in the same role as one's self had participants

feeling grateful for not having to cope and plan for their sibling with a disability's future

care alone. Notably, having another non-disabled sibling can help alleviate the pressure

and emotional burden of future planning for a sibling with a disability. While some

participants who were one of three children in their families mentioned challenges with

coordination and differing levels of responsibility, having multiple siblings allows for

better understanding and sharing of emotions.

> *I have a hard and dark time thinking of the future. Thinking about how I have*
>
> *another sibling makes me feel comfortable. – Participant Sibling 2*

As expressed in this chapter, an individual's childhood and growing up experiences

when having a sibling with a disability can be complex. Among participants in this

unique circumstance, one's understanding of the future when having a sibling with a disability can vary and look different from non-disabled sibling relationships. In conclusion, reoccurring themes and emotions that surfaced among participant interviews emphasized the need for alternative care options and support for families when planning their loved ones' futures.

## 6.3 Care Dependability

In families with children with disabilities, the natural care dependability extends beyond the primary caregiver and to other family members who often step up to provide support and assistance, creating a network of reliability that is both necessary and commendable.

Throughout the study, participants relayed the various complexities when it came to supporting another individual with a disability. Participants in the study relayed that their forms of communication with their siblings were verbal and written. One participant noted that they infrequently used sign language to support their verbal communication with their sibling. In their youth years, the consensus among all participants was that they were relied upon but less than their parents. Interestingly, a few participants with another non-disabled sibling in the picture noted that they were even less needed to support their sibling with a disability because there was always another member of their family to share the accountability. Uniquely, one participant disclosed that they lived with their mother and in a single-family home growing up which required them to support at a nearly equal capacity as their parent. When asking individuals if they

viewed their sibling with a disability's care as complicated, seven participants responded no. Interestingly, one participant mentioned that even though their sibling's care is required 24/7, they still felt that their sibling's care is not difficult. This participant rationalized that when adequate supports are in place and a routine is followed, their sibling's care is manageable. Notably, the three participants who commented that their sibling's care is complicated all had siblings with a disability whose needs were always evolving. Participants with a sibling whose care needs are consistently changing said it could sometimes be challenging to understand how to support their siblings best. One day's effective care practice might not be the best consistent care practice. When their sibling's care needs or temperament are continually changing, it's difficult to understand how to best support them.

> *Their care gets better or worst at certain times. When you believe that you can impact it, sometimes it becomes a loop, hard and frustrating. It depends on the day. – Sibling Participant 5*

Seven participants who mentioned caring for their sibling in youth still provide care for their sibling today. One participant who didn't provide care for their sibling in their childhood still doesn't provide care. One participant who didn't provide care for their sibling in youth now does provide care and lastly, one participant who did provide care for their sibling in youth no longer cares for their sibling. Collectively, among all participants, the capacity of care across the board remains the same from childhood to adulthood. Participants who currently care for their sibling with a disability noted that the

capacity of care has increased or remained the same but looks different from their childhood as their sibling's needs have shifted. Regardless of the capacity of care level experienced among participants, half of the participants identified their understanding of the future will require them to support their sibling at an even larger capacity than at the current time. Increased capacity of care required to support their sibling was notably identified when referencing their parent's age and the transition in guardianship or roles within their family over time.

> *Now that my parents are older, I feel that I'm the one to step-up. – Sibling*
> *Participant 9*

Standard care requirements in youth and current-time among participants in support of their sibling with a disability included physical care followed by socially supporting. Typical physical care tasks identified among all participants included watching, supervising and personal support. Two other infrequent forms of care mentioned less consistently among all participants included mental and emotional support. At the time of the study, no participants relayed having to support their sibling financially or spiritually. Participants were asked about their personal drive or external pressures when it came to supporting their sibling with a disability. When asking participants the rationale for supporting their sibling's care while growing up, four participants said that it was a mix of internal drive and expectations from their parents, two participants said it was all personally driven and, one participant mentioned supporting because it was obligated by their parents. When asking participants in the current time what their

stance was on caring for their sibling, only six participants mentioned feeling obligated.

Of these six participants in the current time, one mentioned it being internally driven and

externally demanded, three participants said it was all internally driven and lastly two

mentioned it being externally expected by their parents. Collectively, the number of

participants who felt obligated to care for their sibling reduced over time and as they

aged. Notably of this reduction, there was an increase in participants who were

obligated by their families to support their sibling with a disability and additionally, less

internally driven. Uniquely, the only participant in the study who currently has their

sibling living with them and their newly formed family mentioned that it has never felt an

obligation to support their sibling.

As parents age, it becomes reasonably challenging to determine future care plans for

loved ones. Individuals with siblings with disabilities strongly desire to provide the best

care for their siblings regardless of their parents set expectations for them. While only a

small number of participants considered their sibling's care a top priority during

childhood, six participants mentioned their sibling's care is currently a top priority for

them. Notably, four participants who said their sibling's care is not a priority for them

now still iterate that they do care just not at an immense scale.

Caring for another family member at a young age can sometimes come at an expense.

Five participants noted that they sacrificed areas of their life to support their sibling with

a disability growing up. Most participants mentioned sacrificing social areas of their life

to assist their sibling. A common example mentioned by participants was missing out on

activities with friends because they were caring for their sibling. Seven participants

mentioned that they felt that their siblings with a disability depended on them growing

up. Among the participants with a third non-disabled sibling and felt they were

depended on, three participants noted that they found their dependency was less

required because there was another sibling in the picture. Uniquely, participants in the

study with another non-disabled sibling were able to understand the particular

differences between them as they were depended on by their sibling with a disability.

Even though five participants noted a decrease in their sibling's dependence on them

since childhood, particularly after moving out of the family home, many participants

currently feel a sense of responsibility towards their sibling with a disability. Four

participants expressed that they felt responsible in childhood and in current time for their

sibling. Out of the six participants who initially did not feel responsible for their sibling

during childhood, three participants now express feelings of responsibility and

additionally, three participants still do not feel responsible. Collectively, there was an

increase in participants feeling responsible for their siblings as they have aged. One

participant importantly noted that being a sibling inherently involves a fundamental level

of responsibility and their sibling's disability needs are an added set of responsibilities.

Three participants further mention that they not only felt responsible for the purposes of

supporting their sibling but additionally to their family. Expressed by these participants

was the need to step up in support of their sibling with a disability when they felt that

their remaining family members, particularly parents, at certain times weren't adequately

addressing the needs of their sibling. This is a unique recognition by individuals when it

comes to stepping up as participants relayed their understanding of being able to

provide better care to their sibling than their parents and ultimately support the family. Recognizably, this level of responsibility felt and experienced by participants goes beyond typical sibship roles and can be seen as more parental in nature.

*With age, I feel more responsible to make sure my sibling is good. I do my best to do my part with my family. – Participant Sibling 2*

In families where children have disabilities, the responsibility of caregiving goes beyond the primary caregiver and is often shared among other family members. As a result, a network of support and dependability is formed, which is essential and praiseworthy. The relationships between family members and siblings with disabilities can be intricate and may evolve over time due to various factors. As parents grow older and become less able to provide care, the responsibility of caring for individuals with disabled siblings is understood among other family members to increase.

## 6.4 Understanding, Maturity & Relationships

Participants varied in responses when asked how their relationship with their sibling with a disability stood now compared to their childhood. Collectively among participants, there was a minimal shift when it came to ageing and closeness with their sibling. A total of six participants expressed being close in childhood whereas in current time, eight participants identified being close with their sibling. Out of all the interviews completed, two participants expressed a shift to no longer having a good relationship with their sibling when compared to their childhood years. A common reason for the loss

of relationships was no longer living under the same roof and having less frequent time with one another. On the other hand, four participants who expressed having tense relationships in childhood now expressed feeling their relationship with their sibling has improved. A common reason for the improvement was personal growth and maturity that enabled individuals to understand their siblings better and further supported their connections and relationship. Lastly, four participants who mentioned being close in childhood and still holding good relationships with their sibling commented on how frequently they continue to connect and see their sibling with a disability after moving out of their family home. Overall, findings suggest that relationship dynamics between participants and siblings with disabilities are complex and can change over time.

> *Growing up our relationship was combative. As I matured and became more patient much has improved. – Sibling Participant 6*

> *I learned most of my sibling's caretaking as I later matured. I watched my parents and elder sibling to understand. – Sibling Participant 7*

Given that a significant proportion of participants reported having maintained or strengthened their sibship relationships from childhood, it's good to consider the factors that have contributed to these positive outcomes. Understanding, maturity and time are notable factors that consistently surfaced throughout participant interviews. Many participants who had difficulties connecting and comprehending their reality in childhood relayed that with time they were able to mature and grasp their sibling's needs better.

As individuals aged, they were able to understand how to communicate with their families and siblings which resulted in stronger connections. Particularly notable among over half of the participants' interviews was the concept of understanding and the practice of patience when it came to supporting their sibling.

> *Having a sibling with a disability can improve your character. It has benefits such as being more patient and kinder. – Participant Sibling 6*

> *Be patient and give a lending hand. Not everyone works at my fast pace so being patient to others. – Participant Sibling 7*

Understanding the scope of their siblings needs was important for participants because only until they were able to grasp how to best support their sibling, were they able to care better for them. This concept surfaced frequently when participants described transitioning out of childhood where they knew less and into adulthood where they were able to practice their supports more. Living with a person who has a disability gave the participants a unique outlook on life. During the interviews, all the participants shared their perspective on how to interact with people outside of their immediate family circle. They mentioned that their experience of growing up with a disabled sibling had given them a lens through which they could view others and a better understanding of how to treat others. This understanding would not have been possible without their particular life experience.

*I reflect a lot on having a sibling with a disability. It has coloured my whole view. I come from it with a justice lens and approach things in my life differently. – Participant Sibling 10*

The unique experiences of the participants in the study highlight the impact that having a sibling with a disability can have on an individual's sense of maturity. In this research, it is unclear at what development rate participants' maturity exceeds sibships without disabilities. Nevertheless, it is noteworthy that even at a young age, the participants recognized their important roles within their families. It is interesting to consider the perspective of the four participants who felt responsible for supporting and caring for their siblings during childhood when exploring how maturity is perceived at a young age. Two participants particularly noted how they felt more mature than their peers growing up from their experience in having a sibling with a disability. Another participant reflected on their exposure to a sibling with disability at a young age allowed them to develop a better understanding of equality and how to interact with other individuals, which gave them a sense of maturity beyond their years. These insights shed light on the various ways in which having a sibling with a disability can shape an individual's sense of maturity and understanding of the world.

*My experience was unique. You're forced to grow up early. Especially as a young caregiver. – Sibling Participant 1*

*I felt like I had more knowledge and how to treat and interact with other disabled individuals and other children my age better. I knew the idea of equality early on in contrast to other kids my age. – Sibling Participant 7*

While the study identified several participants with similar experiences such as better understanding, time and maturity which led to better relationships in adulthood compared to childhood, there were two participants who experienced worsened relationships with age. With few participants with worsened experiences and different reasonings for this occurrence, it is difficult to determine the factors contributing to their negative experiences within their sibling dynamic.

## 6.5 Identity and Independent Views

When asking participants to describe what it's like to have a sibling with a disability, the overall collective response was positive. Participants highlighted several arguments and discussions, such as when having a sibling with a disability in a current society's desire for a conventional system, they are able to understand the world from a different lens. An example that frequently came up was understanding the injustices of ableism in our current society. All participants expressed appreciation for having a sibling with a disability, feeling thankful and grateful for their sibling's presence in their lives. However, participants also acknowledged that it could be difficult at times which leads to overcoming challenges and ultimately shaping who they are today. Overall, participants' experiences with their siblings were multifaceted and circumstantial. At the end of the day, all participants expressed a sense of love for their family members and want their sibling and parents to live well.

*My experience - I wouldn't change it for the world. – Sibling Participant 1*

When participants were asked about their views based on their experience, many perspectives emerged. They expressed thankfulness for life and the need to protect their siblings with disabilities, acknowledging the important lessons they have learned from them. They also noted their ability to understand how amazing their siblings are and the humbling experience of having a sibling with a disability. Participants felt that their lives and families were unique, and they had learned to be more caring individuals as a result of their experiences. They expressed gaining confidence in being inclusive

but noted the difficulty of describing their siblings when they were younger and labelling them. Some participants still find it challenging to support their siblings with disabilities at times, but overall views have shifted from childhood, and the many believe that without their experiences, they would not be as kind or understanding towards others.

*They make you a better person. I think we're the lucky ones. – Sibling Participant 9*

*It's an amazing thing. Our family has had ups and downs but we are close thanks to my sibling. It's not always easy but we are lucky. My sibling is an amazing source of love and makes everyone feel good. – Sibling Participant 2*

When asked what they have taken away and learned from their siblings with disabilities, participants shared a variety of responses. They noted learning to be patient and compassionate, finding joy in the little things, and treating others with respect. Participants also mentioned being able to recognize the best qualities in people, as well as understanding that everyone faces struggles in life. They emphasized the importance of leading with empathy, lending a giving hand, and looking beyond someone's disability. Participants noted that having a sibling with a disability made them appreciate their family more and embrace radical acceptance. Additionally, they recognized that people with disabilities are capable of much more than they are often credited for, highlighting the importance of recognizing and valuing the abilities and strengths of individuals with disabilities.

*Being able to identify what is the disability & what is the person is a real skill.*

*Only people who have consistent interactions are able to know the difference. –*

*Sibling Participant 3*

Of the participants, nine expressed that even though they have experience supporting their sibling with a disability, it can still be challenging to connect and provide the best care. They noted that supporting someone with a disability can be an ever-evolving process that requires ongoing learning and adaptation. In particular, three participants struggled with their siblings' continuously changing care routine, which left them feeling drained and challenged in understanding and supporting their sibling. These experiences highlight that even with a positive overall view of having a sibling with a disability, there can be difficulties and challenges that arise, requiring ongoing support and attention to maintain a healthy and positive relationship.

Overall, nine participants in the study had a prominent drive to support their whole family, not just their sibling with a disability. Participants' roles changed over time as they aged into adulthood. Five participants noted that as they grew older, their role and position within the family shifted. They felt less like siblings and more like parents, taking on caregiving responsibilities for their sibling with a disability. Interestingly, two participants who were younger than their sibling with a disability felt that as they grew into adulthood, they now felt like the older sibling in their relationship. As parents aged, stepping into a different position felt common among participants. Four participants

noted that they felt like the peacekeepers of their family and needed to hold the family together. However, some participants who felt they kept the peace in their families had difficulties leaving their family homes to live independently because they could no longer keep the peace in their families. It was evident that participants understood their role in their families, recognizing when they had to step up and fill certain roles in support of the whole family, not just their sibling.

When participants were asked questions about how they perceived themselves as humans, there was a general positive collective response. All participants in the study responded that they thought they were good people and a good sibling to their brother or sister with a disability. When asked to describe themselves in three words and how their parents viewed them in three words, five participants shared words of the same tone and meaning on how they viewed themselves similar to their parents. Three participants used better words to describe themselves, indicating a high level of self-esteem and confidence. However, two participants used words that described how their parents viewed them better than their own self-perception, suggesting a potential struggle with self-esteem and self-worth. Overall, participants had a positive self-image and were aware of their role as a supportive sibling to their sibling with a disability.

> *Having a sibling with a disability makes you appreciate family more. – Sibling Participant 5*

*You learn about the world through a different lens. I wouldn't be where I am*
*because I wouldn't have had this perspective and insight. A lot of door have*
*opened for me. – Sibling Participant 3*

All participants expressed that having a sibling with a disability impacted who they are today and made them better people. They acknowledged the challenges and difficulties that came with supporting their sibling but also the positive impact it had on their character and values. Participants felt a sense of purpose in being an important person in their sibling's life, and this motivated them to be a better version of themselves. Interestingly, nine participants in the study mentioned gravitating towards other people with disabilities outside of their family, indicating a heightened awareness and sensitivity towards individuals with disabilities. Overall, participants gained valuable life lessons and experiences through having a sibling with a disability, which impacted their personal growth and sense of empathy towards others.

## 7. DISCUSSION

Disability research often fails to recognize other family members of the family especially siblings of individuals with disabilities who are heavily involved and critically important to their family's stability. Traditionally studies lean towards wanting to understand the adverse effects when "raising" a child with a disability all while dismissing the many diverse perspectives and experiences of all family members. Studies show that siblings of individuals with disabilities describe their experiences as positive and are willing to act as future primary caregivers. Naturally, there are common challenges when living

with an individual with a disability however, there are many gaps in literature that dismiss these positive experiences of individuals who have siblings with disabilities (Trandovski et al., 2018; Paul et al., 2022). The majority of disability research has focused on the deficiency model and focused on the negative implications. It is important that there is an increased focus on the growth perspectives and potential constructive experiences individuals obtain as a result of being challenged by the demands of life when having a sibling with a disability (Milevsky & Singer, 2011). In analyzing the findings of this study, highlighted are participants many positive self-perceptions along with positive views of other family members including their sibling with a disability. Siblings of people with disabilities are a heterogenous group and it is important to absorb and reflect on their experiences because they are prone to unique perspectives and being able to further describe their sibling's lifestyle differently than others in their family (Friedman & Oleksa, 2017). By amplifying the voices of siblings of individuals with disabilities, readers gain a deeper understanding of the daily realities experienced by other family members through the lens of someone who is intimately familiar with this way of life. Siblings of those with disabilities can define their quality of life differently from that of their family. Therefore, it's valuable to account for the sibling's experiences (Moyson & Roeyers, 2012). It was important to provide participants the opportunity to voice their opinions and understanding of how they perceived themselves and other members of the family in this study. While precedent studies in this field of research focus heavily on the perceptions of parental views towards their child with a disability, this study was able to leverage alternative perspectives and capture a sibling's views of themselves and other family members. Further, this study allowed

participants to rationalize how they inherently feel and compose themselves based on their experiences. It was found that the majority of participants in the study expressed that their unique circumstances growing up in a family with someone who has a disability has positively impacted their way of live and influenced who they are independently as a person. Overall, this study importantly shifts the one-directional focus in disability-sibling research to better account for other members of the family.

Existing disability relationship research tends to focus on current in-time experiences or specific life periods when gathering data from participants. Furthermore, disability studies tend to focus on children. In cases where participants gathered for studies are adolescents or older aged adults, the information collected draws on current time experiences rather than longitudinal experiences from childhood into adulthood. This transition age experience is commonly dismissed from research and intercepts readers to corelate youth and young adulthood experiences that can impact current time practices. Thus, methodological practices in precedent research can be limiting (Sommantico et al., 2020), because they are unable to incorporate longitudinal data which can better rationalize and support the lived experiences and data in disability research. When accounting for childhood and adulthood experiences in this study, the data analyzed can summarize one's whole life experiences up to current time and encompass larger timeline findings. Overall, this study was able to successfully capture longitudinal data that was able to support a sibling's perception of themselves along with life long experiences which to support their rationale of how they compose themselves.

When observing sibling relationships when involving a disability, there is an emphasis

on the shared human agency of togetherness. Important factors in sibling relationships

include perceptions and attitudes of the family, general family dynamics and constructed

family relationships over the course of their lifetime (Avieli et al., 2019). While all of

these factors are critical to understand the experiences and perceptions of family

members, this study provides insight on an individual's interdependence relative to their

family along with their need to individually develop separately from their family. A

common response among participants was the need to develop independently from

their family unit while being present for their families and supportive of their sibling with

a disability. Recognizably during the young adult stages of life, this study's findings

reflects the importance of individuals leaving their family home to pursue a career or

educations so that they may develop themselves independently. With multiple pathways

for acquiring independence, this concept is especially important for individuals who will

required to increase their supportive care towards their sibling in later life years and as

their parents age out of their capacity to care.

Sibship relationships emphasize the shared agency of togetherness built from shared

childhood and history. Growing up together provides a platform for partnership and

creates special bonds and unique qualities to surface (Avielli et al., 2019). Personal

qualities such as maturity and understanding were correlated to good sibship

relationships and are comparative characteristics to other sibling disability research that

currently exists. Although these qualities are precedingly touched upon as an outcome

of having to care for their sibling with a disability, observed in studies with younger aged children and from the viewpoint of the researcher, this particular study pulled data relevant to these characteristics solely from the perspective of the sibling themselves. Participants were able to recognize that they acquired these attributes themselves from their sibship experiences.

While there is an overall lack of research into understanding perceptions and sense of self of other members of the family when related to someone with a disability, there are even fewer Canadian and provincial specific studies in the disability research field. Precedent Canadian studies observing the position and viewpoints of siblings of those with disability are spars. As knowledge and experience are gained from caregivers of those with disabilities including family members, high-quality and regularly updated research remains important (Sullivan et al., 2011). Contestably, this study is one of few Canadian studies that examines the lives of siblings in families with someone who has a disability and accounts for the direct perspectives of the sibling. It is important to expand disability research to account for the experiences of members relative to people with disabilities and continue adding to the spars body of knowledge that currently exists.

## 8 IMPORTANT CONSIDERATIONS

### 8.1 Conflict of Interest

The author of this research study happens to have a sibling who has a disability and thus the idea of this particular research hypothesis was originally constructed based on personal experiences. To remove any conflicts of interest, the researcher did not part-

take in the study. Additionally, the researcher selected a research analysis method that would allow themes to form naturally from the experiences of the participants of the study. Thus, results were derived solely from the participants and not the researcher.

## 8.2 Limitations

With the study positioned in the field of disability research, there were difficulties in acquiring Research Ethics Board (REB) consent. To please the REB review panel, additional measures had to be accounted for with this particular study. Even though the study was seeking the opinions of the participants aged over 18 and able to consent for themselves, REB required an Assent Form be included in the study for parents (legal guardians) or the participant's siblings who have disabilities themselves to assent for their family members to part-take in the study. This presented difficulties when trying to recruit participants because it added another layer of consent to the study from individuals who were not participating directly in the study. Canadian research case studies with similar study approaches which did not require an Assent Form were presented to Research Ethics Board to argue that an Assent Form was not necessary and detrimental to the study. This approach was not successful and an Assent Form was used in order to please the REB and receive the green light for the research.

Recruiting participants was also challenging because individuals aged over the age of 18 might not have had a living parent to assent for them and/or their sibling with a disability was unable to assent for them. Additionally, in the case where a sibling or parent was capable to sign, potential participants felt guilted to participate in the study

as they were unsure if their parents or siblings would want them to participate.

Research Ethics Board's requirement to have a second family member assent to

participate was a deterrent to many potential participants and ultimately hampered the

study because fewer people wanted to take part in the study. For older aged

participants, individuals particularly felt that they did not require assent from another

member because their parents were significantly older. In this circumstance,

participants who were already mature adults felt old enough to consent for themselves.


## 8.3 Future Work

As research in this field continues to grow, it is becoming increasingly important to

account for the lived experiences of family members in developing programs and

strategies to support them. While parents have been more extensively studied than non-

disabled siblings in families where a member has a disability, there is a need for

increased studies on other perceptions of other family members. Moreover, there is a

need to examine the perceptions of those with disabilities and how they view

themselves and their experiences with family members, which has received even less

attention in research.


Furthermore, as this study was conducted solely in Ontario, Canada, there is a need to

expand the study to account for inter-provincial experiences and perspectives.

Additionally, while the study found no financial implications and generally positive views

and experiences among participants, it would be worthwhile to interview families from

low-socioeconomic backgrounds to determine if they hold similarly positive perspectives despite facing financial challenges.

In summary, this study underscores the importance of listening to and accounting for the experiences of family members in understanding the impact of disabilities on individuals and families. It also highlights the need for further research in this area to ensure that support programs and strategies are informed by a diverse range of perspectives and experiences.

## 8.4 Further Need

Discussing the future care of a sibling with a disability can be a difficult topic to broach, particularly for young adults who may not have had previous experience in planning for long-term care. However, having these conversations early on can be beneficial in ensuring that appropriate arrangements are made for the future care of the sibling with a disability. To support families in these discussions, there is a need for better resources and program initiatives that provide information about disabilities and how to better care for individuals with disabilities. Programs that support family members of those with disabilities can also be beneficial, providing a safe space to discuss concerns and receive support. Additionally, resources that help families navigate the transition of care from parents to their children or other family members can be helpful. Connecting individuals with siblings who have disabilities to like-minded others can also be beneficial, providing opportunities for shared experiences and support. Overall, better

resources and program initiatives can help families to better plan for the future care of

their sibling with a disability and feel more confident in their ability to provide support.

*I went to sibling workshops and they made me feel less alone. I'm happy to know*

*there are others out there like me. – Sibling Participant 3*

*There's not enough disability information out there. Information on adult disability*

*needs and adult resources. – Sibling Participant 1*

## 9. CONCLUSION

Understanding the lived experiences and dynamics of family members when one member identifies as having a disability is vaguely researched in current bodies of knowledge. In particular siblings in such families are further rarely focused on in relationship disability research. Ontario-based research into understanding the lived experiences and identification of siblings of those with disabilities was long overdue. With conditioned high levels of involvement naturally occurring, continued efforts in disability research must seek to obtain experiences and knowledge from other family members. Valuable insight can be gathered from family members as we can gain perspectives of other lived experiences and personal interpretations to comprehend the needs of these particular family members.

As previously noted, siblings of individuals with disabilities have distinctive and diverse experiences due to their unique upbringing. This research sheds light on the personal challenges and advantages experienced by participants with a sibling with a disability. The study offers valuable insights into the needs of these individuals and the support that can be provided to them in the future. The study effectively captures how the participants perceive themselves based on their experiences, which have arguably played a crucial role in shaping their identity and self-awareness. Their experiences with a sibling with a disability have influenced their personal growth and how they conduct themselves in life. Even though many participants experienced the complex realities of having a sibling with a disability, this study was able to collect positive intrapersonal and

interpersonal information. Overall, when researching the experiences relative to one's

understanding and sense of self, we can better understand these individuals and inform

how to support them best moving forward.

## 10. ETHICS STATEMENT

The author sought all relevant ethical approvals. Ethical approval was provided by

OCADu's Human Research Ethics Committee (approval number 2022-80).

# A. REFERENCES

Adeoye-Olatunde, Omolola A., and Nicole L. Olenik. "Research and scholarly methods: Semi-structured interviews." *Journal of the american college of clinical pharmacy* 4.10 (2021): 1358-1367.

Avieli, Hila, Tova Band-Winterstein, and Tal Araten Bergman. "Sibling relationships over the life course: Growing up with a disability." *Qualitative health research* 29.12 (2019): 1739-1750.

Bigby, Christine. "Parental Substitutes: The Role of Siblings in the Lives of Older People with Intellectual Disability." *Journal of Gerontological Social Work*, vol. 29, no. 1, 1998, pp. 3–21, https://doi.org/10.1300/J083v29n01_02.

Bowen Murray. *Family Therapy in Clinical Practice*. Jason Aronson 1978.

"Bowen's Theory: History and Concepts." *Bowen Theory Academy, https://bowentheoryacademy.org/bowen-theory/bowen-theory-history-and-concepts.* Accessed January 21, 2023.

Bronfenbrenner, Urie. "Toward an experimental ecology of human development." American psychologist 32.7 (1977): 513.

Calatrava, María, et al. "Differentiation of self: A scoping review of Bowen Family Systems Theory's core construct." Clinical Psychology Review 91 (2022): 102101.

Caspi, Jonathan, ed. Sibling development: Implications for mental health practitioners. Springer Publishing Company, 2010.

Cebula, Katie, and Hanna Kovshoff. "Editorial - Understanding Sibling Relationships in Developmental Disabilities." *Research in Developmental Disabilities*, vol. 99, 2020, pp. 103607–103607, https://doi.org/10.1016/j.ridd.2020.103607.

Chambers, Cynthia R. "Siblings of individuals with disabilities who enter careers in the disability field." *Teacher education and special education* 30.3 (2007): 115-127

Corby, Deirdre, Laurence Taggart, and Wendy Cousins. "People with intellectual disability and human science research: A systematic review of phenomenological studies using interviews for data collection." *Research in Developmental Disabilities* 47 (2015): 451-465.

Crossno, Mary Ann. "Bowen family systems theory." *Marriage and family therapy: A practice-oriented approach* (2011): 39-64.

Cuzzocrea, Francesca, et al. "Parents' Competence and Social Skills in Siblings of Disabled Children." *Social Behavior and Personality*, vol. 42, no. 1, 2014, pp. 45–57, https://doi.org/10.2224/sbp.2014.42.1.45.

Davis, Kate, and Susana Gavidia-Payne. "The impact of child, family, and professional support characteristics on the quality of life in families of young children with disabilities." *Journal of Intellectual and Developmental Disability* 34.2 (2009): 153-162.

Dew, Angela, et al. "Post-Parental Care: a New Generation of Sibling-Carers." *Journal of Intellectual & Developmental Disability*, vol. 29, no. 2, 2004, pp. 176–79, https://doi.org/10.1080/13668250410001709520.

De Caroli, Maria Elvira, and Elisabetta Sagone. "Siblings and disability: A study on social attitudes toward disabled brothers and sisters." *Procedia-Social and Behavioral Sciences* 93 (2013): 1217-1223.

Ferguson, Philip M. "Mapping the family." *Handbook of disability studies* (2001): 239-247.

Flick, Uwe, ed. *The SAGE handbook of qualitative data analysis*. Sage, 2013.

Friedman, Carli, and Aleksa L. Owen. "Defining disability: Understandings of and attitudes towards ableism and disability." *Disability Studies Quarterly* 37.1 (2017): 2.

Gibbs, Graham. *Analyzing Qualitative Data*. 2nd edition., SAGE Publications Ltd, 2018.

Goldsmith, Laurie J. "Using Framework Analysis in Applied Qualitative Research." *Qualitative Report* 26.6 (2021).

Guy-Evans, Olivia. "Bronfenbrenner's ecological systems theory." https://www.simplypsychology.org/bronfenbrenner.html (2020).

Härkönen, Ulla. "The Bronfenbrenner ecological systems theory of human development." (2001).

Harty, M., et al. "Exploring Sibling Attitudes Towards Participation When the Younger Sibling Has a Severe Speech and Language Disability : Research." *SAJCH : the South African Journal of Child Health*, vol. 10, no. 1, 2016, pp. 47–51, https://doi.org/10.7196/SAJCH.2016.v106i1.1046.

Hayden, Nikita K., et al. "A Population-Based Study of the Behavioral and Emotional Adjustment of Older Siblings of Children with and Without Intellectual Disability." *Journal of Abnormal Child Psychology*, vol. 47, no. 8, 2019, pp. 1409–19, https://doi.org/10.1007/s10802-018-00510-5.

"Introduction to the Eight Concepts." The *Bowen Center for the Study of the Family, https://www.thebowencenter.org/introduction-eight-concepts.* Accessed January 21, 2023.

Johnson, Genevieve Marie, and Korbla P. Puplampu. "Internet use during childhood and the ecological techno-subsystem." Canadian Journal of Learning and Technology 34.1 (2008): n1.

Lampis, Jessica et al. "Differentiation of Self and Dyadic Adjustment in Couple Relationships: A Dyadic Analysis Using the Actor-Partner Interdependence Model." Family process vol. 58,3 (2019): 698-715. https://doi.org/10.1111/famp.12370

Langdridge, Darren. *Phenomenological psychology: Theory, research and method*. Pearson education, 2007.

Meltzer, Ariella, and John Kramer. "Siblinghood through Disability Studies Perspectives: Diversifying Discourse and Knowledge About Siblings with and Without Disabilities." *Disability & Society*, vol. 31, no. 1, 2016, pp. 17–32, https://doi.org/10.1080/09687599.2015.1127212.

Meltzer, Ariella. "Embodying and Enacting Disability as Siblings: Experiencing Disability in Relationships Between Young Adult Siblings with and Without Disabilities." *Disability & Society*, vol. 33, no. 8, 2018, pp. 1212–33, https://doi.org/10.1080/09687599.2018.1481016.

Meyer, Donald, and Patricia F. Vadasy. Living with a brother or sister with special needs: A book for sibs. University of Washington Press, 2014. Web.

Milevsky, Avidan, and Orly Singer. "Growing up alongside a sibling with a disability: A phenomenological examination of growth and deficiency in adulthood." *Research in Developmental Disabilities* 130 (2022): 104336.

Moyson, T., and H. Roeyers. "'The Overall Quality of My Life as a Sibling Is All Right, but of Course, It Could Always Be Better'. Quality of Life of Siblings of Children with Intellectual Disability: The Siblings' Perspectives." *Journal of Intellectual Disability Research*, Accepted 13 January 2011, vol. 56, no. 1, 2012, pp. 87–101, https://doi.org/10.1111/j.1365-2788.2011.01393.x.

Paat, Yok-Fong. "Working with immigrant children and their families: An application of Bronfenbrenner's ecological systems theory." Journal of Human Behavior in the Social Environment 23.8 (2013): 954-966.

Paquette, Dede and John Charles Ryan. "Bronfenbrenner's Ecological Systems Theory." (2001).

Paul, Alicia M., et al. "Experiences of siblings of people with intellectual disabilities: Multiregional perspectives." *Family Relations* 71.2 (2022): 671-685.

Roper, Susanne Olsen, et al. "Caregiver Burden and Sibling Relationships in Families Raising Children With Disabilities and Typically Developing Children." *Families Systems & Health*, vol. 32, no. 2, 2014, pp. 241–46, https://doi.org/10.1037/fsh0000047.

Rum, Yonat, et al. "Are there positive effects of having a sibling with special needs? Empathy and prosociality of twins of children with non-typical development." *Child Development* (2022).

Ryan, Dede Paquette–John. "Bronfenbrenner's ecological systems theory." Retrieved January 9 (2001): 2012.

Scabini, Eugenia, and Claudia Manzi. "Family Processes and Identity." *Handbook of Identity Theory and Research*, Springer New York, 2011, pp. 565–84, https://doi.org/10.1007/978-1-4419-7988-9_23.

Sommantico, Massimiliano, Santa Parrello, and Barbara De Rosa. "Sibling Relationships, Disability, Chronic, and Mental Illness: Development of the Siblings' Experience Quality Scale (SEQS)." *Journal of Developmental and Physical Disabilities* 32.6 (2020): 943-961.

Sullivan, William F., et al. "Primary care of adults with developmental disabilities: Canadian consensus guidelines." *Canadian Family Physician* 57.5 (2011): 541-553.

Taylor, Tina M., et al. "Family Cohesion and Positive Sibling Relationships in Families Raising a Child with or Without a Disability." *Exceptionality : the Official Journal of the Division for Research of the Council for Exceptional Children*, vol. ahead-of-print, no. ahead-of-print, 2022, pp. 1–17, https://doi.org/10.1080/09362835.2022.2100391.

Thomas, David R. "A general inductive approach for qualitative data analysis." (2003).

Trandovski, Kristina, and Shelley L. Watson. "Sibling Experiences in Families of a Child With a Disability: Down Syndrome, Cystic Fibrosis, and Cerebral Palsy." *Journal on Developmental Disabilities*, vol. 23, no. 2, 2018, pp. 120–21.

Vella Gera, Janet, et al. "An Insight into the Lives of Young Siblings of Disabled Children in Malta." *Disability & Society*, vol. 36, no. 1, 2021, pp. 58–80, https://doi.org/10.1080/09687599.2020.1712188.

Yeh-Chen, K. Siblings of a child with an intellectual disability: identifying those at risk. Canada: National Library of Canada. (2000). Web.

## B. Figure Sources

Figure 1 - Bowen Murray. *Family Therapy in Clinical Practice*. Jason Aronson 1978.

Figure 2 - Johnson, Genevieve Marie, and Korbla P. Puplampu. "Internet use during childhood and the ecological techno-subsystem." Canadian Journal of Learning and Technology 34.1 (2008): n1.