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Siblings of people with intellectual disability: Relationships and decision-making across the life span

Wendy Simpson

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Siblings of people with intellectual disability:
Relationships and decision-making across the life span

Wendy Simpson

A thesis submitted for the degree of
Doctor of Philosophy

School of Arts and Humanities
Edith Cowan University

February 2021
Abstract

A growing amount of research focuses on siblings of children with disabilities. However, limited evidence exists to provide a solid understanding and depth of knowledge of the issues that affect adult sibling relationships when one has intellectual disability. Since sibling relationships are the longest lasting family relationship, they are becoming more important because people with disability are outliving their parents or main caregivers. The increased longevity of people with disability has a societal and economic impact that has been recognised in the context of the recently introduced National Disability Insurance Scheme (NDIS) in Australia. By exploring the experiences of siblings who have a brother or sister with intellectual disability, this study aimed to understand how family characteristics and childhood experiences influence sibling relationships and decision-making across the life span.

Utilising a mixed methods approach—predominantly a qualitative study design—a total of 79 adult siblings of a person with intellectual disability from Perth, Western Australia, completed an online survey and/or participated in an interview. Participants ranged in age from 18 to 70+ years of age. Qualitative data were analysed using a thematic analysis process, guided by Braun and Clarke’s (2006) six-phase framework. Four major themes were constructed that captured the experience of growing up with a sibling with intellectual disability: relationships, knowledge and understanding of disability while growing up, siblings as carers and the consequences for family.

The findings revealed that the birth or diagnosis of a child in the family with intellectual disability resulted in a change in the family dynamics, a focus on the child with disability and parental differential treatment. Siblings reported a sense of having missed out while growing up and an ascribed or assumed role of carer. The variables that influence the relationship between siblings when one has intellectual disability were found to be broad, including individual, family and disability characteristics. In addition, this study found evidence to support findings from earlier research that correlates growing up with a sibling with disability and a propensity to follow a career path in a helping or service profession. Limited evidence was found in this study of a mutually beneficial close relationship with a sibling with intellectual disability that did not have elements of care, protection or a sense of responsibility attached. Findings also revealed that in adulthood, siblings often felt ‘disconnected’ from their sibling with intellectual disability when formal support services were in place, sometimes leading to
discord between service providers and siblings regarding the nature of support for their sibling with intellectual disability.

These findings have implications for policy and practice in disability services because they highlight the importance of holistic family inclusion that includes siblings to enhance natural relationships and supported decision-making with siblings with intellectual disability. Recommendations include the recognition of siblings in policy and legislation, particularly in the NDIS; the inclusion by disability support and early intervention services of siblings in family discussions, planning and decision-making; and making readily available augmentative and alternative methods of communication as an imperative means of promoting sibling connectedness when one has intellectual disability. This study adds to the literature on adult sibling-disability research from an Australian perspective.

**Key words:** siblings, relationships, intellectual disability, decision-making, family inclusion
Declaration

I certify that this thesis does not, to the best of my knowledge and belief:

i) incorporate without acknowledgement any material previously submitted for a degree or diploma in any institution of higher education;

ii) contain any material previously published or written by another person except where due reference is made in the text of this thesis; or

iii) contain any defamatory material.

Signed: [Redacted]

Date: 23/2/2021
Acknowledgements

There are many people I need to thank for their support during my journey of self-discovery and my quest for knowledge. Fifteen years after I started this journey, I thought my quest for knowledge would come to an end, but even as I complete this thesis I am wondering where this will lead me, thinking of the huge amount I believe I am yet to learn.

My family have been beside me all the way, and my husband Dean has been my rock. He has been with me through the tears, laughter and surprises, but he has always been there. Without him, this thesis would not exist. My children, and the four grandchildren I have gained since I commenced my studies in 2006, are the reason I have kept going. I want, hopefully, to inspire my children and grandchildren to strive to be the best they can be. There have also been losses. As I was completing my Master’s degree in 2015, I lost both of my beloved parents, but I know they were proud of me, so I continued on. I have a lot to thank them for.

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In the final year of my PhD I have also had support from the Australian Government through a Higher Degree by Research Training Scheme Scholarship. This has enabled me to concentrate on my thesis in my final year. I feel honoured and privileged to have received this accolade.

A big thank you to Rachel Wheeler who edited the thesis in compliance with D and E of the Australian Standards for Editing Practice, as required by the Institute of Professional Editors’ Guidelines for Editing Research Theses.

But most all of I wish to thank the participants of this study. I have had the privilege to have an insight into a very precious window of their lives. The tears that we shared, the joy that I witnessed and the time I have spent with these wonderful people has had a monumental impact on my life. We have so much to learn from the siblings of people with disability.
This very special comment will remain with me forever:

I think there’s a lot that, as a society, we could learn. And perhaps there will be creative people out there that come up with strategies and protocols and things that will make the lived experience for future generations something different to the lived experience that I had.

To the 79 siblings, thank you, from the bottom of my heart.
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<th>Description</th>
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<tbody>
<tr>
<td>AAC</td>
<td>Augmentative and alternative communication</td>
</tr>
<tr>
<td>ABS</td>
<td>Australian Bureau of Statistics</td>
</tr>
<tr>
<td>AIHW</td>
<td>Australian Institute of Health and Welfare</td>
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<tr>
<td>ASD</td>
<td>Autism spectrum disorder</td>
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<tr>
<td>CDT</td>
<td>Critical disability theory</td>
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<tr>
<td>CRPD</td>
<td><em>Convention on the Rights of Persons with Disabilities</em></td>
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<tr>
<td>DALYs</td>
<td>Disability-adjusted life-years</td>
</tr>
<tr>
<td>DS</td>
<td>Down syndrome</td>
</tr>
<tr>
<td>DSA</td>
<td><em>Disability Services Act 1993 (WA)</em></td>
</tr>
<tr>
<td>DSC</td>
<td>Disability Services Commission</td>
</tr>
<tr>
<td>DS NMDS</td>
<td>Disability Services National Minimum Data Set</td>
</tr>
<tr>
<td>ECU</td>
<td>Edith Cowan University</td>
</tr>
<tr>
<td>ICF</td>
<td>The International Classification of Functioning, Disability and Health</td>
</tr>
<tr>
<td>ICIDH</td>
<td>International Classification of Impairments, Disabilities and Handicaps</td>
</tr>
<tr>
<td>ID</td>
<td>Intellectual disability</td>
</tr>
<tr>
<td>NDA</td>
<td>National Disability Agreement</td>
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<tr>
<td>NDIA</td>
<td>National Disability Insurance Agency</td>
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<tr>
<td>NDIS</td>
<td>National Disability Insurance Scheme</td>
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<tr>
<td>NDIS Act</td>
<td><em>National Disability Insurance Scheme Act 2013 (Cth)</em></td>
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<td>NMDS</td>
<td>National minimum data set</td>
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<td>SDAC</td>
<td>Survey of Disability, Ageing and Carers</td>
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<tr>
<td>SLCG</td>
<td>Slow Learning Children’s Group</td>
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<tr>
<td>UK</td>
<td>United Kingdom</td>
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<tr>
<td>US</td>
<td>United States</td>
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<tr>
<td>WHO</td>
<td>World Health Organization</td>
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A note on the abbreviations used in the thesis:

Throughout this thesis I use the abbreviations ID for intellectual disability, ASD for autism spectrum disorder, and DS for Down syndrome. When referring to a person, for example, sibling with intellectual disability, these terms are written in full.
Definition of terms

**Autism spectrum disorder (or autism):** A developmental disorder characterised by symptoms of difficulty with social interaction, restricted or repetitive behaviour and impaired communication skills, evident from early childhood (Australian Institute of Health and Welfare, 2017).

**Decision-making disability:** Individuals who have a cognitive disability and need support to make decisions or require a substitute decision-maker (Office of the Public Advocate, 2015).

**Deinstitutionalisation:** The closure of institutions and the relocation to group or community living for people with disability (Wiesel & Bigby, 2015).

**Down syndrome:** A genetic condition, also sometimes known as trisomy 21, which may result in some level of intellectual disability or developmental delay (Down Syndrome Australia, 2020).

**Intellectual disability:** A reduced ability to understand, learn or apply new skills, which begins in childhood and has a lasting effect on development (World Health Organization [WHO], n.d.).

**Life span:** The period of time of an individual’s life from birth to death (Cicirelli, 1995).

**Medical model of disability:** A model that views disability as a medical problem of an individual requiring medical care to treat or correct the problem (WHO, 2002).

**Mixed methods:** A research design in which researchers mix quantitative and qualitative methods to address a research purpose (Plano Clark & Ivankova, 2016).

**Normalisation:** The normalisation principle means “making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society” (Nirje, 1969, p. 19).

**Phenomenology:** Phenomenology is the study of the lived experience of individuals, searching for a common meaning within a particular concept or phenomenon (Creswell, 2014).

**Quality of life:** An individual’s perception of the quality of their life from a physical, psychological and social viewpoint (WHO, 1997).
**Short-term accommodation:** Also known as respite accommodation or respite care. More recently, the term ‘short-term accommodation’ is preferred.

**Sibling-disability research:** This is a term that acknowledges research with a focus on people with a sibling, or siblings, with disability (Meltzer, 2017).

**Social models of disability:** Social models of disability view disability as a social problem in an environment that does not meet the needs of an individual (WHO, 2002).

**Social role valorisation:** Further development of the concept of ‘normalisation’ led to a redefinition to ‘social role valorisation’. This is defined as the “establishment, enhancement, or defense of the social role(s) of a person or group, via the enhancement of people’s social images and personal competencies” (Wolfensberger, 1983, p. 435).

**Supported accommodation:** In this thesis, the term ‘supported accommodation’ refers to group homes, cluster homes or individual accommodation for people with disability, supported by paid staff.
Chapter 1  Introduction

Research has shown that the life expectancy of people with disability has undergone faster rates of growth than that of the general population since the late 1900s (Bigby, 2010) and that many children with disability are now outliving their parents (Australian Government, 2011). Siblings often provide the care or support for their sibling with intellectual disability when their parents are no longer able to provide it (Arnold et al., 2012; Bigby, 1997; Davys et al., 2011; Dew et al., 2004; Heller & Caldwell, 2006). Representing the longest lasting family relationship (Cicirelli, 1995), sibling relationships are becoming increasingly important and play a vital role in the lives of people with disability (Heller & Arnold, 2010; McHale et al., 2016; Walker & Ward, 2013).

The increased longevity of people with disability has a societal and economic impact that has been recognised in the context of the recently introduced National Disability Insurance Scheme (NDIS) in Australia (Meltzer & Davy, 2019). The support that families, friends and natural networks can provide to people with disability is considered essential in NDIS planning to ensure that plans for the “reasonable and necessary” support they require throughout their lifetime can be achieved (Kendrick et al., 2017, p. 4).

This study takes a life-span perspective to assist understanding of how relationships between siblings when one has intellectual disability (ID) change over the lifetime, influenced by past experiences and future expectations. Cicirelli (1995) believes that to understand sibling relationships it is necessary to consider this perspective. A life-span perspective can explain the significance of age gaps between siblings and the impact and long-term effects of experiences in childhood (Cicirelli, 1995), such as career choice or the decision to provide care for a sibling with intellectual disability as they age (Saxena & Adamsons, 2013). Sibling relationships are unique, and connectedness and commitment to their sibling with intellectual disability will change over the life span, “constantly evolving and subject to continuous redefinition” (Atkin & Tozer, 2013, p. 237).

This thesis begins with a purpose statement to define the aims and scope of the study. Disability statistics in Western Australia (WA) and Australia and an introduction to relevant sibling-disability research are presented to provide a background to the
study. The significance of the study is described, and the research questions are defined. The chapter closes with a summary of the structure of the thesis.

1.1 Purpose and aims of this study

The purpose of this sequential, explanatory mixed methods study was to gain a greater understanding of the experiences that influence relationships between siblings when one has ID, and how family characteristics and childhood experiences influence decision-making across the life span. This study aims to add to the previous literature and evidence though understanding sibling relationships from a Western Australian context to inform current and future disability services and legislation.

1.2 Scope of the study

This study focused on people who have a sibling with intellectual disability to capture their experiences across the life span. ID is defined by the World Health Organization (WHO) as a disability that has a lasting effect on development and affects intelligence and social functioning, accompanied by a reduced ability to understand or learn new or complex information or skills (WHO, n.d.). In WA, the Office of the Public Advocate use the terminology ‘decision-making disability’ when referring to individuals who need support to make decisions or who require a substitute decision-maker, which might be as a result of ID, mental illness or acquired brain injury (Office of the Public Advocate, 2015). The recruitment for this study excluded people with a sibling with physical disability for whom no cognitive or decision-making disability was present, as well as those with a sibling for whom decision-making impairment had occurred as a result of mental illness, acquired brain injury or other condition in adulthood. In addition, since this study took a life-span perspective, siblings who experience age-related disabling health conditions or diseases that manifest in adulthood were not included in this study. Any age-related health condition, acquired disability or disease not present in childhood would not have had an impact on sibling experiences that began in childhood and extended through to adulthood. Siblings with a coexisting physical and intellectual disability were included in this study cohort.

1.3 Background

The following section presents the data that reports on the prevalence of disability by type in WA and Australia, and an explanation of how age-related disability affects the data. The NDIS is introduced in this section, and the unique way the NDIS was launched in WA that differed from the other states of Australia. The purpose of this
section is to provide a justification for the scope of this study and the focus on siblings with intellectual disability (which includes Down syndrome) and autism spectrum disorder as the most prevalent primary disability.

1.3.1 Disability prevalence in Western Australia and Australia

Several statistical methods of data collection in Australia provide state and national data on the prevalence of disability. The Australian Bureau of Statistics (ABS) conducts a census every five years, and data relating to this is readily available to the public. In addition, the ABS has conducted the Survey of Disability, Ageing and Carers (SDAC) at regular intervals since 1981. The SDAC collates data and demographic information to measure the prevalence of long-term health conditions and the need for support for older people, people with disability and carers in Australia (ABS, 2020).

The disability data collected in WA and Australia demonstrate that people with intellectual disability and autism spectrum disorder (ASD) represent the largest cohort of people with disability in WA (Office of the Public Advocate, 2015). However, the symptoms of ASD can vary from mild to severe, and while ASD may create barriers in education, employment and self-care (Australian Institute of Health and Welfare [AIHW], 2017), not all ASD diagnoses are associated with ID. Since the data collected in the SDAC are based on the identification of ASD with disability which has lasted, or is likely to last, for six months or more at the time of the survey (AIHW, 2017), they are the most reliable data reporting on the prevalence of ASD in Australia. It is important also to note that these data collection methods categorise people with Down syndrome (DS), and other genetic causes of ID, in the ID cohort. The SDAC also collects data on the prevalence of other conditions that may adversely affect decision-making, such as acquired brain injury, learning disabilities and developmental delay, all reported separately.

In the 1980s, disability data collected in the United Kingdom (UK) began to include disability caused by chronic disease related to ageing (Bury, 1996). According to Bury (1996), this resulted in chronic disease related to ageing dominating the statistics (with over half of the population who reported having disability over 75 years of age), thereby “underlining a trend away from disabilities caused by trauma and medical conditions in early life, to disorders in later life” (pp. 21–22). In Australia, the most recently published SDAC data at the time of the completion of this study (2020) also illustrated this trend; results revealed that differences of disability prevalence rates across the states and territories depend on the average age of the population in that state.
WA recorded the second lowest prevalence rate, at 16.4%, and Tasmania the highest prevalence rate, at 26.8% (ABS, 2020). The ABS (2020) attributed this difference to the greater number of older residents in Tasmania compared with WA. By removing the effects of age structure, the SDAC estimates an age standardised disability rate for all Australians at 16.1% (ABS, 2020).

It is also problematic to provide the prevalence of ID or ASD in the total number of people who reported having disability with any accuracy. This may be related to the decisions regarding diagnosis, including clinician understanding and diagnostic tests, and the difficulty in measuring the prevalence if people do not access formal support services. To place some perspective on the prevalence of disability in WA not related to conditions associated with ageing, statistics provided by the AIHW and the National Disability Insurance Agency (NDIA) that measure disability by access to funded disability support services are helpful.

### 1.3.2 Western Australian disability service users

The Australian Government has been collecting disability service user data since 1994 under the *Commonwealth, State and Territory Disability Agreements*, but it was not until 2004 that a minimum data set was collected for an entire financial year (AIHW, 2016). Renamed the *Disability Services National Minimum Data Set (DS NMDS)* in 2009, it is an annual reporting mechanism that requires all funded disability service providers to provide data for all service users, for each type of service they access. Data collected from the DS NMDS in 2018–2019 shows that 46% (n = 11,606) of people who accessed disability services in WA in 2018–2019 listed ASD or ID as their primary disability (see Figure 1.1; AIHW, 2020).
Since 2013, disability services in Australia have been transitioning to the NDIS, administered by the NDIA. The ideals of the NDIS centre on self-directed and individualised support for people with disability, with more choice and control over the delivery of their support (Kendrick et al., 2017), thereby moving away from welfare-based support systems (Reddihough et al., 2016). At the time of the introduction of the scheme, WA had already been providing self-directed, individualised support under the administration of the WA Disability Services Commission for some time (Kendrick et al., 2017; Reddihough et al., 2016), but the introduction of the NDIS meant that this would be the approach to service delivery for people with disability nationwide (Wilson et al., 2020). Trial sites were launched in South Australia, Tasmania, New South Wales and Victoria in 2013, with the Australian Capital Territory, the Northern Territory and Western Australian trial sites commencing in 2014 (Reddihough et al., 2019).

As a result of the political environment in WA at the time of the launch of the NDIS, and to preserve WA’s previous investment in the disability sector, WA initially opted to run two trials: one trial of the national NDIS administered by the federal government and one trial of a WA-based NDIS scheme, using the same principles as the national scheme but administered by the state government (Commonwealth of Australia, 2014). Following a WA state election in 2017, the commonwealth and state
governments announced a bilateral agreement for WA to join the nationally delivered NDIS, including a plan to begin state-wide transition to the scheme in April 2018 (Government of Western Australia, 2017). Since the commencement of the NDIS, the scheme has been implemented throughout the state geographically; consequently, not all people with disability in WA had access to the scheme at the same time. The geographical transition to the scheme was completed at the time of this study.

The most recent data provided by the NDIA at the time of this study reports that 59% (n = 16,099) of the 27,277 people who access the NDIS in WA listed ASD or ID as their primary disability (see Figure 1.2).

![Primary disability of people accessing NDIS in WA, March 2020](image)

Figure 1.2 Primary disability of people accessing the NDIS in WA, March 2020

Note. Total 27,277 service users. Down syndrome is included in the ID cohort. (NDIA, 2020)

The NDIA data indicate an increase in the number of people with a diagnosis of ASD who access services through the NDIS. A similar increase in ASD prevalence was reported in national data sets (AIHW, 2017). This apparent increase of the prevalence of ASD has been explained by the NDIA as a reflection of the phasing of the scheme because more people with autism spectrum disorder access the scheme over time than previously captured in the data (NDIA, 2019). A further explanation may be that the criteria for diagnosis of ASD in children have changed over the last 10 years, and, together with an increased understanding of ASD among practitioners, data that reports on the prevalence of ASD has increased rather than an increase in prevalence of the
syndrome itself (Anderson et al., 2016; ABS, 2019b). In addition, the AIHW suggested that the prevalence of ASD may be overestimated in the data (AIHW, 2017).

1.4 Significance of the study

Research exploring sibling relationships was limited until the 1980s, and there have been few publications in the area (Edward, 2011; Stoneman, 2005). Furthermore, few studies have explored adult relationships between siblings when one has disability (Arnold et al., 2012; Saxena & Adamsons, 2013), although several have focused on children or adolescents (Begum & Blacher, 2011; Breslau, 1982; McHale et al., 2016). Moreover, limited research exists written from a life-span perspective, since many studies were undertaken with younger siblings and did not explore age-related circumstances (Saxena & Adamsons, 2013). The existing literature is limited in the area of adult sibling relationships explored from the perspective of the sibling without disability, rather than that of a parent or parents (for example Arnold et al., 2012; Begum & Blacher, 2011; Breslau, 1982; Mulroy et al., 2008).

An increasing number of studies compared two disability groups, such as siblings with autism spectrum disorder and siblings with Down syndrome (e.g., Hodapp & Urbano, 2007; Orsmond & Seltzer, 2007), or focused on one type of disability (Carr, 2005). Despite the growing amount of research focused on siblings of children with disability, limited evidence exists that provides a solid understanding of the experiences that have influenced sibling relationships when one has ID (Stoneman, 2005). This gap is particularly notable in the Australian context.

To understand sibling relationships, the broader social and service context needs to be considered. In Stoneman’s (2005) examination of research themes relating to siblings and disability, the importance of the wider ecological environment that affects sibling roles and relationships was acknowledged. To advance understanding of the issues that influence sibling relationships, it is important that sibling-disability research places the sibling relationship at the centre of the research and all other influences are considered based on their proximal and distal influence thereafter (Stoneman, 2005). Stoneman’s model closely resembles Bronfenbrenner’s ecological systems theory (Bronfenbrenner, 1979), and this was considered when constructing the theoretical framework to underpin this study.

Fifteen years after the publication of Stoneman’s 2005 paper, there remains a dearth of evidence that advances understanding and knowledge of sibling relationships when one sibling has intellectual disability, particularly from the perspective of the
sibling without disability. The environmental context and contemporary attitudes towards disability arising out of disability reform over the last several decades, such as deinstitutionalisation, normalisation and rights-based practice, have had an impact on families and informal support networks (Kendrick et al., 2017). A large portion of the existing literature dates from the late twentieth century, and the full impact of rights-based practice may not have influenced adult family relationships at that time. In a review of the literature on siblings of adults with intellectual disability, Heller and Arnold (2010) identified that the context of care altered greatly over the period of the articles covered in their review (1986 to 2007), such as the effect of deinstitutionalisation on the family unit, the change in demographics because of longer life expectancy and the contemporary living options that are now available to people with disability. In Australia, disability reform, such as the NDIS, and new legislation have greatly altered the provision of care and support in the disability sector. New Australian research that explores the impact of disability reform on sibling relationships when one sibling has ID is required to enhance our understanding from a life-span perspective.

The limited literature available, particularly from an Australian perspective, reinforces the need for further research that seeks a greater understanding of the complex relationships between siblings when one has ID. Furthermore, research that explores the life-span perspective, such as this current study, can provide valuable information for current and future policy and legislation in the disability sector. This study seeks to bridge this gap.

This study is significant for three reasons: 1) it adds to the existing literature that explores adult sibling relationships when one has ID from the perspective of the sibling without disability; 2) it seeks to understand the experiences of growing up with a sibling with intellectual disability and the influences of those experiences on relationships and decision-making; and 3) it provides further evidence that supports the importance of the role of siblings and natural networks in the lives of people with intellectual disability (Kendrick et al., 2017). This study was conducted in the context of recent Australian legislative policy, particularly the National Disability Insurance Scheme Act 2013 (NDIS Act), in which the importance of family inclusion and the natural networks of support in the lives of people with disability are recognised.
1.5 Study design

This study utilised a mixed methods research design that combines both quantitative and qualitative approaches for data collection, collected sequentially. The rationale for this was to gain a broad understanding of these unique relationships, then through the purposive selection of participants to explore some of the experiences in more depth (Creswell, 2014; Tashakkori & Teddlie, 2010). Furthermore, the purpose of using mixed methods in this study was for validity, based on determination of the accuracy of the findings (Creswell, 2014). Mixed methods data collection, or ‘triangulation’, utilises data from different sources to add to the validity of a study (Creswell, 2014). Further description of the rationale for using mixed methods research is provided in Chapter 3.

Data were collected from a web-based survey and then followed up with semi-structured interviews with purposefully selected participants. The survey questions collected demographic data about participants and their sibling with intellectual disability (e.g., age and gender) and data about the characteristics of participants’ siblings’ disability and participants’ family and childhood experiences (see Appendix 1 for the survey). In the second stage of this study, semi-structured interviews explored participants’ experiences in greater depth (see Appendix 2 for the Interview Guide).

1.6 Research questions

According to Onwuegbuzie and Leech (2006), several steps precede the determination of research questions to ensure that the researcher is clear about what the study is hoping to discover. These steps comprise identifying the following: the significance of the study (Onwuegbuzie and Leech used the word ‘goal’); the objective of the study (to explore, describe, explain, predict or influence); the rationale for the use of qualitative, quantitative or mixed methods; and the research purpose. These steps have been identified earlier and therefore the research questions can now be determined.

The purpose of writing clear research questions is to ensure that the study has a framework and that it maintains a distinct direction and relevance to what the researcher is hoping to discover, thereby keeping the researcher focused on the purpose of the study (Onwuegbuzie & Leech, 2006; Plano Clark & Badiee, 2010). Onwuegbuzie and Leech (2006) stated that “research questions delimit the study, revealing its boundaries” (p. 478).
Mixed methods studies employ both qualitative and quantitative research questions that differ in the way they are presented (Creswell, 2014; Onwuegbuzie & Leech, 2006). Qualitative questions are ‘open-ended’, meaning that they allow the participant to describe their experiences by answering ‘what’ or ‘how’ questions with the purpose of exploring, understanding or discovering the participants’ experiences (Creswell, 2014). Qualitative research questions are also influenced by the research approach undertaken for the study; for example, ‘What are the experiences of …’ indicates a phenomenological study (Onwuegbuzie & Leech, 2006). Quantitative research questions are typically more specific and may be descriptive, comparative or indicate a relationship (Onwuegbuzie & Leech, 2006). According to Onwuegbuzie and Leech (2006), these questions are usually begin with ‘What is the relationship between …’ or ‘What are the influences of …’. 

The mixed methods research question is more complex. Onwuegbuzie and Leech (2006) stated that the mixed methods research question needs to “embed both a quantitative research question and a qualitative research question within the same question” (p. 483). However, Creswell (2014) suggested that in a mixed methods study the researcher should provide a quantitative research question, a qualitative research question and a question that addresses the mixed methods, presented at different points in the study. In a mixed methods study in which one stage builds on the other, the mixed methods research question will emerge as a result of mixing the two stages of the study (Creswell, 2014). According to Plano Clark and Ivankova (2016), the mixed methods research question should address the overall intent of the study.

The method of sequential data collection used in this study allows for the first stage (the survey) to inform the second stage (the interviews), and specifically to select topics for further consideration in the interviews and the development of the questions for the interviews. This is a dynamic process in which the responses from the survey questions are examined, allowing for a ‘reframing’ of the research question to explore responses or a phenomenon in greater depth (Tashakkori & Creswell, 2007). The reframing of the research question also provides an opportunity to evaluate whether the survey answered the research questions.

The central research question and sub-questions are presented below. The first sub-question necessitated the collection of quantitative data, and the remaining sub-questions are predominantly qualitative in nature.
Central research question

What are the family characteristics and lived experiences that influence sibling relationships and decision-making across the life span when a sibling has intellectual disability?

Research sub-questions

1. What individual and family characteristics influence sibling relationships in childhood and adulthood?

2. How do the participants perceive having a sibling with intellectual disability affect the family?

3. How did the provision of information to participants about their sibling’s disability affect sibling relationships and connectedness?

4. How has the participants’ experience of growing up with a sibling with intellectual disability influenced their decisions and choices across their life span?

5. What are the participants’ expectations regarding the future care and support of their sibling with intellectual disability?

The research question developed for the second stage of this study that informed the interview guide is presented at the end of Chapter 4, following the process described above (Tashakkori & Creswell, 2007). However, a preliminary overarching research question for the second stage of this study could be stated as, *How do the selected experiences identified in stage one contribute to the current relationship between siblings?*

The mixed methods, or integrated question (Plano Clark & Ivankova, 2016; Tashakkori & Creswell, 2007) is presented following the presentation of the research question for stage two. As previously discussed, the purpose of this approach was to devise a mixed methods research question that considers both stages of the study, the content of the study (Creswell, 2014) and the overall intent of the study (Plano Clark & Ivankova, 2016).

1.7 Thesis structure

The thesis comprises seven chapters. This introductory chapter has provided some background to the thesis topic, briefly introducing the literature that explores
sibling relationships. This chapter has also outlined the parameters and significance of the study so that the purpose and research questions could be defined.

The second chapter reviews the literature that explores the influences on sibling relationships when one has disability. Firstly, the chapter commences by considering the definitions of disability and the models and approaches to disability that underpin this thesis. Secondly, the themes that are identified in the prior literature are presented, including those of family and individual characteristics that influence sibling relationships, a sibling’s expectation to provide care or support for their sibling with intellectual disability in the future, childhood experiences and family relationships, and the information and support siblings received that may have influenced those relationships. Studies that explored the context of policy and advocacy and the impact on people with a sibling with intellectual disability are also reviewed.

Chapter 3 presents the study’s research design in a framework suggested by Denzin and Lincoln (2005). This chapter defines my assumptions as I undertook this study, explains the interpretive framework and underpinning theory used, presents the methodological approach and methods used for data collection, and describes the process of the data interpretation and evaluation.

Chapter 4 presents the findings from the first stage of this study and concludes with an explanation of how the participants were selected for interview, and how the interview guide and research questions were developed for the second stage. Chapter 5 presents the findings from the interviews conducted with selected participants in the second stage of this study. These chapters present descriptive quantitative data and qualitative data. Qualitative data from both stages of this study were analysed using the thematic analysis process described in Chapter 3. Thematic analysis and the development of the themes were guided by Braun and Clarke’s (2006) six-phase framework. Data are presented to demonstrate the themes developed, using verbatim statements from the participants.

Chapter 6, the discussion chapter, presents the findings from both stages of this study and synthesises them to find meaning and answers to the research questions. Finally, Chapter 7 concludes the thesis. It revisits the impetus for the study, presents the study’s contribution to knowledge and identifies the limitations. The thesis closes with recommendations for policy, practice and further research.
Chapter 2 Literature review

This chapter begins with a presentation of the commonly accepted definitions of disability and ID that can be applied and understood in the context of this study. This chapter also considers the literature relevant to disability models and approaches to provide an understanding of coexisting theoretical responses to disability. The literature review continues with an examination of the themes from the literature relevant to sibling-disability research.

2.1 Definitions of disability

To provide a consistent definition of disability, the WHO published the *International Classification of Impairments, Disabilities and Handicaps* (ICIDH) in 1980 to be used as a tool for the “classification of the consequences of disease … and of their implications for the lives of individuals” (WHO, 1980, p. 1). Bury (1996) provided definitions of the terms *impairments, disability* and *handicap* in the context of the ICIDH:

impairment referred to abnormality in the structure of the functioning of the body, whether through disease or trauma; disability referred to the restriction in ability to perform tasks, especially those associated with everyday life and self-care activities; and handicap referred to the social disadvantage that could be associated with either impairment and/or disability. (p. 19).

The ICIDH was able to link impairment, disability and handicap to imply a relationship between the cause and effect of the biological process and outcomes. As Berghs et al. (2016) explained, “disease leads to impairment, which leads to disability, which leads to handicap” (p. 28).

The ICIDH has undergone several revisions since its inception. In the 1993 reprint of the ICIDH, the WHO acknowledged some problems with the definitions used, particularly in the use of the word ‘handicap’, and they recommended a full revision of the tool (WHO, 1980). In a review of the history of the ICIDH, Pfeiffer (1998) criticised the language and perspectives used in the initial document and its subsequent revisions, believing that it had not moved on since its development 20 years earlier. The criticisms that Pfeiffer (1998) identified include the implication of the causal link between ‘impairment’ and ‘disability’, the conceptualisation of impairment as a medical problem
that required a cure or treatment, ‘victim blaming’ of people with disability, and the ‘handicapper’ language that devalues the lives of people with disability (Pfeiffer, 1998). A model that considers social elements needed to be incorporated into any definition of disability (Berghs et al., 2016).

Subsequently, the *International Classification of Functioning, Disability and Health* (known as the ICF) was released and officially endorsed by all WHO member states (including Australia) in 2001 as a means to describe health and health-related conditions within a standard language and framework (World Health Organization, 2002). Despite being intended as a tool that considers the impact of health and disability on function in society, it focuses on the level of health of individuals and populations and is designed for use in health and health-related sectors. While the ICF is an important tool, it has the corollary effect of classifying health conditions and diseases that cause disability (including age-related conditions such as arthritis and hearing loss) together with disability that has been experienced from birth, such as DS, ASD and ID.

The WHO’s first collaborative global research project in 1990, the Global Burden of Disease study, measured disability-adjusted life-years (DALYs) as an estimate of the years of life lost as a result of disease and injury resulting in premature death (Murray & Lopez, 1994). In the *Bulletin of the World Health Organization* in 1994, Murray and Lopez (1994) identified challenges with the measurement of DALYs. The influence of factors such as comorbidities, and the likelihood that having one disability increases the probability that an individual will have other disabilities, poses a challenge for statisticians (Murray & Lopez, 1994). Challenges include the inability to include *all* diseases in the estimates (such as idiopathic diseases with no known cause), and the difficulty of collecting extensive age- and sex-specific information, particularly in developing countries (Murray & Lopez, 1994). Murray and Lopez (1994) suggested that the philosophy of the Global Burden of Disease study is that it is better to make “an informed estimate of disability … than to have no estimate at all” (p. 481). In a scoping study that examined the literature related to the models and theories of disability, Berghs et al. (2016) described the measurement of DALYs as a potentially insensitive method of measuring the experience of disability without connecting experiences to the broader social environment. According to Berghs et al. (2016), within 10 years of the DALYs first being measured, there was increasing criticism of the value of collecting self-reported data that may be biased depending on culture and experience.
The Australian SDAC (conducted by the ABS since 1981) also collects data based on disability that is a result of disease and injury. Thus, the prevalence of disability is a measure of disability experienced across a lifetime, including age-related illnesses. For this reason, it is important to articulate clearly the definition of disability that provided the parameters for this study, and the reasoning behind the exclusion of certain disability types.

2.1.1 Defining disability for this study

To provide a definition of disability that can be applied and understood in the context of this study, I have chosen to focus on two definitions: the definition that underpins the Disability Services Act 1993 (WA) (DSA) and the definition of disability defined by the WHO for the ICF, discussed in section 2.1. Since this study focuses on ID, I also provide the definitions of ID from the Department of Communities (WA) and the WHO.

The DSA was proclaimed in 1993 by the newly formed Disability Services Commission in WA. The DSA defines disability as a condition that may be intellectual, psychiatric, cognitive, neurological, sensory or physical in nature and may restrict “communication, social interaction, learning or mobility” (Government of Western Australia, 1993). In addition, the DSA states that the use of the term disability denotes a disability “which results in a need for continuing support services” (p. 3).

However, this definition gives the impression that anyone defined as having disability (under the DSA) has a reliance on formal support services. Just as people with disability may not have increased health needs in comparison with the population without disability, not all people with disability rely on support services or consider themselves to have disability (Owens, 2015). Any definition of disability needs to consider who has defined it and for what purpose. The DSA definition is represented in Figure 2.1.
The second definition of disability to be discussed here is the ICF definition from the WHO. The ICF definition is called the ‘biopsychosocial’ model, which is described by the WHO as a “coherent view of different perspectives of health: biological, individual and social” (WHO, 2002, p. 9). The biopsychosocial model views disability as the outcomes of the interaction between the health conditions of individuals and the context in which they are present. The context is influenced by environmental factors and personal factors that shape individuals’ experience of disability (WHO, 2002). The ICF classifies three levels of dysfunction: impairments, activity limitations and participation restrictions. These are illustrated in Figure 2.2.
Figure 2.2 ICF representation of the biopsychosocial model

The ICF classification model can be applied to any health condition, disability or disease at an individual level, service provider level or social level. The application of the ICF model can also assist with the following: policy development that considers the functional status of the population; economic analyses of the modifications to the built and social environment to prevent activity and participation limitations; research and intervention studies by providing a framework that renders studies comparable; and consideration of the environment’s effect on individuals and populations. An example of the application of the ICF model applied to this current study is shown in Table 2.1.

### Table 2.1 Example of the application of the ICF model

<table>
<thead>
<tr>
<th>Health condition</th>
<th>Impairment</th>
<th>Activity limitation</th>
<th>Participation restriction</th>
</tr>
</thead>
<tbody>
<tr>
<td>Spinal injury</td>
<td>Loss of use and sensation in extremities</td>
<td>Use of wheelchair, requires assistance to transfer into a car and use public facilities</td>
<td>Lack of available assistance limits social participation</td>
</tr>
<tr>
<td>Intellectual disability</td>
<td>Cognitive difficulties, developmental delay, lack of communication</td>
<td>Poor communication and inability to express desires and needs limits activities</td>
<td>Poor communication and behaviours are not well received by the community, restriction of social and community participation</td>
</tr>
</tbody>
</table>

*Note.* (Adapted from “Towards a Common Language for Functioning, Disability and Health ICF”, 2002, WHO, p. 9. [https://www.who.int/classifications/icf/training/icfbeginnersguide.pdf](https://www.who.int/classifications/icf/training/icfbeginnersguide.pdf))

Both the *DSA* and the ICF definitions of disability have strengths and limitations. The *DSA* identifies the broad range of classification of disabilities that people can experience and acknowledges the role of support networks in the lives of people with disability; however, it falls short of acknowledging the individual experience of disability not related to diagnosis, such as the context of the family and natural networks. In addition, as suggested earlier, the presence of disability does not necessarily equate to the need for ongoing support services. However, since the *DSA*’s is a definition developed with a focus on services, it is understandable that the need for support services is included in its description. The ICF is a model of classification and does not address support mechanisms to limit restrictions and enable participation. Nevertheless, both definitions were important for this study because together they provide an understanding of disability from the biological, social and individual perspectives of disability.
2.1.2 Defining intellectual disability

This study focused on ID; therefore, it is important to include a definition of this term to define the parameters for this study. The Department of Communities (WA) (2018) definition of ID includes intellectual and developmental disability that has some effect on cognitive ability and is “the result of interaction between developmentally attributable cognitive impairment, attitudinal and environmental barriers (Department of Communities, 2018, What is disability section, para. 7). The WHO definition of ID is broader, adding that ID begins during childhood, and effects development across the life span (WHO, n.d.). The WHO definition of ID includes ASD with associated intellectual impairment. In this instance, the WHO definition of ID is preferred to support the rationale that defined the parameters for this study.

2.2 Models and approaches to disability

This section provides a summary of the models and approaches to disability presented in the disability literature. According to Berghs et al. (2016), a range of models and approaches have contributed to the construction of disability, social and political discourse, public health research and disability policy. Many coexisting models and approaches incorporate disability (Barnes & Mercer, 2003), however, to provide a foundation for this study, I draw from Berghs et al.’s (2016) scoping study of disability literature and focus on four broad models and approaches to disability: the medical model perspective, the social model perspective, the human rights approach and the critical disability studies approach. In the literature, the terminology ‘models’ and ‘approaches’ are interchangeably referred to as models, perspectives, theories or approaches.

According to Berghs et al. (2016), medical models of disability view disability as a ‘deviation from the norm’ with ‘undesirable’ consequences for the individual. The advancement of the medical professions since the early twentieth century led to disability being viewed from a biological viewpoint, that is, an individual characteristic of a person caused by disease or a health condition that required medical treatment or cure (Crow, 1996). Mike Bury (1996) in his examination of the history of the definitions of disability proposed that following World War II, medical specialisations grew along with expanding services and rehabilitation for people with congenital conditions, injuries, trauma and stroke. As a result, medical research also expanded, raising the general profile of disability in society and leading to an understanding of disability as something for the medical professionals to ‘treat’ (Bury, 1996).
Measurements of health and disability are grounded in a medical viewpoint, often focusing on the quality of life of populations and individuals. Measurement tools emerged throughout the twentieth century, such as quality of life scales, health expectancies and DALYs. However, Berghs et al. (2016) criticised the ability of these tools to capture the complexity of disability and consider aspects of social care, advocacy and public policy.

The literature critiques the capacity of medical perspectives to explain an inclusive model of disability. Medical models struggle to conceptualise comorbidities and fail to acknowledge that people may experience various conditions, leading to disability or impairment, over their lifetime (Berghs et al., 2016). In addition, as Berghs et al. (2016) argued, medical models fail not only to recognise quality of life from a social viewpoint but also to acknowledge the experiential and social dimensions of disability. Instead, they focus on disability as something “that should be intervened in, prevented or cured” (p. 37).

The WHO responded to critiques of the medical perspective by incorporating social aspects of the disability experience into the ICIDH in 1976 (Berghs et al., 2016). According to Berghs et al. (2016), despite this intention and subsequent refining of the ICIDH, the WHO still had difficulty overcoming the influence of medical models of disability.

The second perspective identified by Berghs et al. (2016) is the rights-based approach to disability, which is framed in legislation that rendered discrimination because of disability a crime. As early as the 1950s, rights-based practices were evident in disability discourse in Australia (Simpson et al., 2019) and internationally (Berghs et al., 2016). Disability services were influenced by the principle of ‘normalisation’, introduced in Scandinavian countries during the 1960s and articulated by Nirje (1969):

> The normalization principle means making available to the mentally retarded patterns and conditions of everyday life which are as close as possible to the norms and patterns of the mainstream of society. (p. 19)

In 1983, Wolfensberger redefined normalisation as *social role valorisation*, refocusing the “highest goal of normalisation” on the valued social roles of people with disability (Wolfensberger, 1983, p. 435). According to Wolfensberger (1983), if a person is accepted and valued within society, then the other elements of normalisation
are secondary. The social role valorisation hierarchical structure proposes that the enhancement of the social image and personal competencies of an individual, including physical settings, relationships, activities, language and autonomy of rights, represent the ultimate goal of social role valorisation (Wolfensberger, 1983).


> The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity. Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. (p. 4)

In Australia, human rights-based approaches inform disability policy, including the National Disability Strategy 2010–2020 and the NDIS, introduced into Australia in 2013 (Kendrick et al., 2017; Simpson et al., 2019).

The next perspective that Berghs et al. (2016) discussed is the social model, or models, of disability. The social model perspective argues that people with disability are ‘disabled’ by society and their impairments are not the cause of their disability (Oliver, 2013). In his analysis and critique of the social models, Owens (2015) suggested that social models are “enshrined in the doctrines of rights and equality”, which highlight inclusion and participation of people with disability in society (p. 385).

There is some disagreement in the literature about the origins and development of the social model perspective. According to Mike Oliver (2013), the social models of disability stemmed from early disability rights literature published in the United States (US) in the mid-1970s, leading to the introduction of the individual and social models of disability in the UK. However, according to Owens (2015), the social models of
disability evolved during the 1960s in Europe (Owens, 2015). The ‘social relative
type of disability’ was developed in Nordic countries in the 1960s. In this model, the
individual, his or her impairment and the environment interact with each other (Owens,
2015). However, in the 1970s, the UK social model of disability, advanced by the
disability advocacy movement and the claim that people with disability were oppressed
in society (Shakespeare & Watson, 2001), clearly separates disability and impairment
(Owens, 2015). The dismantling of ‘impairment’, and the move away from ‘blaming’ an
individual to holding society responsible for oppression, provided the catalyst for
disability groups that encouraged empowerment and the demand for equal rights
(Shakespeare & Watson, 2001). Owens (2015) also described the North American
social model of disability, which utilises a rights-based approach to understanding
disability, but which, in contrast to the UK social model, does not view disability and
impairment as distinctly separate.

However, several authors (Crow, 1996; Owens, 2015; Shakespeare & Watson,
2001) have critiqued the social model perspective. According to Owens (2015), there
needs to be recognition that social models cannot resolve all social restrictions. UK
social models have traditionally excluded ‘impairment’ from their analyses, suggesting
that impairment does not exist, and if a problem cannot be solved by the social model,
this inhibits or excuses society from tackling the issue (Crow, 1996). Crow (1996)
argues that the implications of impairment need to be acknowledged and that the
personal experiences of people with disability influence their social oppression. In its
endeavour to focus on the social, environmental and attitudinal barriers that people with
disability face, the social models of disability struggle to consider the medical aspect of
disability—namely, that disability affects the body (Crow, 1996). Shakespeare and
Watson (2001) argue that disability is caused by the body and society, and the social
model perspective cannot alone address the barriers people with disability experience.

Other criticisms of the social model perspective include its failure to recognise
culture as an influence on the experience of disability (Shakespeare, 1996) and the
omission of women from the disability movement (Meekosha & Shuttleworth, 2009).
However, Oliver (1996) defended the social models by suggesting that restrictions due
to impairment, gender or race are individual experiences and belong within a ‘social
model of impairment’. In Oliver’s later work (2013), he states that when he proposed
the social model of disability, he did not suggest it was an “all-encompassing
framework within which everything that happens to disabled people could be understood or explained” (p. 1024).

The final approach that Berghs et al. (2016) identified is the critical disability studies approach. According to Berghs et al. (2016), while defining critical disability studies is difficult, it can be simply defined as a challenge to the dissociation between disability and impairment that social models propose. Other authors (Oliver, 1996; Goodley, 2013) supported this definition. Oliver (1996) argued that there is an assumption that people with disability want to achieve ‘normality’, a concept that underpins both the medical and social models of disability, instead of embracing difference. In an examination of the literature that explores and explains critical disability studies, Goodley (2013) argued that the field of critical disability studies ‘reintroduces’ impairment “as a significant element of the disability experience” (p. 634), thus embracing difference. Critical disability studies views disability along a trajectory of human diversity and stresses that impairment and the barriers people face in society contribute to an individual’s experience of disability.

Meekosha and Shuttleworth (2009) explored the emergence of critical disability studies from the disability rights movement during the 1970s to its expansion into the twenty-first century. According to Meekosha and Shuttleworth (2009), critical disability studies challenges the limitations of the medical and social models and proposes a social, political and intellectual approach to understanding the lived experiences of people with disability. Meekosha and Shuttleworth (2009) argued that critical disability studies “can be thought of as a critique of specific approaches to disability” (p. 49).

However, according to Berghs et al. (2016), critical disability studies is complex and builds on the earlier models of disability, particularly social models of disability. Critical disability studies considers the socio-political factors that are inherent in the lived experience of disability (Meekosha & Shuttleworth, 2009). A critical disability studies approach ensures a ‘critical’ lens for understanding how disability research is conducted and how disability is constructed (Berghs et al., 2016).

2.3 Process for literature review

This section reviews the international and Australian literature on sibling-disability research with the aim of identifying previous research in this area and presenting the current knowledge and understanding of the relationships between siblings when one has disability. Literature searches were undertaken through the Edith Cowan University (ECU) online library using databases relevant to disability studies
Some articles were found using direct searches through relevant journals with a focus on ID (for example the Journal of Intellectual Disability Research, the Journal of Applied Research in Intellectual Disabilities and Disability and Society). Key terms and phrases used for the literature search included ‘disability’, ‘siblings’, ‘intellectual disability’ and ‘sibling relationships’. I was led to several more relevant articles through eight literature reviews or meta-analyses of previously conducted sibling-disability research (Davys et al., 2011; Dew et al., 2008; Ferraioli & Harris, 2009; Heller & Arnold, 2010; Mandleco & Webb, 2015; McHale et al., 2016; Rossiter & Sharpe, 2001; Stoneman, 2001).

The search for literature was not bound by date since sibling relationships have been influenced by the emerging ideologies regarding disability since the mid-to-late twentieth century. The review was limited to English language articles, although the country of research origin was not a variable for inclusion or exclusion. I have identified the country of research origin throughout the review. I have also included studies across the life span because this current study focused on adults and their experiences throughout their lives, therefore studies on childhood would also reveal relevant themes.

The literature was mapped and is presented in a table in the Appendix (Appendix 3). According to Creswell (2014), mapping the literature assists with the organisation of the existing literature to build a visual picture of previous research. It also assists with identifying the gaps in the literature and positions this study within the larger body of research.

## 2.4 Factors that influence family relationships

Dominant themes in the literature arose relating to family and individual characteristics that influence relationships within the family, such as parental factors (Davys et al., 2016; McHale & Gamble, 1989; McHale et al., 2016; Orsmond et al., 2009), gender of the sibling and the sibling with intellectual disability (Burbidge & Minnes, 2014; Cuskelly, 2016; Griffiths & Unger, 1994; Orsmond & Seltzer, 2000) and family structure (Begun, 1989; Breslau, 1982; Burke et al., 2016). Other variables, such as the severity of disability or difficult behaviours (Hodapp & Urbano, 2007; Rossetti & Hall, 2015) and geographical distance between siblings (Doody et al., 2010; Greenberg et al., 1999; Orsmond & Seltzer, 2007) may also be a contributing factor to the strength of relationships and sibling involvement in support networks in adulthood. These factors are discussed individually in the following sections.
2.4.1 Parenting

In the review of the literature that focused on relationships between siblings when one child has a disability, Stoneman (2001) found that several parental factors influence the quality of relationships in the family. These factors include parental differential treatment (McHale et al., 2016), parental support for all siblings in the family (Orsmond et al., 2009) and increased parental and family stress as a result of having a child in the family with disability (Davys et al., 2016).

In a 1992 study that examined differential treatment of siblings in families with a child with disability, McHale and Pawletko (1992) suggested that assumptions are often made that parental differential treatment is detrimental to children. However, the evidence suggests that differential treatment is a complex concept and consideration needs to include parent–child activities, discipline, relationships and the individual family context. In McHale et al.’s (2016) later work, the authors explained that while parental differential treatment may imply favouritism of one child over another, for families with a child with disability parental differential treatment is likely, and expected, owing to the increased need for care and support of the child with disability.

In a study in the US comparing children and mothers’ evaluation of a child’s adjustment to having a sibling with disability, McHale and Gamble (1989) reported that siblings of children with disability, despite receiving differential treatment from their parents, experienced no difference in satisfaction with parental treatment than did children without a sibling with disability. The authors suggested this can be attributed to the child’s justification of the extra time parents spend with their sibling with disability. Using the same dataset as McHale and Gamble’s (1989) study, McHale and Pawletko (1992) more closely examined the differences between older and younger siblings in the family. The authors found that even when older siblings were able to justify the differential treatment of a sibling with disability, they might still experience feelings of being excluded or neglected. McHale and Pawletko (1992) also found that parents often compensated for the time they needed to spend with their child with disability by increasing, or at least not reducing, the time they spend with their other children (McHale & Pawletko, 1992). This often resulted in higher levels of anxiety for the other children when they received more favourable parental treatment than their sibling with disability. The anxiety levels were attributed to feelings of guilt because their sibling with disability already experienced ‘limited pleasures’ as a result of their disability (McHale & Pawletko, 1992). The authors suggest that children’s feelings of guilt may
be the motivation for more positive relationships and kinder treatment of their sibling with disability across their life span.

In a study with adult siblings that explored perceptions about a future role caring for a sibling with intellectual disability, Davys et al. (2016) suggested that in addition to reduced or differential parental treatment, the expectation of a caregiving role while growing up had a negative impact on siblings. However, Kovshoff et al. (2017) argued to the contrary. In their review of the literature that focused on siblings of children with autism spectrum disorder, Kovshoff et al. (2017) suggested that despite acquired caregiving responsibilities and reduced parental attention, the negative impact on siblings of children with autism spectrum disorder is unproven, and that study results could depend on key factors such as the research participant (mothers, fathers or the siblings themselves as informants) and the research methodology used.

Equal parental support for all children in the family across the life span has also been found to affect sibling relationships. Orsmond et al. (2009) conducted a study in the US that utilised longitudinal data from the siblings of 406 adolescents and adults with autism spectrum disorder. They found that the lack of parental support could affect the strength of the relationship between siblings for the adults in their study but had less of an impact during adolescence. Orsmond et al. (2009) found a positive association between parental support and positive sibling relationships when parental support had been provided across the life span.

Davys et al. (2016) also found that families experience stress when there is a child with disability in the family, often resulting in conflict regarding concerns for the future, especially as the sibling with intellectual disability and parents age. Nevertheless, despite the high levels of stress in the family, nearly half of the participants in their small study (15 participants) reported a “special bond” between themselves and their sibling with intellectual disability (Davys et al., 2016, p. 224). Orsmond and Seltzer (2007) reported similar findings in their larger study (154 participants) of siblings of people with autism spectrum disorder (mostly with ID) or Down syndrome. Despite the long-lasting stress that affects families with a child with intellectual disability, these effects may not all be negative and may rely on other factors related to ageing (Orsmond & Seltzer, 2007). This concurs with my assumptions as I undertook this study.
2.4.2 Gender

There is disagreement about the effect of gender on sibling relationships in the literature. Adult sibling relationship studies (Burbidge & Minnes, 2014; Cuskelly, 2016; Doody et al., 2010) have found positive relationships and high levels of involvement between the sibling with intellectual disability and their other sibling/s, and that gender did not affect their relationship or their intention to care for their sibling with intellectual disability in the future. In contrast, several other researchers (e.g., Burke et al., 2012; Greenberg et al., 1999; Griffiths & Unger, 1994; Heller & Kramer, 2009; McGraw & Walker, 2007; Orsmond & Seltzer, 2000) have found that gender influences the sibling relationship. These studies concluded that sisters are more likely to have deeper involvement with or provide care for their sibling with intellectual disability than are brothers, or more likely to expect that they would provide care in the future.

In research conducted in the US with 41 parents with a child with intellectual disability, Griffiths and Unger (1994) found that 22% of the families expected that their daughters would be the future caregivers for their child with disability, while none of the families expected this from their sons. In addition to this, of the parents who had nominated legal guardianship for their child with disability, 48% had established their daughters as legal guardians, while only 16% had nominated their sons. McGraw and Walker’s (2016) study explored how sisters (n=10) understand their relationships with their sibling with intellectual disability and found that sisters accepted the “ideology of gendered family care” (p. 487), and did not question the sociocultural propensity for brothers to be less involved in the care of their sibling with intellectual disability. McGraw and Walker’s (2016) results suggested that women may find it difficult to challenge gendered family roles, and that they view themselves as more of a mother than a sister to their sibling with intellectual disability. However, theirs was a small qualitative study and only with sisters of people with developmental disability, thereby limiting its applicability to the context of this current study. In contrast, Cuskelly (2016), drawing on an approximately even balance of gender in her study with 39 adult siblings of people with Down syndrome, found that gender did not influence the intention to provide care in the future. However, Cuskelly (2016) suggested that some of the syndrome-specific characteristics of DS—described by Hodapp and Urbano (2007) as lower levels of behaviour problems and typical sociable personality traits—render the sibling relationship warmer, thereby increasing siblings’ willingness to provide care in the future for their sibling with Down syndrome.
In a sibling study that examined the influence of gender on relationships in adulthood, Akiyama et al. (1996) described two gender-related principles applicable to sibling relationships: gender commonality and ‘femaleness’. According to Akiyama et al. (1996), research that explores the effect of gender on support relationships has been guided by these principles. Gender commonality theory predicts that a stronger relationship between siblings in a same gender dyad is most likely, especially in regards to emotion and affection (Akiyama et al., 1996; Cicirelli, 1995). The principle of femaleness states that the closest relationship is a female–female dyad, and a male–male relationship the most distant (Akiyama et al., 1996).

Previous studies (Begum & Blacher, 2011; Greenberg et al., 1999; Heller & Kramer, 2009; Orsmond & Seltzer, 2000) also referred to the principles described by Akiyama et al. (1996). The gender commonality principle was supported in instances of siblings when one has ID in Begum and Blacher’s (2011) study. Begum and Blacher (2011) explored adolescent sibling relationships with and without ID and found that when neither sibling had disability, mothers reported that cross-gender dyads demonstrated the warmest sibling relationship; however, the opposite was true for siblings when one of the dyad had disability, especially when care or support was a factor. However, it should be noted that Begum and Blacher’s study utilised the mothers as informants, unlike this current study from the perspective of the siblings themselves. Begum and Blacher (2011) argued that the increased amount of caregiving duties that sisters perform when their sibling has ID “could become awkward” in opposite gender dyads (p. 1586).

The principles of gender commonality and femaleness were both supported in Heller and Kramer’s (2009) study of siblings with a sibling with intellectual disability, however, most of the participants in their study were female (more than 90% female participants); therefore, minimal data were collected from male participants. Orsmond and Seltzer (2000) explored the gendered nature of the sibling relationship when one sibling has ID and found no evidence to support the gender commonality principle for sisters. However, they found that brothers demonstrated more positive relationships with their brother with disability than with their sister with disability. Greenberg et al. (1999) reported that sisters experienced closer relationships with their sibling with intellectual disability than did brothers. Both Orsmond and Seltzer (2000) and Greenberg et al. (1999) argued that the principle of femaleness was supported in their
studies based on the fact that sisters reported providing more support to their sibling with intellectual disability and were more likely be the future caregiver.

In Burke et al.’s (2016) US study of people with disabilities, the gender of the sibling with disability was found to influence the relationship between siblings and the propensity for the sibling without disability to provide care. Burke et al. (2016) found that when the sibling with disability was male, he was over four times more likely to receive caregiving from his siblings than were females with disability, regardless of the gender of their sibling providing the care. Orsmond and Seltzer (2000) and Greenberg et al. (1999) disagreed, arguing that the gender of the sibling with intellectual disability did not matter for the participants in their studies. However, the different participant samples in these studies could explain the differences in findings. For example, Orsmond and Seltzer’s (2000) study drew on almost twice as many female siblings without disability as brothers without disability, and Burke et al.’s (2016) study gathered data from the siblings with disability, also with an uneven gender balance (76% female participants with disability). Greenberg’s (1999) study drew on an even balance of gender for the siblings without disability, but a much smaller percentage of sisters with disability (24%).

Stoneman (2005) argued that sibling relationships change over time and at different stages of development, which renders analysis of the influence of gender on the sibling relationship problematic. In addition, the majority of the studies reviewed reported that the greatest proportion of participants were female, so it is difficult to draw conclusions without comparison data from male participants. Several authors (Begun, 1989; Burke et al., 2016; Doody et al., 2010) suggested that controlled sampling processes and active recruitment of male participants (both with and without disability) will validate findings in relation to gender influences on the sibling relationship and the provision of care or intention to provide care in the future.

2.4.3 Family structure

A dearth of literature focuses on family structure and its influence on sibling relationships. However, there is evidence in the sibling-disability research that the structure and characteristics of the family—such as number of children, birth order and age spacing between children—influence relationships within the family and between siblings when one sibling has disability (Begun, 1989; Breslau, 1982; Burke et al., 2016; Mulroy et al., 2008). In a US study with 327 siblings of children with disability, Breslau (1982) found that having a child with disability affected families in which
attention, care and dependency is relevant to birth order in the family. A ‘natural model’ of parental care exists in a family where disability is not present: the youngest child or children in the family may receive the most care or attention from their parents owing to greater dependency based on their age (Breslau, 1982). According to Breslau (1982), when there is a child in the family with disability, this natural model of parental care may be disturbed. Breslau (1982) found that the birth order of children in the family influenced the psychological development of the other child or children depending on whether they were born before or after their sibling with disability. The findings from Breslau’s (1982) study revealed that brothers born after their sibling with intellectual disability demonstrated a greater psychological effect than did older siblings, although this finding was opposite for sisters. The study also found that siblings with wide age spacing born after their sibling with intellectual disability were “psychologically better off” than siblings born close together, regardless of their gender, yet for children born before their sibling with intellectual disability, age spacing did not make a difference (Breslau, 1982, p. 92). Breslau (1982) argued that the early childhood experience of a period of growing up without a sibling with intellectual disability in the family may influence the sibling relationship in a positive way.

In a study of 46 sisters of people with intellectual disability in the US, Begun (1989) found that birth order and age spacing in the family influence the relationship between siblings over the life span when disability is a factor. Begun (1989) found that siblings who were closer in age had a more conflicted relationships than siblings who were widely spaced in age. When there was a significant age gap between siblings, the relationship was more satisfying when the sibling without disability was older than the sibling with intellectual disability (Begun, 1989). Begun (1989) also noted that birth order did not appear to be relevant in middle adulthood, and only affected the relationship in adolescence and early adulthood. However, the study focused on the experience of sisters only and did not recruit male siblings in the study sample. This informed the sampling frame for this study; participant recruitment would target both male and female participants.

Other more recent studies that researched the effects of family size on sibling relationships found conflicting evidence (Burke et al., 2016; Mulroy et al., 2008). In a study that sought to explore sibling relationships from the viewpoint of the sibling with disability, Burke et al. (2016) found that the number of siblings in the family was not a predictor of sibling closeness. In addition, Burke et al. (2016) found that while several
siblings in the family may result in greater cumulative caregiving for the sibling with
disability, only one sibling might take on the caring role and the other siblings might not
share the responsibility of care, potentially leading to strained relationships or feelings
of guilt over lack of involvement with their sibling with disability. Furthermore, if one
sibling among a few is the primary caregiver, it is often the sibling closest in age to the
sibling with disability that is more likely to assume this role (Burke et al., 2016).

In a Western Australian study of the experience of growing up with a sibling
with intellectual disability, Mulroy et al. (2008) found that when there were several
siblings in the family, they may share the support of their sibling with intellectual
disability. Burke et al. (2016) agreed and posited that “by sharing responsibilities,
siblings may experience less caregiving burden and feel more supported in aiding their
brothers/sisters with disabilities” (p. 746). However, both of these studies demonstrated
limitations in the context of this current study: Burke et al. (2016) explored the
experiences of the sibling with disability, and Mulroy et al.’s (2008) study was
conducted from the perspective of the parents.

2.4.4 Characteristics of disability

Doody et al. (2010) found that the severity of a sibling’s disability may affect
the warmth of the sibling relationship. Other studies (Orsmond et al., 2009; Seltzer et
al., 1997) found that difficult behaviour, especially in social situations, may limit
siblings’ involvement with their sibling with intellectual disability or affect the
closeness of their relationship (Rossetti & Hall, 2015). At the time, Rossiter and
Sharpe’s (2001) meta-analysis of sibling-disability literature also found evidence that
disability type and severity affect the siblings without disability.

Hodapp and Urbano (2007) and Orsmond and Seltzer (2007) compared the
impact on sibling relationships when a sibling has autism spectrum disorder versus
Down syndrome. Both studies found that adults with a sibling with Down syndrome
experienced greater contact, and more positive and warmer relationships than did the
adults who had a sibling with autism spectrum disorder. Hodapp and Urbano (2007)
also found that adults with a sibling with Down syndrome experienced better health and
lower levels of depression than did adults with a sibling with autism spectrum disorder.
Siblings of people with autism spectrum disorder have been found more pessimistic
about their sibling’s future than those with a sibling with Down syndrome, and they
may struggle to assume responsibility for their sibling when their parents are no longer
able to provide care (Orsmond & Seltzer, 2007).
Similar findings arose in studies that compared other disability types. In a 2017 study that compared siblings of people with autism spectrum disorder with siblings of people with intellectual disability, Tomeny et al. (2017) found that when ASD was a factor, siblings without disability expressed less positive attitudes and lower levels of life satisfaction than those with a sibling with intellectual disability. Similarly, when comparing experiences of siblings with a brother or sister with Down syndrome or Rett syndrome, Mulroy et al. (2008) found that the Rett syndrome group were more likely to report disadvantage than were the Down syndrome group. However, Mulroy et al. (2008) acknowledged that several other factors may have affected the reports of benefits or disadvantage, including socio-economic status, number of children in the family, birth order and family characteristics. These studies provided evidence of more positive relationships between siblings when one has DS in comparison with other disabilities, such as ASD or Rett syndrome. In contrast to these studies (e.g. Mulroy, 2008; Tomeny et al., 2017), participant experiences in this study are not compared based on the disability that their sibling experiences.

Hodapp and Urbano (2007) suggested that more positive relationships between siblings when one has DS could be related to characteristics of the disability, lower behavioural problems, having more established supports groups for DS, having older or more experienced parents, or knowing the diagnosis either before or at birth. In contrast, ASD is associated with reduced social functioning and difficulty with interpersonal relationships and communication (Orsmond & Seltzer, 2007; Rossetti & Hall, 2015), often affecting sibling relationships (Tomeny et al., 2017). In addition, the average age of a diagnosis of ASD in Australia is four years of age (Anderson et al., 2016); therefore, related behaviour may have already affected the sibling relationship. Similarly, Rett syndrome is more disabling than DS and not diagnosed at birth; hence, it may be a factor that influenced the results of the study by Mulroy et al. (2008). Consistent with these studies, Doody et al. (2010) found that the severity of the disability affected the warmth of the sibling relationship. However, Doody et al. (2010) speculated that disability attributes, such as restricted communication, may give a perception of less warmth in the relationship.

There is disagreement in the literature regarding the disability and the effect of certain characteristics on sibling relationships and the intention to provide care in the future. Burke et al. (2012) explored the factors that influence future caregiving of siblings with intellectual disability, and found that their sibling’s health, functional
ability and behaviours did not influence the prediction of future caregiving. Greenberg et al. (1999) hypothesised that behavioural problems would limit involvement with and future caregiving for their sibling with intellectual disability; however, they found evidence in their study to the contrary. Both studies identified limitations in their data collection methods that may have affected their assessment of future caregiving for siblings with intellectual disability, related to general versus specific questions about expectations of future caregiving. Despite these limitations, both Burke et al. (2012) and Greenberg et al. (1999) found characteristics of the sibling’s disability did not affect sibling relationships, in contrast to other studies (Doody et al., 2010; Hodapp & Urbano, 2007; Mulroy et al., 2008; Orsmond & Seltzer, 2007; Tomeny et al., 2017).

2.4.5 Geographic proximity

Several authors (Burke et al., 2012; Doody et al., 2010; Heller & Kramer, 2009) were able to associate a close geographical distance between siblings to the provision of care or support for a sibling with intellectual disability. Burke et al. (2012) and Heller and Kramer (2009) found a correlation between geographic proximity and the expectation to provide care or support in the future. In Rossetti and Hall’s (2015) study that examined the contexts that affect sibling relationships, geographic proximity between siblings was found to be one of the contexts that influence the quality of sibling relationships when one has ID, possibly related to the frequency of contact.

In an Australian study that explored the relationship between adults with a sibling with cerebral palsy and associated communication difficulties, Dew et al. (2011) posited that while geographic proximity supports ease of contact with a sibling with intellectual disability, it is not inevitable that distance will affect the sibling relationship. In addition, Dew et al. (2011) suggested that a lack of shared communication between siblings as children may predispose them to “emotional as well as geographic distance between siblings in adulthood” (p. 253). Dew et al. (2011) suggested that geographic distance between siblings may be ameliorated by the use of augmentative and alternative communication (AAC). Rossetti and Hall (2015) agreed but found that adults in their study did not use AAC methods to assist with communication with their sibling with intellectual disability. They suggested that information and support about AAC interventions should be provided to siblings, which may assist when communication is limited and geographic proximity to their sibling with disability inhibits a close relationship.
There is a dearth of literature exploring geographic proximity and the impact on sibling relationships. The increased use of technology and the internet for online social interaction (Perkins & LaMartin, 2012) ensures there is an opportunity for siblings to utilise these means to assist with communication and connection between siblings when distance is a factor (Heller & Kramer, 2009). The review of the literature for this study revealed only one paper that focused entirely on the use of internet technology for adults with ID (Perkins & LaMartin, 2012); however, the study was limited in that it did not provide evidence that sibling relationships could be enhanced through the use of internet technologies and instead focused on the internet as a social support for people with intellectual disability. Nevertheless, Perkins and LaMartin (2012) suggested that siblings may be able to provide support to their sibling with intellectual disability in the use of and familiarity with technology, thereby improving communication and connectedness between them when distance is a factor.

2.5 Caregiving

A considerable body of literature has explored sibling caregiving responsibilities while growing up with a sibling with intellectual disability (Davys et al., 2016; Graff et al., 2012; McHale & Gamble, 1989; Mulroy et al., 2008; Stoneman, 2001, 2005). Burke et al. (2016) found that when an individual has a sibling with intellectual disability, they are more likely to have greater family caregiving responsibilities than are individuals without a sibling with intellectual disability, and even more likely if there are no other siblings in the family. Bigby et al. (2015) posited that even when support services were in place and their adult sibling with intellectual disability lived in supported accommodation, they were involved in their sibling’s life and hoped to influence the quality of care and safeguard their sibling’s wellbeing in the future.

The extent to which siblings consider the actual tasks involved in caregiving and the concept of ‘care’ require further examination. Heller and Kramer (2009) state that while parents may identify their other children as future primary caregivers of their child with disability, the role of a primary carer is less clear. Care tasks may include guardianship, advocacy or co-residency (Heller & Kramer, 2009), or more personal tasks and activities of daily living.

Kröger (2009) examined care concepts in disability studies, stating that the term ‘care’ changed since the mid-twentieth century from referring to caring about someone to caring for someone. For people with disability, the concept of needing a carer may be disempowering, suggesting dependency and loss of control (Kröger, 2009). In Garrett’s
(2018) examination of key words in social work and social welfare, he states that over

time the meaning of the word ‘care’ has altered, from the concept of welfare with

negative connotations, to the neoliberal understanding in the late-twentieth century of

self-responsibility and empowerment (Garrett, 2018), that perceives the ‘welfare state’
as obsolete. Garrett (2018) states that in the UK the term ‘care’ has been replaced with

words that de-emphasise the disempowerment of people with disability, such as

‘personal assistance’, ‘help’ or ‘support’. This is an attempt to redefine care from a

negative or derogatory term, and a move away from the medicalisation of care, to

encompass much more. However, Kröger (2009) posits that the use of alternative words

for care brings little to free people with disability from the “historical load of

oppression” (p. 407). Kröger (2009) states that critical disability studies, building on the

social model of disability (discussed in section 2.2), highlights the “discriminatory and
disempowering practices” of the labour market and care systems, which are “major

barriers against the full social participation and citizenship of disabled people” (p. 404).

Nevertheless, the concept of care for people with a sibling with intellectual
disability is subjective, and may vary across the lifespan depending on individual

experiences. The following section provides a discussion of the literature that explores
caregiving as a ‘young carer’ and the expectation to provide care in adulthood.

2.5.1 Young carers

In Australia an increasing amount of research focuses on the concept of ‘young carers’ (Carers Australia, 2020). According to Becker (2007), young carers often care for a parent, or sometimes a sibling, grandparent or other relative with disability, long-
term illness or a mental health condition. Owing to the limited amount of research that
focuses on young carers who provide care for a sibling, the literature reviewed includes

general young carer research that provides evidence of siblings caring for a sibling with

intellectual disability (for example, Becker, 2007; Moore & MacArthur, 2007; Smyth et

al., 2011; McDougall, 2018).

Carers Australia (2020) define young carers as young people up to 25 years of

age who provide informal and unpaid care to someone else, usually a family member or

friend with an illness or disability. In 2018, it was estimated that there were more than

235,000 young carers in Australia (Australian Bureau of Statistics, 2020); however, it is
difficult to ascertain exact numbers because young people themselves may not identify

as a carer (Australian Institute of Family Studies, 2016) or may conceal their role as a
estimated that approximately one-third of 14–15-year-old young carers who provided care for someone who lived with them cared for a sibling, and almost 70% assisted their sibling with core activities, such as personal care, mobility and communication. The evidence suggests that young people who have a sibling with intellectual disability often provide informal care for them, either alongside or instead of their parents (Dew et al., 2004; Meltzer, 2017).

An Australian study by Meltzer (2017) explored the relational and social policy implications of care between siblings when one has disability. Meltzer (2017) drew on qualitative data from a previous study on 25 siblings with disabilities and 21 of their siblings without disabilities (aged between 15 and 29) to understand how siblings perceived care and the implications of care for their relationship. Participants in their study described care as personal care, managing behaviours, supervising their sibling with disability and supporting their parents in tasks in the home (Meltzer, 2017). Meltzer (2017) found that siblings without disabilities were often reluctant to identify with care roles and often placed boundaries on the type of care they provided (for example, toileting, showering and personal care). Similarly, some siblings with disabilities also imposed boundaries and would not ask for help from their siblings with personal care. Siblings with and without disability in Meltzer’s (2017) study often described care as “helping out”, which provides an understanding of the relational implications of care between siblings and “allows siblings to frame the care that happens between them as part of a more normative exchange of assistance between siblings, rather than as a consequence of disability” (p. 1021). To address the ambiguous meaning or interpretation of ‘care’ that is highlighted in the literature, the survey design for the first stage of this study used the terminology ‘support’, intending to encompass the broader meaning of care.

In a global study that reviewed research and statistical evidence about young carers from the UK, Australia, the US and sub-Saharan Africa, Becker (2007) found that young carers have much in common irrespective of where they live, and that the informal care that children provide is often not recognised. According to Becker (2007), unpaid care provided by a family member is referred to as informal care and rarely conceptualised as care work. Australian studies by Smyth et al. (2011) and Moore and McArthur (2007) both agreed that young carers often do not self-identify as carers but instead believe that the care roles they perform are a normal aspect of helping out their
parents. This situation may be related to societal norms that dictate that children are recipients of care and not caregivers themselves (Becker, 2007; Smyth et al., 2011).

In a UK study by Tozer et al. (2013), siblings of people with autism spectrum disorder who provided care for their siblings as children described a sense of obligation to their sibling, and the provision of support and ‘a break’ for their parents. Familial obligation to provide care was also acknowledged in a Western Australian study (McDougall et al., 2018) that explored the lived experience of young carers who provided care for family members. According to McDougall et al. (2018), it is challenging for young carers to navigate between the role of a carer and being a young person themselves, which affects their attendance at school or work and their relationships with peers. In addition, young carers may experience a conflict between ‘finding their own way’ as a teenager and young adult and the sense of obligation that comes with being a young carer (McDougall et al., 2018).

Smyth et al. (2011) suggested that because many young carers do not recognise themselves as carers, it becomes problematic for service providers to ensure that they receive the support they need. In Moore and McArthur’s (2007) Australian study, young carers reported that the best way to support them would be to provide the formal services that their relative needed, including personal care, short-term accommodation (respite) and emotional support. Moore and McArthur (2007) found that young carers providing care for a sibling with intellectual disability requested assistance with supervision to keep their sibling safe and to enable their greater participation in education, employment and social activities. Young carers were reluctant to identify what their own needs were, preferring to place the needs of their family members ahead of their own. Becker (2007) agreed and suggested that this hidden group of young carers are not likely to be the recipients of formal services themselves because service providers may not acknowledge the role of a sibling in the provision of care. Other barriers to accessing formal services might include the perceived quality of available services, negative experiences in the past, lack of knowledge about eligibility or available services and a reluctance to seek assistance for fear of unwanted scrutiny of the family (Moore & McArthur, 2007).

However, despite the challenges identified here, some authors (McDougall et al., 2018; Moore & McArthur, 2007) identified positive aspects to being a young carer. Moore and McArthur (2007) found that the participants in their study reported positive impacts of providing care, such as the development of skills and higher self-esteem and
resilience. McDougall et al. (2018) found that young carers in their study “derived personal meaning” from the role of carer, which led to an improved quality of life for the person they provided care for (p. 577). Similarly, the young carers in Smyth et al.’s (2011) study identified several benefits to self-identifying as a young carer, including recognition and validation of the important role they played in their sibling’s life, acknowledgement of the increased responsibility that accompanied the role of a young carer and the realisation that peer networks can provide previously under-resourced support.

The limitations of the studies reviewed here should be noted. The study by McDougall et al. (2018) was limited by size; moreover, only seven participants in their study (of 13) cared for a sibling with physical or intellectual disability, chronic illness or a mental health condition. Likewise, Moore and McArthur’s (2007) study did not focus only on caring for a sibling (although 19 of the 50 participants cared for a brother with disability) and, despite its size, did not specifically report on the experiences of sibling carers. Smyth et al. (2011) conducted focus groups with 68 young carers who provided support to a range of family members, and while the authors did identify that some participants in their study cared for a sibling with intellectual disability, they did not identify the number of participants who did so. This current study was not designed to focus on the participants’ perception of being a young carer; however, it was intended to capture their experiences providing care or support for their sibling with intellectual disability while they were growing up.

2.5.2 Expectation to provide care in the future

As a result of increased life expectancy of people with disability, several authors (Bigby, 1997; Cuskelly, 2016; Doody et al., 2010; Hodapp & Urbano, 2007) highlighted that many children with disability will outlive their parents, and consequently there will be a need for other family members to provide care for an adult child with disability when parents are no longer able to. In a review of the literature related to adult siblings of people with a learning disability, Davys et al. (2011) stated that, as next of kin, siblings are often expected to take on the role of caregiver for their sibling with disability when their parents are no longer able to. Bigby’s (1997) Australian study exploring sibling roles for older siblings with ID highlighted the instrumental tasks that may be included in the provision of care, including decision-making, management of finances, advocacy for formal services and support for activities of daily living. According to Bigby (1997), siblings are influenced by parental expectations to provide
care for their sibling with intellectual disability and often fulfil those expectations of involvement and caregiving in the future.

In an Australian study that explored the later life relationships between siblings when one had moderate to severe cerebral palsy, Dew et al. (2014) found that siblings felt a sense of obligation to provide support for their sibling when parents could no longer provide care. The sense of obligation was noted regardless of whether siblings grew up together or apart and was linked to the recognition that their sibling would require ongoing support as he or she aged. However, it should be noted that Dew et al.’s (2014) study concerned adults with moderate to severe cerebral palsy, not necessarily associated with ID. Nonetheless, the recognition of ongoing support throughout the life span is similar to the requirements of people with intellectual disability; therefore, the findings are relevant in regard to the expectation of future care for the siblings in this study.

The intention to provide care at the time of data collection may not result in actual care in the future (Burke et al., 2016; Burke et al., 2012; Cuskelley, 2016). In Burke et al.’s (2012) large study that explored the predictors of future caregiving of adult siblings with intellectual disability, siblings whose parents were currently less able to provide care for their sibling with intellectual disability had lower expectations to provide care in the future. According to Burke et al. (2012), this lower expectation can be explained by construal theory. Construal theory proposes that the distant or imminent likelihood of an event may affect an individual’s response to that event (Burke et al., 2012). For example, events that are more imminent may be thought of in more concrete, contextual terms, and events that are yet some distance away are accompanied by more abstract reasoning. Burke et al. (2012) argued that this theory can explain why some studies report siblings’ greater expectation to provide care when the event is some distance away. As the event becomes closer, the reality regarding the level of care required for their sibling becomes more concrete; therefore, expectations become more realistic (Burke et al., 2012). In addition, other events that happen between data collection and the actual provision of care, such as having a family, partner or career (Burke et al., 2016; Cuskelley, 2016; Greenberg et al., 1999; Tozer & Atkin, 2015), may be the concrete, contextual terms that dictate the ability to provide care (Burke et al., 2012).

Construal theory could also explain the differences in the reported measures of expectation to provide care based on the age of the study participants. In an Australian
study, Cuskelly (2016) suggested the self-reported expectation to provide care in the future is reflective of the age of the participants at the time of the study. Cuskelly (2016) and Burke et al. (2012) both suggested that adults in younger age groups may not have considered future care for their sibling with disability and possibly view this as something they would need to consider only when their parents were no longer able to. As they age, it is possible that the consideration of future care may evoke different responses (Burke et al., 2012; Cuskelly, 2016).

Previous studies (Cuskelly, 2016; Greenberg et al., 1999; Tozer & Atkin, 2015) have emphasised that family and work commitments as siblings become adults may result in unanticipated changes to the intention to provide care for their sibling with intellectual disability in the future. In Bigby’s (1997) study of older adults with intellectual disability who had remained at home with their parents until middle age, transition to sibling care from parental care was only a temporary arrangement for half of the sample (n = 62). Unanticipated changes to the ability to provide care for their sibling with intellectual disability in Bigby’s study included ill health, increased care required by other members in the family and unanticipated stress relating to the provision of care. Tozer and Atkin’s (2015) small qualitative study found that factors relating to partnerships, parenting and work commitments may influence the quality and frequency of contact with a sibling with intellectual disability, especially when siblings have families of their own. According to Cuskelly (2016), the adult siblings with a sibling with Down syndrome in her study, reported that during midlife, family commitments may take precedence over the relationship with their sibling, although in older life and when children have grown this may revert to the earlier closer relationship. However, Greenberg et al. (1999) found that for siblings in their study, while having children at home themselves rendered support of their sibling with intellectual disability difficult, it did not affect their expectation of future care.

Disagreement exists in the literature regarding the influence of gender on the expectation to provide care in the future. For example, Cuskelly (2016) found sisters did not expect to provide care at higher rates than brothers in their study. In contrast, others (Burke et al., 2012; Doody et al., 2010) argued that sisters had higher expectations of providing future care than did brothers. The difference in the findings could be a result of differences between the sampling frames in these studies. Cuskelly’s (2016) study had a relatively even balance of gender; however, both Burke et al. (2012) and Doody et al. (2010) drew on a much higher proportion of female participants (76% and 82%,
respectively). Cuskelly suggested that the lack of difference between genders regarding expectation to care could be partly due to the low recruitment rates of male siblings in other studies.

Bigby (1997) suggested there is no moral obligation to provide care for a sibling with intellectual disability, or even a right to be involved in his or her life decisions or planning for the future. Similarly, a person with disability may not wish a sibling to be involved in his or her care or decision-making, or for the sibling to be referred to as his or her carer (Bigby, 1997). Siblings Australia (2017), a national support and information organisation that works with siblings with a sibling with disability, argued that it is not always in the best interests of the sibling with disability for a sibling to be referred to as a carer because it denotes a relationship that lacks individual identity and dignity in the sibling relationship. Bigby (1997) suggested that the sibling with disability may not experience a close relationship with their sibling or feel that their sibling acts in their best interests. In a small British study of 13 young adults with a sibling with disability, Rawson (2010) argued that it is important for service providers to be respectful of the level of involvement that individuals wish to have in their sibling’s life. Service providers can provide the support and knowledge the siblings need when and if they require it, which will boost “self-confidence by reinforcing the value of their contribution” in the life of their sibling with disability (Rawson, 2010, p. 231). The siblings Rawson (2010) interviewed reported their concerns that a lack of involvement in the preparation and planning for their sibling with disability early in their lives would ill-prepare them to provide care or support for their sibling in the future. Service providers can learn from siblings and acknowledge the support and valued roles that siblings can offer to their sibling with disability (Bigby, 1997; Siblings Australia, 2017) and how their long-term commitment contributes to the wellbeing of their sibling with disability (Bigby et al., 2015).

2.5.3 Future planning

There is general acceptance across the literature that families could benefit from involving siblings in future planning (Arnold et al., 2012; Bigby, 1997; Heller & Arnold, 2010; Heller & Kramer, 2009; Rossetti & Hall, 2015). However, Heller and Kramer (2009) and Bigby (1996) found that the majority of families had not made explicit plans for the future, nor had parents involved the other siblings in the family in future planning. Bigby’s (1996) Australian study focusing on the nature and implementation of plans for the future of their adult child with intellectual disability
found that few parents had made explicit plans. When plans had been made, more than 80% had nominated siblings to oversee future financial or practical care of their sibling with intellectual disability. However, when plans are implicit, parents often assume that their other child or children will take over the care of their child with disability when they are no longer able to, although parents often do not involve siblings in this decision (Bigby, 1996).

Several studies (Arnold et al., 2012; Heller & Kramer, 2009; Rossetti & Hall, 2015; Tozer & Atkin, 2015) reported siblings’ concerns regarding the future care needs of their sibling with intellectual disability. In a study that examined the factors influencing future planning, Heller and Kramer (2009) found that adult siblings would like support services to provide more information to assist them to plan the transition from parental care to sibling care. Later work by Arnold et al. (2012) and Rossetti and Hall (2015) produced similar findings. Siblings’ need for information and support concerning the future care of their sibling with intellectual disability was often a source of frustration and stress for them (Rossetti & Hall, 2015).

In Tozer and Atkin’s (2015) British study, siblings reported feeling frustrated about future planning when formal services were not ‘proactive’ in their engagement, and that their involvement was only considered in a time of crisis or when a problem emerged. This is similar to my own experience as a disability service provider. Tozer and Atkin (2015) also sought practitioners’ perspectives on sibling involvement with their sibling with autism spectrum disorder and found that practitioners agreed practice was often ‘reactive’ with sibling engagement and often failed to acknowledge the experiences of adult siblings while growing up and their role as caregivers throughout their life span. Tozer and Atkin suggested that collaborative planning for the future between practitioner and siblings could ameliorate challenges and clarify expectations of care and support in the future for both sibling and practitioner.

2.6 Sibling experiences

There is agreement across the literature that there are both challenges and positive experiences for siblings growing up with a sibling with intellectual disability. For example, challenges include managing family stress (Giallo et al., 2012; Graff et al., 2012), and positive effects include the development of personal attributes, such as greater empathy (Cuskelly & Gunn, 2003). The following sections discuss both the challenging and positive experiences, as well as how siblings’ career choice might be influenced by experiences of growing up with a sibling with intellectual disability.
2.6.1 The challenges experienced by siblings

Seligman and Darling (2007) examined the variables that contribute to an understanding of the impact of having a child with disability in the family in their book *Ordinary Families: Special Children*. According to Seligman and Darling (2007), the ‘mystery’ of their sibling’s disability as they were growing up, feelings of ‘having caused the disability’, concerns over ‘catching’ the disability, and resentment that their parents’ attention was focused on their sibling with intellectual disability are examples of challenges that siblings face. Seligman and Darling (2007) also suggested that siblings without disability may have concerns about the future for their sibling with intellectual disability, which vary depending on the age of the sibling without disability. Seligman and Darling (2007) provided an example: children between the ages of six and nine may have questions about their sibling’s ability to do things, their speech and their motor development, while from 10 years of age children may be concerned about their sibling’s future, similar to their parents’ concerns (Seligman & Darling, 2007).

Several studies (Atkin & Tozer, 2013; Giallo et al., 2012; Graff et al., 2012) described challenges that siblings experience growing up with a sibling with intellectual disability. In an Australian study exploring the mental health of siblings of children with disability, Giallo et al. (2012) found that young siblings self-reported behavioural issues such as anger, non-compliance, hyperactivity and high levels of stress relating to life with their sibling with intellectual disability. Similarly, in a study exploring the experiences of adolescents with a sibling with Down syndrome, Graff et al. (2012) described the challenges participants experienced growing up with a sibling who required parents’ extra attention, especially when additional health problems were present. Some of the challenges the adolescents in their study experienced related to their sibling’s behaviour or the additional responsibilities that their parents expected them to shoulder. In addition, parental stress related to caring for a child with disability, stretched finances and strained personal relationships were a concern for all the family members (Graff et al., 2012). In Atkin and Tozer’s (2014) study with adult siblings of people with autism spectrum disorder and intellectual disability, participants reported resentment regarding their early life revolving around their sibling with intellectual disability; for example, some siblings described their childhood as “chaotic” and “struggle” (p. 231). For some siblings in the study, the effects of having a sibling with intellectual disability continued into adulthood. Half of their participants (n = 10) reported having sought counselling as adults to “help make sense of the past” (p. 231).
In a British study focusing on siblings with life-limiting genetic conditions, Brown et al. (2017) found that siblings experienced similar feelings of grief to their parents following the diagnosis of their sibling’s disability and throughout life. However, the authors also reported that siblings developed resilience as a result of their experience, and welcomed “open and honest” discussions to enable their understanding about their sibling’s disability at a young age (Brown et al., 2017, p. 1759).

As discussed previously, several studies (Hodapp & Urbano, 2007; Orsmond & Seltzer, 2007; Tozer & Atkin, 2015) reported that young siblings without disability often took on greater responsibilities in the family when compared with their peers. According to Smyth et al. (2011), increased care responsibilities of young carers may evoke feelings of isolation, potentially leading to withdrawal from peer networks and activities. However, young carers are often reluctant to seek support in their caring role, even when they acknowledge that they have greater care responsibilities than their peers (Smyth et al., 2011).

Atkin and Tozer (2013) suggested that a sibling’s sense of responsibility for their sibling with intellectual disability may continue into adolescence and young adulthood when “negotiating independence when leaving home” (p. 231). In adolescence and young adulthood, it is common to desire independence away from the family home. However, while the transition to independence, such as leaving home, may initially provide a sense of freedom for siblings, feelings of guilt and worry about their sibling with intellectual disability may continue to distance them from their peers (Atkin & Tozer, 2013). As parents and/or their sibling with intellectual disability increasingly rely on the support of siblings without disability in the family, the decision to leave home may be even more challenging. Atkin and Tozer (2013) suggested that to counteract this, some siblings may choose to live close to their family or stay in the family home until their sibling with intellectual disability has transitioned into other accommodation. However, it is possible that some siblings may choose to move further away than they otherwise would to distance themselves from the family (Atkin & Tozer, 2013).

Previous studies (Hodapp et al., 2010; Seltzer et al., 1997) found that the presence of a sibling with intellectual disability in the family may affect the other siblings in the family regarding relationships, parenthood and plans for their future. In Seltzer et al.’s (1997) US study with 329 adult siblings of people with intellectual disability, participants were asked to rate the extent of the effect of having a sibling with
intellectual disability on 11 domains of their lives, including choice of partner, whether to have children and plans for the future. More than 69% of participants stated that having a sibling with intellectual disability affected their choice of partner, 75% felt it affected their decision to have children and 44% said that it affected their plans for the future. However, Seltzer et al.’s (1997) study was limited to siblings who identified as being the most, from all siblings in the family, involved with their sibling with intellectual disability, and therefore findings could not be considered generalisable to all siblings in the family (Seltzer et al., 1997). In a large US study with 1,160 adult siblings with a sibling with intellectual disability, Hodapp et al. (2010) reported that female siblings were more likely to delay marriage and having children than were male siblings, which the authors attributed to the expectation that female siblings will be providing care for their sibling in the future. In addition, siblings expressed concern that poor decisions regarding partners may negatively affect their sibling with intellectual disability or affect their ability to provide care or support for their sibling in the future (Hodapp et al., 2010).

Previous sibling-disability research (Ferraioli & Harris, 2009; Glasberg, 2000; Taylor et al., 2008) found that the delay, or hesitancy, in respect to having children may be related to concerns about passing on genetic conditions. In a US study exploring siblings’ understanding of ASD, Glasberg (2000) found that concerns about having a child of their own with ASD begin as early as the teenage years, correlating with the realisation of how limiting their sibling’s life with ASD might be. In Ferraioli and Harris’s (2009) review of the literature exploring the impact of having a sibling with autism spectrum disorder across the life span, the authors suggested that it is a question of acceptance of risk when considering having children if there is a genetic predisposition to disability. The decision not to have children may be more far reaching. According to Ferraioli and Harris (2009), young people may find that their choice of marriage partners is reduced if they make a decision not to have children based on their fears.

Evidence of the acceptance of risk was apparent in Carr’s (2005) longitudinal study (over a period of 35 years), which asked mothers of children with Down syndrome if their other children had expressed concerns that they would have a child with Down syndrome. More than 40% of the siblings in the study expressed concerns, and seven of those siblings underwent prenatal testing for DS during their pregnancy. Similarly, Taylor et al.’s (2008) longitudinal study of 268 siblings of adults with
intellectual disability also found that siblings may be concerned about the genetic cause of, or predisposition to, disability—a concern that is more illuminated depending on the characteristics and severity of their sibling’s disability.

In a study comparing the experiences of siblings with a sibling with autism spectrum disorder or a sibling with Down syndrome, Orsmond and Seltzer (2007) found that participants were more likely to report that having a sibling with Down syndrome affected their feelings about having their own children than were those who had a sibling with autism spectrum disorder. Their study revealed that siblings of adults with autism spectrum disorder exhibited lower levels of marriage and parenthood than those with sibling with Down syndrome, which the authors attributed to the possibility that these siblings may have characteristics of the “broader autism phenotype”—“subtle characteristics associated with ASD that are thought to be genetic in nature” (Orsmond & Seltzer, 2007, p. 273). Orsmond and Seltzer (2007) suggested that further research is required with siblings who have a sibling with intellectual disability to explore the effects of a sibling’s disability type and characteristics on decisions to have children.

### 2.6.2 The positive experiences of having a sibling with intellectual disability

Previous studies (Cuskelly & Gunn, 2003; Giallo et al., 2012; Greenberg et al., 1999; Seltzer et al., 1997; Tozer & Atkin, 2015) have provided evidence to support the positive aspects of growing up with a sibling with intellectual disability. According to Seltzer et al. (1997), siblings in their study with a brother or sister with intellectual disability reported an overwhelmingly more positive assessment of their experience than did siblings with a brother or sister with mental illness. In addition, Seltzer et al. (1997) argued that the time of life that a sibling’s brother or sister receives a diagnosis of disability contributed to participants’ acceptance of the disability, and that a likely explanation for this is the ‘exposure’ to disability experienced while they were growing up.

Using the same dataset as Seltzer et al. (1997), Greenberg et al. (1999) posited that positive relationships while growing up and strong emotional family bonds may predispose siblings to a warmer relationship and connectedness as they age. This is particularly true when there is a quality relationship during adolescence (Greenberg et al., 1999). Tozer and Atkin (2015) and Cuskelly (2016) supported Greenberg et al. (1999), and they suggested that a sibling’s strong commitment to their sibling with intellectual disability as adults can be attributed to the relationship they established when they were growing up. Cuskelly (2016) added that positive family relationships
contribute to positive mental health outcomes in both siblings in a dyad when one has disability.

However, Rossetti and Hall (2015) argued that a close childhood relationship does not always predispose siblings to a close adult relationship, and that, likewise, some relationships may improve as siblings age. Tozer et al. (2013) posited that adult sibling relationships are complicated, and for people with a sibling with intellectual disability, their relationship is influenced by their past experiences, current circumstances and their expectations of the future.

Growing up with a sibling with intellectual disability has also been found to affect sibling behaviours and personal attributes positively (Mandleco & Webb, 2015). In an Australian study that explored the quality of sibling relationships when one has DS, Cuskelly and Gunn (2003) reported children demonstrated more kindness and empathy towards a sibling with Down syndrome than did children with a sibling without disability, and this effect was even greater between same gender dyads. Graff et al. (2012) reported closer family relationships and greater patience and acceptance of disability when a sibling had DS when compared with a similar cohort without DS. In addition, both Graff et al. (2012) and Cuskelly and Gunn (2003) reported that siblings were more involved in the lives of their sibling with Down syndrome in childhood and adolescence than were the comparison group. However, both Graff et al.’s (2012) and Cuskelly and Gunn’s (2003) were studies of children and young people (<19 years); therefore, the personal attributes described only represent those experienced in childhood to young adulthood. In a meta-analysis of the literature pertaining to sibling-disability research, Rossiter and Sharpe (2001) concluded that while there were fewer studies of adults with a sibling with intellectual disability, it is assumed that in adulthood, cognitive and social development would have matured and positive psychological function may provide better means of coping with stressors associated with their sibling’s disability.

In Giallo et al.’s (2012) Australian study, social support, access to appropriate health and disability services, and attitudes and acceptance within their local community were found to contribute to positive outcomes for children with a sibling with intellectual disability while they are growing up. While Giallo et al. (2012) identified the potential benefits of Australian family-centred disability services, they acknowledged that disability services in Australia largely focus on the child with disability and not the needs of the siblings. The authors recommended that the
promotion of siblings’ wellbeing “is not only important for siblings themselves but is also an important step towards supporting the whole family, and ultimately the child with a disability” (Giallo, et al., 2012, p. 42). The findings and recommendation by Giallo et al. (2012) informed the search for NDIS documentation for this study to support their findings.

2.6.3 Choice of career

There is evidence in the literature (Chambers, 2007; Davys et al., 2016; Marks et al., 2005; Martins, 2007) to support an assumption that an individual’s career choice is influenced by the life experience of having a sibling with disability. The US study by Marks et al. (2005) focused on the impact of having a sibling with intellectual disability and the choice of career in special education. Marks et al. (2005) found that all participants in their study attributed their choice of career to the experience of having a sibling with intellectual disability. However, this was a small study utilising seven participants, all of whom were recruited to the study as a person with a sibling with intellectual disability. Martins (2007) also undertook a small study in the US that explored the career choices of 25 siblings of people with autism spectrum disorder, and compared them with a control group of people without a sibling with autism spectrum disorder. When compared with the control group, people with a sibling with autism spectrum disorder were found to be more likely to pursue a career in a service field such as psychology, health care or teaching. Similarly, the study by Chambers (2007) was a small study of eight participants, all of whom worked in the disability field. Chambers (2007) found that the reasons the participants gave for their choice of career included experiences with their sibling with intellectual disability or experiences with other people with disability. In addition, participants felt that as a result of their past experiences, they brought to their role personal qualities of empathy, understanding, patience, perseverance and credibility.

Davys et al. (2016) also found an association between growing up with a sibling with intellectual disability and career choice for the 15 adult siblings of people with intellectual disability in their study. This was an incidental finding in Davys et al.’s (2016) study since it did not focus on career choice. Nevertheless, Davys et al. (2016) found that more than half of their sample (n = 9) worked or volunteered in health or social care, suggesting a correlation between career choice and the experience of growing up with a sibling with intellectual disability.
The studies reviewed here employed small participant samples; therefore, it is difficult to suggest that their findings are generalisable. There is also evidence (Konstam et al., 1993) that the experience of having a sibling with intellectual disability does not influence career choice. In Konstam et al.’s 1993 study, which explored the impact of having a sibling with intellectual disability on career choice, no evidence was found to suggest a significant difference in career choice of siblings of people with disability when compared with siblings of people without disability. Seligman and Darling (2007) stated that they had been cautious not to make the “theoretical leap between the development of compassion, tolerance and empathy, and the selection of a particular career goal”, and they suggested that for some siblings their challenging childhood may predispose them to seek career goals outside of the helping professions (p. 251). There is limited evidence of research that has focused on career choice for siblings of people with disability, and the available literature is limited by sample size; however, Seligman and Darling (2007) suggested that future research focusing on this phenomenon could explore the correlation further. It is for this reason that participants in this study were asked about their career choices.

2.7 Sibling support

There is evidence (see Love et al., 2012; Seligman & Darling, 2007) to suggest that the provision of information to siblings at an early age will enhance the relationship between siblings across the life span. Some authors (Atkin & Tozer, 2013; Davys et al., 2016) also suggested that service providers can assist siblings with a sibling with intellectual disability to plan effectively for the future by recognising the role of siblings in the lives of people with disability. Atkin and Tozer (2013) posited that sibling support mechanisms may also enhance the wellbeing of siblings. The following section provides a discussion in greater depth of the sibling-disability research that considers the information and support provided to siblings who have a sibling with intellectual disability.

2.7.1 Learning about disability

Seligman and Darling (2007) suggested that the lack of information provided to children about their sibling’s disability may lead to unanswered questions and fantasies about the cause of their sibling’s disability and the implications for the future. Parents are not always well informed themselves, and may feel that hiding the truth from younger children may protect them (Seligman & Darling, 2007). According to Seligman and Darling (2007), parents may feel a sense of shame and reluctance to “burden their
children with the truth” (p. 236). Reluctance by parents to share information with siblings was also noted in Skotko and Levine’s 2006 study. Skotko and Levine (2006) explored siblings’ reactions to having a sibling with Down syndrome, and they suggested that parents might have concerns that the other siblings in the family could respond negatively to the reality of their sibling’s disability. However, the authors found that regular ongoing discussion with siblings and the provision of age-appropriate information sends messages to siblings that parents are happy to discuss their sibling’s disability. Skotko and Levine (2006) suggested that parents and their children can research the “tough questions together”, enabling a discovery process, “teaching brothers and sisters where and how to find the answers” (p. 3).

In a US study that explored the impact of Angelman syndrome, a rare neurogenic disability characterised by severe ID, on the sibling relationship, Love et al., (2012) recommended that the provision of information about Angelman syndrome to other siblings in the family will improve understanding of the condition and provide children with strategies to respond to challenging behaviours and assist with the development of coping mechanisms. According to Love et al. (2012), not only does the provision of sufficient information help siblings understand their sibling’s disability, it may also improve the relationship between siblings. In Davys et al.’s (2016) study conducted from the perspective of adults with a sibling with intellectual disability, sibling needs were highlighted by all participants in their study. This included training on how to support their sibling with intellectual disability in childhood, and the need for “detailed advice and information” in adulthood (p. 226).

In a Western Australian–based study by Leonard et al. (2004) with 119 parents accessing RettNet, an internet-based information and support service established by the International Rett Syndrome Association, the internet was found to be a reliable source of information that was otherwise difficult to find. The principal motivation for joining RettNet for the participants in their study was to seek information related to Rett syndrome, a rare neurological disorder (Leonard et al., 2004). Rett syndrome is also a relatively recently described syndrome (first described in 1983); therefore, the availability of information for parents and practitioners may be limited (Leonard et al., 2004). While Leonard et al.’s (2004) study focused on information for parents, nevertheless, it highlighted not only the challenges for families when seeking the information they need regarding disability but also the amount of information readily available for siblings in the family, particularly for rare conditions. Leonard et al. (2004)
suggested that parents can gain a high level of support from internet-based services, which thereby decreases feelings of isolation and increases social support and access to practical advice.

In a review of the literature that considered the internet as a social support mechanism for carers of adults with intellectual disability, Perkins and LaMartin (2012) suggested that information and resources could be incorporated into carer support and informational websites to provide a “user friendly” way for siblings with and without disability to access the information they need (p. 59). According to Perkins and LaMartin (2012), at the time of their study older adults were not utilising the internet to the same capacity as younger adults; however, this will change as the population ages, increasing the proportion of older adults with skills in the use of technology. According to Perkins and LaMartin (2012), the building of “virtual communities” for support and as a source of information is no less relevant than traditional face-to-face methods and may provide information to assist with access to future planning and aged care, and which acts as a “springboard for political action” for siblings of people with disabilities (p. 59).

2.7.2 Formal services and support mechanisms for siblings

In a British study exploring the experiences of 21 siblings of people with autism spectrum disorder and intellectual disability, Atkin and Tozer (2013) argued that service providers find it difficult to engage with the complexity of sibling relationships. They suggested that the natural support network for people with disability may be enhanced by appropriate early engagement with service providers, “shared intelligence” between families and service providers, and recognition of the role of siblings (Atkin & Tozer, 2013, p. 40). Early engagement with support services will develop trust and rapport with families to facilitate sibling involvement from childhood through to adulthood. According to Atkin and Tozer (2013), this would assist siblings to be involved with their sibling with intellectual disability at the level they wish and provide them with information to assist with decision-making preferences to contribute to the lives and plans for the future of their sibling.

Atkin and Tozer (2013) and Davys et al. (2016) argued that the lack of support from services, lack of confidence in services and the negative attitudes towards services led to a sense of distrust in service provision. Using the same dataset as Atkin and Tozer (2013), Tozer and Atkin (2015) further explored siblings’ engagement with service providers and found that most of the participants in their study reported that they did not
have contact with services until they were adults; therefore, services viewed their involvement in the lives of their sibling with intellectual disability as a resource—the “taken for granted background of family care”—and were neglectful of their needs (p. 350). For the participants in Tozer and Atkin’s (2015) study, their past experiences with the formal care system resulted in low expectations, “where service staff might not even know they existed” (p. 347). In a mapping project to ascertain the current support available in Australia for siblings, Siblings Australia (2017) found that service providers often do not recognise the role of siblings and the unique relationships between them and their sibling with intellectual disability. According to Siblings Australia (2017), it would be beneficial for service providers to work alongside siblings without disability, recognising their needs as independent from the needs of their sibling with intellectual disability (Siblings Australia, 2017).

According to Orsmond et al. (2009), early engagement with service providers offers other benefits for siblings, such as establishing positive coping strategies. Skotko and Levine (2006) suggested that early engagement with service providers could provide support to enable siblings to manage the confusion and additional worry about their sibling’s disability. In a small Hong Kong–based study of six siblings of people with intellectual disability, Ying Li (2006) highlighted the need for support and information for siblings early in life to alleviate the stress that affects some adults with a sibling with intellectual disability and better prepare them for a role as an advocate or carer. Atkin and Tozer (2013) suggested that early engagement may assist with developing rapport with service providers and ensure that siblings are equipped with the information and confidence they require to support decision-making for their sibling with disability, if and when their sibling needs it. Furthermore, a lack of engagement with service providers while growing up, and during the future planning process, may affect the success of future caregiving roles because siblings may not be fully aware of the issues that parents have “had to deal with” (Heller & Kramer, 2009, p. 218).

In a US study that examined the support needs of 139 siblings of people with intellectual disability, Arnold et al. (2012) found that while there are existing networks and services for parents and their children with disability, siblings are often not included in these networks. This is especially a concern when parent carers can no longer provide support and the responsibility is transitioned to siblings (Arnold et al., 2012). Arnold et al. (2012) found that a high priority for siblings is enhancement of the formal support system to address their needs.
There is limited evidence available that focuses on the support needs of siblings of people with disability. The mapping project by Siblings Australia (2017) is the only literature available focusing on the support services available for siblings with a sibling with intellectual disability in Australia. In addition, many of the studies drew on small sample sizes (e.g., Atkin & Tozer, 2013; Rawson, 2010; Ying Li, 2006), which limits their generalisability. Nevertheless, from the review of the available literature, there appears to be limited formal support available for siblings of people with disability in Australia, which ranges from ‘one-off’ events to sibling camps or young carer specific support networks (provided by Carers Australia and Carers WA; Siblings Australia, 2017).

2.8 Disability policy and legislation

Although young carers are increasingly recognised in policy and services, the needs of people who have a sibling with intellectual disability are rarely acknowledged from a policy perspective (Meltzer, 2015; Tozer & Atkin, 2015). Policy and discourse often group siblings of people with disability as carers, and as many siblings who have a sibling with intellectual disability do not wish to identify themselves as a carer (Meltzer, 2017), they may remain obscured from formal services and support (Meltzer, 2017; Smyth et al., 2011). In addition, data that reports on sibling carers may be skewed by carers whom are not known to services, including siblings who provide support for their sibling with intellectual disability (Australian Institute of Family Studies, 2016; Moore & McArthur, 2007).

Since the 1970s and the rise of the advocacy and self-advocacy movements in Australia, the human rights of people with disability have been on the political agenda (Simpson et al., 2019). Several organisations exist in Australia that advocate for the rights of people with disability; however, organisations that advocate for siblings of people with disability are less common. In Australia, Siblings Australia raises awareness of the needs of siblings and advocates for siblings at a policy level (Giallo et al., 2012; Siblings Australia, 2017). Similar organisations operate in other countries (Sibs UK, Sibs NY and the Sibling Leadership Network across the US; Giallo et al., 2012).

In the US study by Arnold et al. (2012), which examined the support needs of adult siblings with a sibling with disability, the authors argued that siblings of people with disability are often “left out of the disability advocacy movement” (p. 379). Arnold et al. (2012) believed that siblings are an underused resource in the disability advocacy
movement, and that involvement in disability policy and advocacy may assist with the inclusion of support and information that is currently inadequate for siblings and for people with disability. According to Arnold et al. (2012), siblings could be an “untapped constituency for policy advocacy that can increase the power in the disability advocacy movement”, and together siblings can support each other to advocate for policy change to ensure that support and resources are allocated appropriately to address their unique needs (p. 379).

In an analysis of Australian policy documents related to family inclusion in disability services, Taylor (2011) found that while it is the intention of policies to meet the needs of families (including siblings) with a child with disability, there is a gap between intention and what is achieved in practice. Taylor (2011) made recommendations to audit disability services against policies to ensure that the benefits of ‘whole of family’ inclusion are met. However, since Taylor’s 2011 study, Australia has undergone major policy reform with the introduction of the NDIS. One of the guiding principles of the NDIS Act 2013 is to “strengthen, preserve and promote positive relationships between the child and the child’s parents, family members and other people who are significant in the life of the child.” (p. 8). Therefore, it would be expected that since the introduction of the NDIS changes would have been made to disability service provision commensurate with the recommendations made by Taylor (2011); however, this is not evident. At the time of writing, there are two main disability policy initiatives in Australia: the National Disability Strategy 2010–2020 (NDS), which has a broad focus on rights, and social and economic inclusion; and the NDIS, which is the funding for the delivery of individualised support to people with disability to meet the aspirations of the NDS (Hallahan, 2015). However, according to Siblings Australia (2017), there is little recognition of siblings in these policies, which tend to focus only on parents as the decision-makers and recipients of family support.

In a content analysis of NDIS documentation, Meltzer and Davy (2019) found that the NDIS Act, the NDIS rules and the NDIS Price Guide (which guides organisations on how to charge for the services they offer) fail to conceptualise relationships as anything other than ‘informal support’ (with one noted exception in the NDIS Operational Guidelines). Meltzer and Davy (2019) suggested this indicates that informal support is viewed as a source of support that “mitigates the cost of other formal services provided through government and NDIS funding”, thereby effectively downplaying the role and importance of relationships (p. 256). The NDIS
documentation also fails to consider the relational, age and gender appropriateness of informal support. Such appropriateness would ensure that the support a sibling would provide to a sibling with intellectual disability is otherwise socially acceptable in a sibling relationship where disability is not present (Meltzer & Davy, 2019). A policy approach that recognises the contribution of siblings is needed to understand the complex and individual ways that siblings experience their relationships with each other, and not just as a provider of informal care (Meltzer, 2017; Smyth et al., 2011).

### 2.9 Conclusion to this chapter

The impact of having a sibling with intellectual disability has been increasingly explored in previous studies; however, there is a dearth of research that has explored the impact from a life-span perspective, particularly in WA. To address the gap in understanding individual, family and disability characteristics that affect sibling relationships across the life span when one sibling has ID, the research design for this current study utilised a mixed methods approach to data collection to understand the ‘lived experience’ of siblings. There is limited evidence of research that has explored the experiences of siblings since the introduction and implementation of the NDIS in Australia. The roles of families and natural networks have been recognised in the ideals and values of the NDIS; however, less clear is the influence of the NDIS on the experiences of siblings of people with intellectual disability. This current study also seeks to strengthen evidence of how early experiences growing up with a sibling with intellectual disability, regardless of disability diagnosis, influence not only the relationship between siblings as adults, but also the obligation, or expectation, to care for their sibling with intellectual disability in the future.
Chapter 3  Research design

To provide a framework for a study, Creswell (2014) suggested that researchers define the philosophical assumption that underpins the study and embed this into the interpretive framework. Denzin and Lincoln (2011) provided an unambiguous way to do this. Their overview of the research process begins with the researcher’s assumptions and contribution to the study, the theoretical paradigms and frameworks used, the methodological approach (or research strategies) that the study undertakes, and the methods for data collection and analysis selected to conduct the research. Finally, the researcher undertakes the interpretation of the findings and evaluation of the data. Identification of the theoretical framework in research provides a systematic understanding of the perspective of the research (Creswell, 2014).

The philosophical assumptions that underlie this study, the interpretive framework and underpinning theory, and the methodology and methods that were selected for this study were chosen as the best approaches to answer the research questions. This chapter is structured using the framework suggested by Denzin and Lincoln (2011), as outlined in Table 3.1. The chapter concludes with a discussion about the ethical and risk management issues relating to this study, and the credibility and confirmability of the findings.
Table 3.1 The research process used in this study

<table>
<thead>
<tr>
<th>The research process outlined by Denzin and Lincoln (2011)</th>
<th>Research process used in this study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phase 1: Researcher assumptions and contribution to this study</td>
<td>Assumptions that the contributions of siblings of people with disability are often undervalued in society and service provision. Researcher experience within the disability sector and previous research undertaken. Ethical and political issues related to human research</td>
</tr>
<tr>
<td>Phase 2: Theoretical perspectives</td>
<td>Ontology (the nature of reality)—critical realism Epistemology (the theory of knowledge)—social constructivism Ecological systems theory Critical disability theory Family life cycle perspective</td>
</tr>
<tr>
<td>Phase 3: Methodological approach (research strategies used)</td>
<td>Transcendental phenomenology (Moustakas, 1994)</td>
</tr>
<tr>
<td>Phase 4: Methods used for data collection and analysis of the data</td>
<td>Survey with delimited responses, free text and Likert scales Interviews Manual thematic analysis and computer-assisted software (Nvivo)</td>
</tr>
<tr>
<td>Phase 5: Interpretation and evaluation of the data</td>
<td>Includes the voices of the participants A description and interpretation of the problem Contributions and recommendations</td>
</tr>
</tbody>
</table>

Note. (Adapted from Denzin & Lincoln, 2011)

3.1 Phase 1: Researcher assumptions

The philosophical assumptions underlying this study assisted with the formulation of the research questions and the decision-making process for data collection methods to answer the questions (Creswell, 2013). As a researcher within the disability sector, and having worked within disability organisations, my own assumptions needed to be considered while I undertook the research. Firstly, I held an assumption based on my own experience that the importance of the relationship between siblings when one has disability is often disregarded by service providers. I also assumed that early engagement with siblings without disability may improve their coping ability and resilience, thereby improving the relationship with their sibling with intellectual disability. This assumption stemmed from the research I undertook for my Master’s thesis and reviewing the literature for both my master’s degree and this study.
Denzin and Lincoln (2011) suggested that acknowledging the historical, ethical and political issues that a researcher brings to the research is an important part of this phase. My earlier studies included historical perspectives of disability, and the ethical challenges that research with people with disability, as a vulnerable group of research subjects, poses. Disability reform has changed how disability is constructed, individually and from a societal perspective, and disability research and disability policy responses have adapted to redress past inequalities in human and social rights (Simpson et al., 2019).

The theoretical paradigms and the framework described below explain how I interpreted my findings while undertaking this study, shaped by my own experiences and from the participants’ view of their lives and experiences (Creswell, 2013).

3.2 Phase 2: Theoretical perspectives

The ontology informing the theoretical perspective of this study is critical realism, and the epistemology is social constructivism. According to Crotty (1998), realism deals with the nature of reality and the notion that realities exist independently of belief or knowledge; however, it acknowledges our perceptions of reality may be distorted by our social, cultural and biological formation. Although reality exists, perceptions are not wholly objective and must be approached critically. The research design in this study utilised a critical realist approach; the methodology chosen assisted understanding of the experiences of siblings with a sibling with intellectual disability, in lieu of just describing them. Social constructivism was described by Crotty (1998) as the understanding of knowledge as a ‘socially constructed’ meaning. According to Creswell (2013), in social constructivism, participants in the study seek to understand the “world in which they live” to develop meaning of their experiences through their interactions with others (pp. 24–25). The goal of this study was to elicit the participants’ experiences of having a sibling with intellectual disability, their subjective meanings and their socially constructed interpretations. This approach contends that there is no singular explanation for the experiences of an individual’s interaction with others; therefore, individuals have diverse views of society (Crotty, 1998). Crotty (1998) explained that realism in ontology and constructivism in epistemology are “compatible” (p. 11) and are often chosen as the theoretical perspectives in phenomenological research.
3.2.1 Ecological systems theory

Ecological systems theory considers the broader social context that influences people’s lives (Bronfenbrenner, 1979). According to Stoneman (2005), Bronfenbrenner’s ecological systems theory is an essential model for researching sibling relationships, particularly when disability is present. Bronfenbrenner’s theory, which he referred to as “the ecology of human development”, begins by placing the individual at the centre of the ‘system’, which incorporates a “nested arrangement” of further systems that the individual exists within (Bronfenbrenner, 1979, p. 21). These systems are the microsystem—an individual’s home, day care, school, workplace and neighbourhood; the mesosystem—a system of the microsystems; the exosystem—a setting that does not include the individual but may affect them, such as the individual’s parent’s workplace, network of friends and the community; and the macrosystem—law, policies and culture (Bronfenbrenner, 1979; Saxena & Adamsons, 2013). Saxena and Adamsons (2013) also included the ‘chronosystem’, which relates to time: the “sociohistorical events” that influence an individual’s experiences (p. 303).

Saxena and Adamsons (2013) suggested that an ecological framework (they referred to it as a ‘bioecological framework’) can be applied to the field of sibling-disability research and that, in addition, the framework can assist understanding of the influences of the ‘systems’ that are present over the life span for siblings. A diagrammatic representation of the bioecological framework that Saxena and Adamsons suggested in relation to research regarding siblings of people with disabilities is presented in Figure 3.1.
Bioecological, or systems, theory was selected for this study as the overarching theoretical framework because it recognises the role of the individual (the person who has a sibling with disability) and the relationship within and between the environments in which they exist. As Saxena and Adamsons (2013) suggested, the application of bioecological theory to sibling research provides a rich understanding and a ‘bigger picture’ perspective, and uncovers the finer details of siblings’ experiences.

Two further theories contributed to the theoretical framework developed for this study. These are critical disability theory (CDT) and family life cycle theory.

### 3.2.2 Critical disability theory

CDT is a relatively recent theory that provides a basis for the research and analysis of issues relating to disability (Hosking, 2008). According to Hosking’s (2008) formulation of CDT, it is grounded in the social model perspective of disability. Meekosha and Shuttleworth (2012) expanded on Hosking’s presumption and stated that while the social perspective was one of the tools employed in their analysis of CDT, it incorporates a “complex conceptual understanding of disability oppression” (p. 50).
CDT challenges the assumption that disability is a ‘misfortune’ and that people with disability want to achieve ‘normality’ instead of embracing their differences (Pothier & Devlin, 2006). According to Pothier and Devlin (2006), the context in which CDT is understood is important. CDT is theory “that emerges from the bottom up, from the lived experiences of persons with disabilities, rather than from the top down, from the disembodifying ivory tower” (Pothier & Devlin, 2006, p. 9). Hosking (2008) stated that the rationale of CDT is the emancipation of people with disability, which can be achieved by exploring experiences to challenge existing conditions.

Hosking (2008) upheld the belief that CDT-based research must feature the voices of people with disability themselves, however Arnold et al. (2012) argued that the contribution siblings can make to the lives of their sibling with intellectual disability would add further value to the way services are delivered and the way practitioners operate in the disability sector. CDT framed my initial thinking and approach to this study, however because of the personal nature of connection between siblings, the bioecological perspective is more relevant. There are inherent tensions in aligning systems theory with critical disability theory, however these tensions are resolved through the macro elements of a systems approach that captures the constructions of the participants’ world view.

3.2.3 Family life cycle theory

The third theory that underpins this study is family life cycle theory, which recognises that roles within the family change over the course of a life time (Ferraioli & Harris, 2009; Whiteman et al., 2011). The affect that the role change from sibling to carer has on sibling relationships is unique to each sibling dyad; however, family life cycle theory can provide an understanding of the changes that siblings undergo throughout the life span and help to explain the complex relationships they experience.

Family life cycle theory is evident in the research of Atkin and Tozer (2013), who identified that adult siblings often struggle to maintain close connections to their sibling with intellectual disability because of family and social commitments. In normative sibling relationships (those in which neither sibling has disability), the significance of the relationship between siblings increases as they age; however, when one sibling has disability it is likely to affect sibling relationships in different ways (Ferraioli & Harris, 2009; Taylor et al., 2008). According to Taylor et al. (2008), this can be attributed to several factors. When a sibling provides instrumental and emotional support to a sibling with intellectual disability, the relationship may be based more on
caregiving than on mutual companionship. Siblings with a sibling with intellectual
disability are also likely to have “higher levels of solidarity with their family of origin”
and may be concerned about the genetic cause or predisposition to disability, depending
on the characteristics of their sibling’s disability (Taylor et al., 2008, p. 906).

I selected CDT and family life cycle theory for this study because they offer a
strengths-based approach that endorses a model of support within the family. These
theories assist with the understanding of the complex system of relationships within
families, and the strength of the natural networks that families can provide. A strengths-
based approach can be found in the research of several authors (Bigby, 1997; Heller &
Caldwell, 2006; Ormond & Seltzer, 2000) and is useful when considering the strength
of the relationship between siblings when one has disability.

3.3 Phase 3: Methodological approach

The methodological approach used in this study was phenomenology, which was
first described by Husserl in the early twentieth-century, and later modified by Van
Kaam, Van Manen, Giorgi and Collaizzi, among others (Tesch, 2013). According to
Tesch (2013), phenomenology is the study of the lived experience of individuals. It
searches for a common meaning in relation to a particular concept or phenomenon
(Creswell, 2014). This study was approached using Moustakas’ (1994) method of
transcendental phenomenology because it allows participants opportunities within both
stages of the study to describe their experiences. Moustakas (1994) defined
transcendental phenomenology as a descriptive process in which the researcher
acknowledges the assumptions of their experience and ‘sets them aside’ so they have a
fresh perspective of the phenomenon (p. 34). Transcendental phenomenology places
less emphasis on the interpretations that the researcher makes regarding the lived
experiences of the participants, but focuses instead on the descriptions of the
experiences themselves (Creswell, 2014). Analysis of the data results in the
identification of significant themes, enabling the description of the textural and
structural aspects of the experience and thereby gaining an overall ‘essence of the
experience’ (Moustakas, 1994). Creswell (2014) provided a procedure for conducting
phenomenological research using Moustakas’ method:

1. Determine the suitability of phenomenological research methodology for the
research problem.
2. Determine the phenomenon to be studied.
3. Decide what the broad philosophical assumptions are, and ‘set aside’ own experiences.

4. Collect data through phenomenological methods, such as interviews, observations or written responses.

5. Two broad questions form the basis of this study—“What is your experience” and “What has influenced or affected your experience”? Questions are open-ended and are able to provide an understanding of the lived experience of the participants.

6. Analyse the data by identifying ‘significant statements’ and cluster the meanings into themes. This is termed ‘horizonalisation’ by Moustakas (1994).

7. Use the themes to write the ‘textural’ and ‘structural’ descriptions of the experience.

8. Describe the ‘essence’ or common experience of the participants as a synthesis of the textural and structural descriptions (Adapted from Creswell, 2013, pp. 81-82).

3.4 Phase 4: Methods

The data collection for this study utilised a mixed methods approach. Creswell (2014) suggested that it is useful to provide basic definitions and descriptions of the method. Moreover, since mixed methods research is a relatively new method of data collection, it is essential that this section clearly outlines the justification for using the method, and the mixed methods design selected.

3.4.1 Sequential explanatory mixed methods research design

Mixed methods research is a process that considers multiple viewpoints from both qualitative and quantitative research methods (Creswell, 2014; Johnson et al., 2007; Plano Clark & Ivankova, 2016). Creswell (2014) described the benefits of combining qualitative and quantitative data in mixed methods research, which are useful to outline here (Table 3.2).

Qualitative research typically engages in ‘open-ended’ questions, seeking ‘meaning’ from the experiences of individuals; quantitative research measures variables through ‘closed’ questioning, typically represented numerically; mixed methods research collects both qualitative and quantitative data and ‘mixes’ the results (Creswell, 2014). Tashakkori and Creswell (2007) described mixed methods research as an integration of the qualitative and quantitative elements of the research, which results in
a conclusion that is more comprehensive and meaningful than does either method in isolation.

Table 3.2 Benefits of qualitative and quantitative methods of data collection

<table>
<thead>
<tr>
<th>Qualitative research data can:</th>
<th>Quantitative research data can:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• assist in providing a theoretical framework</td>
<td>• identify individuals for qualitative data collection</td>
</tr>
<tr>
<td>• validate survey data</td>
<td>• identify representative and unrepresentative cases</td>
</tr>
<tr>
<td>• interpret statistical relationships found in quantitative data collection</td>
<td>• address the ‘incongruency’ of experiences and indicate the full range of participants who should be sampled</td>
</tr>
<tr>
<td>• explore individual responses</td>
<td>• address the limitations of ‘limited-sample’ qualitative studies</td>
</tr>
<tr>
<td>• contribute depth to quantitative data</td>
<td></td>
</tr>
<tr>
<td>• suggest ‘leads’ that quantitative data collection may not address</td>
<td></td>
</tr>
</tbody>
</table>

A mixed methods research design was selected for this study in response to the research questions, and the tools selected (survey and interviews) were considered the best methods to find answers to the research questions (Plano Clark & Badee, 2010; Tashakkori & Teddlie, 2010). The rationale for selecting a mixed methods research design for this study is the ability to corroborate responses from the survey with follow-up interviews to explain the responses in more depth (Johnson et al., 2007).

According to Creswell (2014), mixed methods research design is either two-phased or multi-phased; therefore, a decision must be made regarding the collection of the data—either simultaneously or sequentially—and a rationale presented for choosing the design. Explanatory sequential mixed methods research designs typically undertake the quantitative phase first; then, the qualitative phase builds on the quantitative phase of the research (Creswell, 2014). As the intention of this study was to make meaning of the personal experiences of people with a sibling with intellectual disability but maintain a broad perspective to address the gaps in the existing literature, it was appropriate to select the explanatory method and undertake a survey initially to capture experiences from a range of demographics.

Convenience sampling, the method used for recruitment of participants for the first-stage survey for this study, involves recruiting participants because they are ‘convenient’ cases (Lavrakas, 2008). Participants for the first stage of this study were recruited to complete an online survey designed to collect demographic data and information that formed the basis of the semi-structured interview questions in stage two. There was an opportunity for participants to answer some of the questions
qualitatively (open-ended questions), which were used with the descriptive quantitative data (mostly demographic data) to assist in grouping the participants by commonality for stage two (number of siblings in the family and birth order in the family). The use of surveys to collect qualitative data is not new, however the potential for qualitative surveys to add to the richness of data is often not recognised (Braun et al., 2020). The survey used in the first stage of this study was not fully qualitative, however the open-ended questions were treated qualitatively, in keeping with the tenet of Moustakas’ (1994) method of transcendental phenomenology. According to Braun et al. (2020), the use of surveys to collect qualitative data may be appropriate when a ‘wide-angle lens’ is required and there is scope for additional data collection as a follow-up to the survey.

In the second stage of this study, a purposeful sample of participants was selected from the sample who completed the first-stage survey. Since the aim of a second stage is to follow up on the results of the first stage or to explore a phenomenon further, it is preferable that participants for interview are selected from the participants from the first stage (Creswell, 2014). This was possible in this study because a higher-than-expected number of participants who completed the survey provided their details consenting to be contacted for interview. (Two participants who were interviewed did not complete the survey but were referred to this study through friends. Both of these participants met the criteria for inclusion in the interviews.)

3.4.2 The survey

The survey collected basic demographic information, such as age, gender, other siblings in the family, age of sibling with intellectual disability and their disability diagnosis. Further closed-ended questions enquired about the living arrangements of participants’ sibling with intellectual disability (at home with family, independent or supported living, or living with sibling), the care or support provided to their sibling with intellectual disability, and the presence of partner and/or children. Additional open-ended questions allowed for free text to gain an understanding of relationships and influences on connectedness to participants’ sibling with intellectual disability. The survey employed ‘skip logic’ so that participants who had a sibling with intellectual disability who was deceased were offered questions that take this into consideration.

3.4.3 Sampling frame for the survey

The target population for this study was the portion of the population who had a sibling with disability. This is a very broad description and requires further definition to identify a more specific target sample. Andres (2012) maintained that the population to
be studied needs to be identified by *who, what, where* and *when* questions. The following table, Table 3.3 (modified from Andres’ example) defines the target population for this study.

<table>
<thead>
<tr>
<th>Who</th>
<th>What</th>
<th>Where</th>
<th>When</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less specific</td>
<td>Adults</td>
<td>Sibling with a disability</td>
<td>Australia</td>
</tr>
<tr>
<td>More specific</td>
<td>Adults, any gender</td>
<td>Sibling with ID/autism with ID, any gender, diagnosis as a child &lt; 12 years, no specific requirement for sibling with intellectual disability to be currently living</td>
<td>Perth, Greater Capital City Statistical Area (see Appendix 4)</td>
</tr>
</tbody>
</table>

*Notes.* (Adapted from Andres, 2012). ID is an abbreviation for intellectual disability.

The participants for the survey were recruited through social media, existing networks and people known to me, disability service organisations, disability-specific media (websites and newsletters) and local media. The survey was presented online through Qualtrics, a web-based survey tool available through the university. The link to the survey was provided in the information sheet that promoted the survey on social media and via other methods (see Appendix 5). Participants were able to log on to the survey and complete it in their own time.

### 3.4.4 The interviews

Creswell (2014) described the nature of the emergent design of qualitative research. As Creswell (2014) suggested is appropriate to this method, the types of questions that were asked in the interviews in stage two were developed following the analysis of the first stage, to explain the lived experiences of the participants better.

### 3.4.5 Sampling frame for the interviews

The sample of participants for the semi-structured interview stage was selected from the participants of the online survey in stage one (except for the two participants described earlier). The sample was purposefully selected from the participants who provided their details for contact. Creswell (2013) suggested that participants are selected on the basis that they can “purposefully inform an understanding of the research problem and central phenomenon in the study” (p.156). Purposeful sampling is not without challenges and is reliant on what emerges from the data collection in the
survey phase (Palinkas et al., 2013). Since the survey collected data using a qualitative method, it was also appropriate to consider data saturation as a delimiter for selection of participants to interview. Data saturation is the continuation of data collection (in this instance, the conduct of interviews) until no new information is being collected (Palinkas et al., 2013).

The sampling method used in this study is described as a *stratified purposeful sampling design* (Palinkas et al., 2013). It was intended that I would capture the variations and themes from the first stage and examine them in depth to identify a focus on the second stage of the study. Since the size of the sample was limited by the number of responses to the survey, the number of participants who agreed to be interviewed in stage two and the themes pursued in the interviews, it is unlikely that this study could claim to represent the population of people with a sibling with disability. It is also unlikely that I would achieve data saturation because the lived experience of having a sibling with disability is a unique and individual experience, affected by several familial factors.

### 3.5 Phase 5: Interpretation and analysis of the data

#### 3.5.1 Data analysis process

Questions in the survey collected demographic information, some questions provided an opportunity for participants to select answers from a list and some questions allowed for free text, collecting qualitative data. The data analysis approach differed depending on the type of question posed. For the quantitative questions in the survey (for example, age, number of siblings in the family), the data were exported to an Excel spreadsheet for analysis. This approach was chosen because it enabled the researcher to sort data by columns and count responses.

The approach to the analysis undertaken for the open-ended questions in the survey and the interview transcriptions from stage two of this study utilised a thematic analysis method. Thematic analysis for qualitative data in a phenomenological study is a method utilised, and modified, by several notable authors and researchers (Braun & Clarke, 2006; Creswell, 2013; Moustakas, 1994; Van Manen, 1997). According to Braun and Clarke (2006), thematic analysis can be described as the identification and analysis of common themes within the data and organisation of the data into a form that enables the researcher to find meanings from the participants’ experiences (Braun & Clarke, 2006; Moustakas, 1994). To enable a salient understanding of the themes, subthemes are organised beneath the themes, focusing on one particular experience or
element of the theme concept (Braun & Clarke, 2006). Vaismoradi et al. (2016) described subthemes as the “summaries and examples drawn from participants’ accounts related to elements that build themes” (p. 107).

Braun and Clarke (2006) stressed the importance of clarifying the process and method of data analysis used when writing the research report in order to evaluate, compare and synthesise it with other similar studies. In addition, Braun and Clarke (2006) chose to explain how they ‘identified’ or ‘constructed’ themes from the data in preference to the more commonly used terminology of ‘emergent’ themes or the ‘discovery’ of themes. This use of terminology, according to Braun and Clarke, represents the “active role” of identification, selection and reporting of themes from within the research data (p. 80).

The six-phase framework that Braun and Clarke (2006) provided for conducting thematic analysis was used in this study when analysing the qualitative survey questions and interview transcriptions. The six phases are presented in Table 3.4, with a description of each phase.

<table>
<thead>
<tr>
<th>Phase of thematic analysis</th>
<th>Description of the phase</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phase 1—Familiarising yourself with the data</td>
<td>Transcription of the data (if necessary), reading the transcriptions and noting initial ideas.</td>
</tr>
<tr>
<td>Phase 2—Generating initial codes</td>
<td>Researcher codes interesting features of the data, manually or with data analysis software.</td>
</tr>
<tr>
<td>Phase 3—Searching for themes</td>
<td>Collation of the codes into potential themes and subthemes within the broader, overarching themes.</td>
</tr>
<tr>
<td>Phase 4—Reviewing themes</td>
<td>Refinement of the themes, applied to the entire data set. Some themes may be merged, while others may be separated into two or more themes.</td>
</tr>
<tr>
<td>Phase 5—Defining and naming themes</td>
<td>Defining and naming the themes—Involves identifying the story of the theme and capturing what each one means. Subthemes may also be identified in this phase. The themes need to be named so they are “concise, punchy, and immediately give the reader a sense of what the theme is about” (Braun &amp; Clarke, 2006, P. 93).</td>
</tr>
<tr>
<td>Phase 6—Producing the report</td>
<td>A final opportunity for analysis and write-up of the report. Includes data extracts and sufficient evidence of the themes. The report needs to go beyond a simple description of the data and develop an argument that relates to the research question.</td>
</tr>
</tbody>
</table>

*Note.* (Adapted from Braun & Clarke, 2006, pp. 86-93)
The six phases of Braun and Clarke’s (2006) framework for thematic analysis has been applied to this study and described below.

Phase 1—The responses from the open-ended survey questions were initially analysed through a manual process of reading the responses and highlighting areas of interest. Data from the interviews were transcribed by an external transcriber; therefore, I listened to the recordings and compared accuracy against the transcriptions. I read the transcriptions more than once to re-familiarise myself with the interview content and took notes of my initial impressions of the data.

Phase 2—For the survey data, the printed copies of question responses were coded manually with highlighter pens, followed by the use of the Qualtrics Text IQ function. The manual analysis of the interview transcriptions was conducted by reading each transcription to ensure that I recalled the actual interview and the sentiment in the responses. This assisted with understanding the context in which responses from the participants was intended, as well as ensuring that I was well acquainted with the data—a vital step in the analysis process (Rowley, 2012).

The interview transcriptions were initially coded manually using the ‘track changes’ function in Microsoft Word. Initial codes were identified and noted in comment boxes, indicating a word or phrase (or paragraph) that summarised the experience of the participant and/or produced an evocative meaning to the response (Saldana, 2016). Once this was completed, transcriptions were uploaded into NVivo, a computer data analysis program and coded electronically.

Phase 3—The initial codes/subthemes that were identified in the survey responses (analysed by question, not by the overall interpretation of the survey) were grouped into initial broader themes. The significance of the themes was identified (consideration was given to the frequency of occurrence). For the interview data, the analysis process continued using NVivo software. Initially, subthemes were identified where some commonality was noted from the initial manual coding process. The construction of the broader themes commenced.

Phase 4—In this phase, the themes were refined, and some subthemes were merged because they represented similar responses. Similarly, the initial themes identified in the responses from the interview transcriptions were refined. There were several instances where data were re-coded and themes or subthemes were merged.
Phase 5—The naming of the subthemes and themes followed a similar process, in which the names chosen were intended to reflect the sentiment of the subthemes and theme they were representing. The names given to the themes and subthemes needed to be able to provide the reader with enough of an explanation to convey the meaning of the themes or subthemes (Vaismoradi et al., 2016); therefore, names chosen for the themes and subthemes were not limited to one word. In the interview analysis, two subthemes were named using the participants’ own words (in vivo coding).

Phase 6—During the process of writing the findings and discussion chapters, further analysis was undertaken and passages of data extracts (the verbatim responses from the participants) were selected that best described experiences relevant to the research questions. The discussion chapter synthesised the findings from both the survey and the interview stages of this study.

3.5.2 The coding methods

Coding is cyclical and will usually be repeated to understand the depth of the data, and to organise and reorganise in the search for patterns (Saldana, 2016). The advantage of using computer-assisted software is its capacity to manage large amounts of data (in this study, there were 20 interviews, varying in length from 3,000 to over 10,000 words). It also assists with the re-coding process, provides the researcher with an opportunity to change their mind about the themes being developed and the ability to move data from one category or theme to another, and counting the frequency of words, codes and themes (Saldana, 2016).

Saldana (2016) suggested that the frequency with which a code occurs can indicate that it is of importance, and a code that occurs less frequently may indicate irrelevance in the data set. However, he also stated that in some instances a less frequent code may provide a unique insight that can be further analysed at a later stage of the study. However, according to Creswell (2013) and Braun and Clarke (2006), counting and reporting on the occurrences of codes or themes may convey quantitative methodology, contrary to the intention of phenomenological qualitative research. Creswell (2013) stated that in his research he may consider the frequency of occurrences of codes, yet not report on them. Nevertheless, “quantitizing the qualitative” (transforming qualitative responses into quantitative by counting the occurrence) may have a place in research that collects both quantitative data and qualitative data, such as a survey with both closed-ended and open-ended responses (Saldana, 2016, pp. 25-26). Saldana (2016) described this as “paradigmatic
corroboration”, in which the results from the quantitative and qualitative data correspond with each other to support the results of the analysis and provide an option to analyse the data from a quantitative viewpoint (for example, comparing frequency of codes between age groups). In this study, the codes and themes from the open-ended questions in the survey are presented with a frequency count, similar to the description by Saldana (2016). However, for the data collected during the interviews I utilised the technique suggested by Creswell (2013), who remained true to the principles of qualitative research. To enable some of the unique, and possibly contradictory, views of the participants to be considered, the coding and themes from the interviews are not presented in a quantitative manner and are weighted equally regardless of the frequency in which they occurred (e.g. the frequency with which a word was said does not indicate how important the word was for the participant).

The final component of the analytic process utilised in this study was the ‘coding method’. Saldana (2016) suggested that more than one coding method is often utilised in the analysis and coding of qualitative data, often “depending on the nature and goals” of the study (p. 69). In this study I used descriptive coding, emotion coding and ‘in vivo’ coding methods. Table 3.5 provides a brief summary of the definitions of these coding methods.

<table>
<thead>
<tr>
<th>Descriptive coding</th>
<th>Emotion coding</th>
<th>In vivo coding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Summarises the statements with a word or short phrase that describes the topic’. Suitable for all qualitative studies, including interview transcripts. Recommended for early career researchers.</td>
<td>Acknowledges the emotions expressed by the participants or interpreted by the researcher. Suitable for all qualitative studies, particularly when exploring participant experiences.</td>
<td>Uses the language of the participants, i.e. verbatim quotes. Suitable for all qualitative studies, but particularly when wanting to express the participants’ ‘voice’.</td>
</tr>
</tbody>
</table>

Note. (Saldana, 2016)

An example of a descriptive code that was constructed during the analysis is the theme of relationships, which denotes the relationships that participants described within the family with their sibling with intellectual disability and with their peers. This became a main theme. Codes that acknowledge the emotions expressed by the participants in this study include the subthemes of participants’ feeling they missed out on opportunities while growing up or feeling that the family situation was ‘normal’ for them. In vivo coding was used to capture the actual words of the participants and
included codes under the theme of *consequences for family* of ‘normal for us’ and ‘missed out’. The themes, subthemes and codes constructed during the analysis of the interviews are detailed in Chapter 5.

In summary, this study utilised an explanatory sequential mixed methods research design, with a convenience sample of participants for the first stage, and a purposeful sample for the second stage of the study. The qualitative data were analysed using a thematic analysis method and interpreted through a paradigmatic corroboration. This is represented diagrammatically in Figure 3.2.

**Survey**
- **Sampling procedure**—Convenience sample promoted through social media, networks of researcher and disability organisations
- **Web-based survey**—Demographic characteristics, closed-ended questions and some open-ended questions
- **Analysis**—Presented in tables, figures and common themes; decision made regarding what characteristics/themes to follow up on in phase two

**Interviews**
- **Sampling procedure**—Purposeful sampling from stage one (participants agreed to participate in follow-up interview)
- **Interviews**—Face-to-face or telephone interviews
- **Analysis**—Thematic analysis using manual techniques and data analysis software

**Interpretation**
- **Paradigmatic corroboration**—Results from the quantitative and qualitative data correspond with each other to support analysis
- **Explanation** of the survey results and ‘meaning making’ of the qualitative results
- **Textural and structural descriptions**, recommendations, further research

Figure 3.2 Summary of the explanatory sequential mixed methods design of this study
3.6 Ethics and risk management

This study received ethics approval from the Human Research Ethics Committee at ECU prior to any recruitment of participants and collection of data. Ethical issues were addressed throughout all stages of the research to ensure that participants were protected, that privacy and confidentiality was maintained, that the research was authentic and credible, and to protect against misconduct in the research process (Creswell, 2014).

Since this study was conducted on human subjects, it was governed by policy and legislation designed to protect research participants. The National Health and Medical Research Council outlines several policies and legislation that were applicable to this study in addition to the ECU Conduct of Human Research Policy (Edith Cowan University, n.d.).

The Australian Code for the Responsible Conduct of Research (National Health and Medical Research Council, 2018a) outlines key principles to demonstrate a culture of responsible research:

- Honesty in the development, undertaking and reporting of research;
- Rigour in the development, undertaking and reporting of research;
- Transparency in declaring interests and reporting research methodology, data and findings;
- Fairness in the treatment of others;
- Respect for research participants, the wider community, animals and the environment;
- Recognition of the right of Aboriginal and Torres Strait Islander peoples to be engaged in research that affects or is of particular significance to them;
- Accountability for the development, undertaking and reporting of research, and;
- Promotion of responsible research practices. (National Health and Medical Research Council, 2018a, p. 2)

Information about the research was provided to potential participants, and their privacy and confidentiality was guaranteed. Informed consent was obtained from all participants prior to their participation in this study. Information and consent were included in the introduction of the Qualtrics survey (see Appendix 1). An information
sheet and consent form for stage two interviews are provided in the Appendices (Appendix 6 and Appendix 7).

It is the responsibility of researchers and institutions to ensure that research is conducted according to the principles outlined above, and that risks to both the participants and the researcher are minimised. I recognised that there was an element of risk to the participants on an emotional level because the survey questions and interview questions may have triggered emotional memories of their life with their sibling with intellectual disability. This was a particular risk in instances where the sibling with intellectual disability was deceased. The participants were advised prior to commencing the online survey, and in the information sheet provided prior to the interviews, that if the questions caused any anxiety or stress that they could withdraw from this study at any time. Participants were provided with information to access appropriate counselling services should they wish to seek support.

As the second stage of this study involved telephone or face-to-face interviews with participants, there was an additional risk that I may have experienced some emotional distress owing to the nature of interviewing participants who were distressed themselves. As a student of ECU, I had access to the university’s counselling services and this was available to me if required. Protective measures were put in place for interviews conducted in the participants’ homes to ensure my safety (contact with a support person prior to and following interviews).

3.7 Credibility and confirmability

The terms ‘credibility’ and ‘confirmability’ used by Lincoln and Guba (1985) were selected as the terms in this study when referring to what some researchers state is the ‘validity’ and ‘reliability’ of research. Terminology used to describe the validity and reliability of research often differs depending on the quantitative or qualitative nature of the research (Creswell, 2013). Lincoln and Guba (1985) believed that in qualitative research conducted from a ‘naturalistic’ (constructivist) paradigm, credibility and confirmability are more appropriate for this type of research. Credibility refers to the quality and trustworthiness of the data collected and the ability of both the researcher and the participants to understand the design of the study (Given, 2008). Confirmability refers to the evidence that the interpretations, or ‘meaning making’, of the participants’ experiences are reflected accurately, and that similar conclusions could be confirmed by other researchers at other times (Given, 2008).
Methods used to collect data that enable ‘rich’ descriptions of the lived experience assist with the triangulation of data that contribute to the credibility of the research (Lincoln & Guba, 1985). Mixed methods research has been described as “methodological triangulation”, which can assist researchers to ensure that findings are validated, in addition to providing “thicker, richer data” than using one method alone (Johnson et al., 2007, p. 115). Fielding and Fielding (2008) explained how triangulation enhances validity in research that utilises a mixed methods approach:

The original conception was that triangulation would enhance validity, understood as agreement in the outcomes of more than one independent measurement procedure, relative to studies employing a single procedure. (p. 555)

Creswell (2014) included ‘triangulation’ as a strategy to assess the accuracy of research findings and as a method of convincing the readers of the accuracy of the research. However, in explanatory mixed methods research designs there are concerns that important themes may not be given the attention they deserve in the second stage, thereby compromising the overall findings (Creswell, 2014). To improve the credibility of this study, all responses from the survey in stage one were given equal weighting during the analysis process.

Creswell (2014) suggested that results of explanatory mixed methods studies are invalidated if the participants for each stage are drawn from two separate samples because this negates the value of stage two building on stage one. At the completion of the survey, participants were asked if they would consent to a follow-up interview, and if so, to leave their name and contact details should they be selected for interview. This was not compulsory, and all participants had the option to complete the survey and not leave contact details. The contingency plan if I did not receive enough participants’ contact details for the stage two interviews would have been recruitment from outside the survey cohort; however, since 48 participants provided their details at the end of the survey, recruitment from elsewhere was not required. As described in section 3.4.1, two participants were interviewed who did not complete the survey through word-of-mouth referral (known as snowball sampling).

To improve the credibility of this study further, following the interview, participants were provided with the transcript from the interview for an opportunity to verify the transcription, make corrections (especially for unclear recordings) and
provide further reflections to add to the interview data. Rowley (2012) stated that this correction and approval opportunity also assists with the analysis process by clarifying any key points. Both Creswell (2013) and Lincoln and Guba (1985) confirmed that ‘member checking’, the process of providing participants with transcriptions, analysis and/or interpretations of the data, contributes to the credibility of the study.

Further to this, to reduce the potential for researcher bias and to check my own interpretation of the data, the themes and codes that were constructed as a result of the analysis of the transcriptions were sent to my supervisors for their opinions and suggestions. Rowley (2012) suggested that it is good practice for other researchers to check the themes and codes following data analysis, thereby reducing potential bias in interpretation (p. 269).
Chapter 4  Findings—Stage one

The survey was open on Qualtrics from April to June 2018. A total of 98 surveys were commenced; 83 of those were completed, and the 15 participants who started the survey but did not complete it exited at different stages in the survey. No pattern was evident in their exit points. Five surveys were deemed ineligible owing to the disability type the participants’ sibling experienced (all reported a physical disability and their answers did not indicate that there was a coexisting ID), and one survey was ineligible owing to location (the family had never lived in Perth and did not live in Perth at the time of the survey). Two participants lived interstate but had grown up in Perth and their sibling with intellectual disability still lived in Perth, while one participant was working overseas at the time of the survey but still considered Perth home; therefore, these participants were included as eligible. An overall total of 77 survey participants were included in this study. The full record of deidentified responses to the survey is attached as Appendix 8.

The survey was designed as a result of the themes generated from the literature review and clustered into five sections (see Table 4.1). The survey was shared with another researcher and my supervisors in draft form prior to conducting it. However, I acknowledge that the survey might have been strengthened if I had also shared the survey draft with a sample of the study cohort. Table 4.1 illustrates how the literature review informed the structure of the presentation of the findings. Subsections within this chapter follow the themes identified within Table 4.1.

<table>
<thead>
<tr>
<th>Themes from the literature review</th>
<th>Questions in the survey</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family and individual characteristics</td>
<td>Demographic questions asking about participants’ age, other siblings in the family, gender, type of disability and decision-making ability of their sibling with disability</td>
</tr>
<tr>
<td>Provision of care and support</td>
<td>Relationship status, family and work commitments, paid and unpaid support that sibling with intellectual disability has (including living arrangement), expectation for future care</td>
</tr>
<tr>
<td>Childhood experiences</td>
<td>Impact on career choices, impact of growing up with SWD (psychological and practical), support for self</td>
</tr>
<tr>
<td>Information and understanding of sibling’s disability</td>
<td>Information about and understanding of sibling’s disability while growing up, current relationship with SWD</td>
</tr>
<tr>
<td>Guardianship</td>
<td>Siblings or self act as guardian for their sibling with disability</td>
</tr>
</tbody>
</table>

Note: SWD is used to represent sibling with intellectual disability in this table.
4.1 Family and individual characteristics

This first section discusses the survey’s demographic questions asking about age, age spacing, other siblings in the family, gender and type of disability that participants’ sibling experienced. This includes the question that asked participants to consider the decision-making ability of their sibling with intellectual disability. These questions are linked to the research question, *What individual and family characteristics influence relationships in childhood and adulthood?*

4.1.1 Identifying as Aboriginal or Torres Strait Islander

The first question in the survey asked participants to indicate their identification as Aboriginal or Torres Strait Islander, or both. The purpose of this question was for statistical reasons and would not have altered the results or analysis for this study. However, if a participant had identified as being Aboriginal or Torres Strait Islander, I would have sought advice from experienced researchers in culturally appropriate protocols were I to interview any of those participants, following the National Health and Medical Research Council of Australia guidelines to ensure merit and integrity in the research process (National Health and Medical Research Council, 2018b). All 77 participants indicated that they did not identify as either Aboriginal or Torres Strait Islander.

4.1.2 Ages, birth order and number of siblings

All participants were asked to provide their age and the age of their sibling with intellectual disability if they were still living (six responded that their sibling with intellectual disability was no longer living). The purpose of asking this question was to provide an opportunity to analyse results by age groups. The 20-year age groups chosen for this study provided a “generational view of the population”, which is useful when considering social and economic influences on the experiences of populations (Australian Bureau of Statistics, 2006b, p. 9). Figure 4.1 presents the age of the participants who responded to the survey and the age of their sibling with intellectual disability.
Note: SWD is used to represent sibling with intellectual disability in this figure

Figure 4.1 Ages of participants and sibling with intellectual disability

As expected, most of the participants had a sibling with intellectual disability within their own generation. When participants indicated that their sibling was aged within another of the age groups, in all but one instance it was the age group immediately before or after their own age group. Only one participant appeared to have a large age gap: the participant was aged 51–70 years and the sibling with intellectual disability was aged 18–30 years. A total of 32 of the participants answered that their sibling with intellectual disability was older than they were, and 44 answered that they were younger. One participant answered that they were the same age.

Participants were asked about the number of children in the family, including their sibling with intellectual disability and themselves. Five participants stated that they had more than one child in the family with disability. Figure 4.2 represents the total number of siblings in the families of each participant who completed the survey.
Figure 4.2 Family size

The largest number of participants (n = 27) answered that they only had one other sibling besides their sibling with intellectual disability and themselves (a three-child family), and 20 participants said there were no other children besides their sibling with intellectual disability and themselves (a two-child family). An unexpectedly large number of participants (n = 17) answered that there were three or more siblings in addition to their sibling with intellectual disability and themselves (a five-or-more-child family), and the lowest number (n = 13) said there were two other siblings besides their sibling with intellectual disability and themselves (a four-child family).

4.1.3 Gender of participants and sibling with intellectual disability

Participants were asked to provide their gender and the gender of their sibling with intellectual disability. The purpose of this question was to determine whether gender was a factor that influenced the provision of care and strength of relationships between siblings when one had a disability. Figure 4.3 shows the genders of the participants and their sibling with intellectual disability, represented in dyads (the first member of the dyad represents the participant, and the second member of the dyad is the sibling with intellectual disability).
One of the participants preferred not to answer this question. Of the remaining participants \((n = 76)\), there were 16 male participants and 60 female participants. Nearly half \((n = 35)\) of the participants were female with a male sibling with intellectual disability. Of these, a similar number was in each age group (except for the single participant in the 70 years plus age group). In the female–female dyad group, the largest percentage were from the 31–50 years age group. In the group of participants whose sibling with intellectual disability had deceased, five were a female–female dyad and one preferred not to answer.

As Figure 4.3 illustrates, 62% of participants who completed the survey had a sibling with intellectual disability who was male. According to the SDAC (discussed in Chapter 1), the rates of ID in Australia are higher for males, which is attributed to the fact that some conditions that are more prevalent in males are more often associated with ID (Australian Bureau of Statistics, 2014).

### 4.1.4 Type of disability

The survey asked participants to provide the type of disability their sibling has or had, in addition to asking about their sibling’s ability to make reasoned/informed decisions for themselves. Owing to the varied nature of disability people experience, even within disability diagnoses, no assumptions were made that an individual with a particular disability type had a ‘decision-making disability’ (see the earlier explanation...
in Chapter 1 regarding the definition of decision-making disability). The ability for participants’ sibling with intellectual disability to make informed decisions may have influenced responses to other questions within the survey, for example, current care and support for their sibling with intellectual disability, expectations of future care and guardianship.

The purpose of this question was not to categorise the sibling with intellectual disability into ‘disability type’; however, it was important to ask this question for two reasons. Firstly, the question was important to validate that all participants in this study had a sibling with intellectual disability. Secondly, understanding the disability type may assist with the analysis of the data and provide a context for the participant’s experiences. For the rationale for the categories of disability in this study, refer to Chapter 1.

Several participants stated that their sibling had coexisting physical or other disabilities (i.e. sensory disability). If participants indicated that their sibling with intellectual disability had two diagnoses (i.e. ASD and ID), the disability listed first was counted. Five participants indicated that their sibling had cerebral palsy; however, they were included in this study because their responses indicated the coexistence of an intellectual or cognitive disability. Those five siblings with disability, and where a specific diagnosis was noted (for example, Rett syndrome and Angelman syndrome), were counted in the ‘other’ category, as shown in Figure 4.4.

Figure 4.4 Disability type experienced by sibling with intellectual disability
Nearly 50% of the participants in this study indicated that their sibling had ID. It is likely that several of the siblings counted in the ID group had DS as their primary disability since all people with DS have some degree of intellectual impairment (Orsmond & Seltzer, 2007).

The following question explored the level of decision-making ability of participants’ sibling. This question was used to eliminate participants who indicated that their sibling had a physical disability and responded, ‘definitely yes’ to “*Does/did your sibling have the ability to make reasoned/informed decisions for themselves?*” This may not have been an accurate way to exclude these participants; however, since not all had provided contact details, there was no opportunity to clarify the disability type.

A greater number of participants answered, ‘probably not’ or ‘definitely not’ (n = 32) to this question compared with ‘probably yes’ or ‘definitely yes’ (n = 24). An additional 21 participants were unsure whether their sibling currently had or previously had the ability to make reasoned or informed decisions for themselves.

4.2 Provision of care or support

This section reports the results of questions in the survey that gathered data regarding how the presence of participants’ own children and spouse/partner affected the relationship with their sibling with intellectual disability, what the expectations were for future care of their sibling and how the living arrangements of the sibling with intellectual disability affected the amount of contact and support provided by the participant.

4.2.1 Relationship status and dependants

The purpose of asking questions about relationship status and dependants was to consider the impact that having a partner and dependants that lived with them had on the participants’ relationship and contact with their sibling with intellectual disability. While asking these questions in the survey alone could not be expected to reveal the effect on the relationship and contact with their sibling with intellectual disability, answers were considered to develop the questions for the interviews as an indication of the family commitments and extent of caregiving.

The majority of the participants were in a relationship and their partner lived with them (see Figure 4.5).
The responses to the question asking participants about their children, dependants or other people they provide care for were grouped into ‘no dependants’ and ‘some dependants’, since participants could select more than one answer. For example, they may have had dependants at home as well as providing care for someone else, or they may not have had dependants at home but provided care for others. Responses were grouped in this way to demonstrate the amount of caregiving participants provided to others. From both cohorts (sibling with intellectual disability who is living and sibling with intellectual disability who is no longer living), 37 did not have any dependants or provide care for others, and 40 either had dependants or provided care for others.

4.2.2 Employment status

The work commitments of the participants may also have affected the sibling relationship and ability to provide care or support for their sibling with intellectual disability. Higher rates of full-time employment may be expected in the younger age groups. A total of 68 participants were employed either full time or part time.
4.2.3 Living arrangements of sibling with intellectual disability

The purpose of exploring participants’ living arrangements was to ascertain whether where participants’ sibling with intellectual disability currently lived (or had lived, for siblings who were no longer living) could have been an influence on the contact with their sibling, and what their current and future expectations to provide care or support might be.

Figure 4.7 Living arrangements of sibling with intellectual disability

Note. ‘Other’ refers to aged care, foster care or hospital.
Of the siblings with intellectual disability in this study, 43% had lived or currently lived at home with parents (n = 33).

This statistics by age group were as follows:

- In the 18–30-year-old age group, 15 participants stated that their sibling with intellectual disability currently lived at home with parent/s, and one participant stated that their sibling with intellectual disability had lived at home with parents at the time of their death (20%).
- In the 31–50-year-old age group, 14 participants stated that their sibling with intellectual disability currently lived at home with parent/s, and one participant stated that his or her sibling with intellectual disability had lived at home with parents at the time of their death (19.5%).
- In the 51–70-year-old age group, one participant stated that his or her sibling with intellectual disability currently lived at home with parent/s, and one participant stated that his or her sibling with intellectual disability had lived at home with parents at the time of their death (2.5%).

4.2.4 Care and support that sibling with intellectual disability currently receives

The purpose of asking participants about the paid and unpaid support that their sibling received was to ascertain the current level of support they were receiving. This would provide an indication of the future care and support their sibling with intellectual disability may need, notwithstanding the increased care or support they may need because of ageing (for example, decline in physical ability or decline in mental health, particularly related to dementia).

Table 4.2 presents the responses from the 71 participants who had a sibling with intellectual disability still living regarding the type of support they currently provided to their sibling. Participants could choose more than one answer for this question. Only six of the participants in the survey currently did not provide any care or support to their sibling with intellectual disability. The options participants could select as ‘type of support’ was broad, intending to capture a comprehensive concept of care described in the literature (Chapter 2, section 2.5).
In addition to support that participants provided to their sibling with intellectual disability, their sibling may also have received support from paid service providers. Fifty-seven of the participants were aware that their sibling received care or support from a paid service provider. Seven participants were not sure whether their sibling received services from a service provider and an additional seven participants stated that their sibling did not receive services from a service provider. Table 4.3 presents the type of support that the sibling with intellectual disability received from paid service providers. Participants could select more than one answer.

### Table 4.3 Type of support provided by service providers

<table>
<thead>
<tr>
<th>Type of support or care from service providers</th>
<th>No. of responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical support with daily living, including personal care</td>
<td>37</td>
</tr>
<tr>
<td>Physical support with transport, outings</td>
<td>49</td>
</tr>
<tr>
<td>Practical home support (for example, housework, shopping)</td>
<td>35</td>
</tr>
<tr>
<td>Support with financial planning, booking of appointments, legal support</td>
<td>19</td>
</tr>
<tr>
<td>Support in the workplace or supported work (sheltered workshop)</td>
<td>20</td>
</tr>
<tr>
<td>Unsure</td>
<td>3</td>
</tr>
</tbody>
</table>

### 4.2.5 Expectation to provide support to sibling with intellectual disability in the future

Two questions explored expectation to provide care in the future. The first of these was to indicate the percentage of participants who expected they would be providing care or support to their sibling with intellectual disability in the future, and the second question asked participants to explain why they thought they would be required or expected to provide care or support in the future.
A total of 52 participants stated that they expected to provide care in the future or probably would provide care in the future, consisting of 11 males (from 16 male participants in this study) and 41 females (from 54 female participants in this study with a sibling with intellectual disability still living). This represents a similar percentage for both genders. Only seven of the participants stated that they did not or probably would not expect to provide care in the future, and three more were unsure.

The final question in this cluster was the first of four questions that were open-ended, allowing for ‘free text’: “Please explain why you think you will need to provide future care”. There were 55 responses to this question. The exclusions consisted of the six participants whose sibling with intellectual disability was no longer living, nine participants who did not see this question (see above) and seven participants who had answered that they would probably not or would not provide care or support in the future to the previous question; therefore, they were not offered this question.

From the manual analysis of this question, 13 subthemes from the initial coding were identified that I considered represented why participants thought they would be providing care or support in the future for their sibling with intellectual disability. I used the Qualtrics Text IQ function to validate this analysis and then summarised the topics the subthemes represented and selected a word or short phrase to describe it, ensuring that the subthemes were examples of the elements that explained the theme (Vaismoradi...
et al., 2016). This is a characteristic of ‘descriptive coding’ (Refer to Table 3.6; Saldana, 2016).

Verbatim quotations (extracts from the data) have been provided to support the explanation of the theme. Participant quotations have each been assigned a code. The code used denotes gender and age group, for instance, M 31–50 represents a male participant aged 31–50 years. Any information in the quotation that would otherwise identify the participant has been changed to maintain confidentiality.

Table 4.4 illustrates the number of times the theme occurred in the responses to the question. Some responses were allocated to more than one theme. I only counted responses in the lack of other support theme if the response mentioned that there were no other siblings or that the other siblings could not or would not provide care or support in the future.

<table>
<thead>
<tr>
<th>Initial codes/subthemes</th>
<th>Frequency</th>
<th>Main themes</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sibling with intellectual disability is ageing / complex needs / needs are increasing with age Ageing parents</td>
<td>18</td>
<td>Ageing</td>
<td>55</td>
</tr>
<tr>
<td>Love/care what happens to sibling with intellectual disability Assumed care Requested to care Parents/family expectation</td>
<td>6</td>
<td>16 2 4</td>
<td></td>
</tr>
<tr>
<td>Support services are inadequate Can’t trust / unreliable support services / carer</td>
<td>11 2</td>
<td>Support services</td>
<td>13 13</td>
</tr>
<tr>
<td>Other siblings cannot or will not provide care or support No other siblings No other family support</td>
<td>1 3 9</td>
<td>Lack of other support</td>
<td></td>
</tr>
</tbody>
</table>

The findings from the thematic analysis of the responses to this question indicate that most participants expected that they would need to provide care or support in the future for their sibling with intellectual disability as a result of their sibling ageing and care needs increasing, or that their parents (most often who provided the current care or support) were ageing. Other themes identified were a sense of responsibility to care, a distrust or perception of inadequacy of formal support services, and an expectation to care as a consequence of lack of other support within the family.
Provision of future care or support theme 1—Ageing

Extracts from the data to illustrate the theme of ageing include “My parents are getting older and once they pass away someone will need to help my sister” (M 18–30); “As a family we don’t believe in group homes, so once my parents die or are no longer able to care for my sister she will live with me or my brother” (F 31–50); and “My parents can’t look after him forever. I will share the load with my other brother as well” (M 18–30). One participant stated that plans had been put in place for the future, but there was still an expectation that she would provide support:

My parents have put in place many services and privately paid support workers so that we will be able to have a sibling relationship rather than a carer relationship when they can no longer assist with this. But he might also need one-off assistance from time to time. (F 31–50)

Another participant described how her parents had not taken steps to put any plans in place for the future:

He lives with my ageing parents. Being my only sibling if he outlives my parents, he will have no one else to take care of his money and oversee his service providers at the very least. He cannot be left unsupervised. My parents talk about getting him into supported living, but never make any action towards it. If something suddenly happened to either parent, I could see myself having to take over his physical day-to-day care. (F 31–50)

One participant highlighted the toll that caring for her sibling with intellectual disability had taken on their mother’s health over their lifetime:

My sibling lives with my parents, my mother’s physical capabilities are decreasing due to wear and tear from almost 30 years of caring for my sister. I have expressed the desire to assist with care to ensure my sister always has someone who truly understands looking out for her. (F 18–30)

These extracts are important because they demonstrate the dominance of the theme of ageing, often underpinning the other themes.
Provision of future care or support theme 2—responsibility

The theme of responsibility was the second most frequent response when participants were asked why they thought they would be providing care in the future to their sibling with intellectual disability. Most often, this response was also linked to ageing parents. Responses that indicated an expectation to care include “It makes sense that I would take on the caring role” (F 31–50); “When he [father] passes away, I expect that I will assist my mum with all decisions and supports regarding my sibling’s needs” (F 18–30); and “As mum and dad start to focus on their own lives a bit I assume my input will be needed” (M 18–30).

Another participant felt a responsibility to care in a compensatory way for the life her sibling with intellectual disability had lived when under the care of parents:

He is my brother and I will always ensure that he is happy, safe and content for the rest of his life. We may lead different lives, but we started out in the same place … He deserved a better life than my parents gave him and I’m going to make sure he now lives that life. Siblings have the longest life journey together. Parents should recognise this. (F 51–70)

Several participants used the words “I expect to”, “I assume I will”, “I would need to” or “I will have to” when describing their expectations for the future, indicating a sense of responsibility to their sibling with intellectual disability over the life span.

Provision of future care or support theme 3—Support services

Participants commented on support services and their perceived inadequacy, or inability, to care for their sibling:

Despite all his funding, his service provider does not provide for all his needs. Family have to still take on a significant amount. And for even those services that are funded, they are not done properly so we have a constant monitoring and advocacy role. The quality of the service providers is so variable. (F 51–70)

For one participant, the fear of her sibling with intellectual disability outliving her and the subsequent reliance on paid support was a concern:
I love my brother and will never stop being involved in his life, but as
my health is rapidly declining my concern is that I may pass away
before him. This is a huge worry for me as that will leave him with
only paid supports, which are good to a point but they’re not the same
as reciprocal relationships. (F 51–70)

Participants provided insights into the support or care services their sibling
currently received and mentioned how their sibling’s support workers enabled regular
contact and outings with their sibling with intellectual disability. Others mentioned
difficulties with service providers when questioning elements of their care:

I felt intimidated and bullied—I didn’t expect or even consider that I
would be treated this way by just looking out for him and making sure
he was safe, happy and content. Isn’t that what siblings do for one
another? (F 51–70)

Participants also indicated that they still provided some level of care or support
for their sibling with intellectual disability, despite them living in supported
accommodation or being recipients of formal care and support services.

Provision of future care or support theme 4—Lack of other support

An additional number of participants stated that they had no option but to
provide care. This was to be expected since either other siblings were not willing or able
to provide care for their sibling with intellectual disability or there were no other
siblings or support available within the family. Some of these responses were also
linked to parents ageing: “Both of my parents are ageing, and of course, I expect to take
on this responsibility in the future as we have no other siblings” (F 18–30); “My parents
are ageing … my brother and I are solo siblings” (F 31–50); and “I would need to quit
my job and care full time for my brother. No one else in my family is capable” (F 31–
50).

One participant described how she expected that she will provide care, despite
there being another sibling in the family:

Because I am his only immediate relative, my parents are both
deceased and I am estranged from my [sibling] … There are no other
options as I am it. His health is declining, and decisions need to be
made all the time. Plus it is just the right thing for me to do, although
hard I couldn’t handle the thought of him having no one that was looking out for him like I can. (F 31–50)

This theme was constructed to distinguish between responses that indicated participants who expected to be providing care because of a sense of responsibility and participants who expected to provide care because they could not see any other option. These data extracts illustrate that difference.

4.3. Childhood experiences

This section presents the results to the questions that were intended to ascertain the impact of growing up with a sibling with intellectual disability on participants’ choice of career. By briefly describing their experiences while growing up, participants indicated the psychological and practical impacts of growing up with a sibling with intellectual disability. Participants were also asked if they had accessed support services for themselves at any stage in their life. These survey questions addressed the research question “How has the participants’ experience of growing up with a sibling with intellectual disability influence their decisions and choices across their life span?”

4.3.1 Career choice

The question about career choice was included in the survey because the literature review revealed that some earlier studies had found a link between career choice in a profession that could be described as a ‘helping or service’ profession and the experience of having a sibling with intellectual disability. According to the ABS, careers in the helping or service professions and organisations that provide care are classified in the divisions of Education and Training (Division P) and Health Care and Social Assistance (Division Q) in the Australian and New Zealand Standard Industrial Classification (ANZSIC) 2006 (Australian Bureau of Statistics, 2006a). Of the 77 participants who undertook the survey, 34 currently worked or had worked in a helping or service profession (for example, teachers, nurses, psychologists, social workers) or within an organisation that provides care (for example, aged care or disability support). These professions fit within Division P or Q in the ANZSIC classifications. This represents approximately 43% (n = 33) of the participants who completed the survey, nearly four times the percentage of people in the general population (11%) in these two categories of employment (Australian Bureau of Statistics, 2019a).
4.3.2 Describing experiences while growing up

My initial manual coding of the question, “Briefly describe your experiences as a child growing up with a sibling with disability” revealed 20 subthemes that I considered represented the invariant constituents of the experience of growing up with a sibling with intellectual disability. To analyse responses to this question, I coded the responses using a descriptive coding method, summarising the experiences described by the participants (Saldana, 2016). Using the Qualtrics Text IQ function, I repeated this process to validate the manual analysis and check meanings in the statements. The original 20 subthemes were clustered to a final seven themes (see Table 4.5).

<table>
<thead>
<tr>
<th>Initial codes/subthemes</th>
<th>Frequency</th>
<th>Main themes</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Developed independence / grew up fast</td>
<td>14</td>
<td>Independence</td>
<td>23</td>
</tr>
<tr>
<td>More understanding/compassionate</td>
<td>9</td>
<td>and maturity</td>
<td></td>
</tr>
<tr>
<td>Needed or wanted to provide care/support for SWD</td>
<td>20</td>
<td>Caring and support role</td>
<td>29</td>
</tr>
<tr>
<td>Protective of SWD</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Greater responsibilities than peers</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family stress or anxiety</td>
<td>16</td>
<td>Psychological impact</td>
<td>22</td>
</tr>
<tr>
<td>Effect on parents’ marriage</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Loneliness</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Embarrassed having an SWD</td>
<td>10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent/parents were embarrassed/ashamed</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Felt sadness for SWD</td>
<td>10</td>
<td>Emotional impact</td>
<td>23</td>
</tr>
<tr>
<td>Felt regret that SWD ‘couldn’t do what I could’</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Normal childhood</td>
<td>14</td>
<td>Positive childhood experiences</td>
<td>30</td>
</tr>
<tr>
<td>Growing up with a sibling with intellectual disability was a positive experience.</td>
<td>16</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Childhood was challenging</td>
<td>7</td>
<td>Negative childhood experiences</td>
<td>20</td>
</tr>
<tr>
<td>Childhood was hard</td>
<td>7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Childhood was difficult</td>
<td>6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>SWD had parents’ attention / SWD focus of attention</td>
<td>20</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Needs/behaviours of SWD limited family outings/activities</td>
<td>8</td>
<td>SWD main focus in family</td>
<td>29</td>
</tr>
<tr>
<td>Jealousy</td>
<td>1</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 4.5 Describing experiences while growing up

Note: SWD is used to represent sibling with intellectual disability in this table

A relatively even distribution of frequency was clustered under each theme for this question. Most responses contained more than one theme. One participant did not provide a response, and two participants responded that they had not lived with their sibling while they were growing up. Predominantly, findings suggest that growing up with a sibling with intellectual disability often resulted in greater *independence and maturity*, which may or may not include the provision of *care or support* for participants’ sibling with intellectual disability (n = 23 and n = 29, respectively). In
addition, growing up with a sibling with intellectual disability had a psychological or emotional impact on participants and/or their family (n = 22 and n = 23, respectively). Participants reported positive childhood experiences (n = 30) and negative childhood experiences (n = 20) and expressed that their sibling with intellectual disability was the main focus of their family, often limiting family outings and activities (n = 29).

Experiences while growing up themes 1 and 2—Independence and maturity and the caring and support role

I grouped these themes together because responses from participants often included responses in both themes. Protection of participants’ sibling with intellectual disability was also included in this theme.

Some participants acknowledged that the increase in responsibility or maturity had a positive effect on themselves: “Having a brother with autism has also certainly taught me to be more understanding and mature” (M 18–30), and “The majority of my parents’ attention was directed towards my sister but it meant that I had to grow up and mature, which has been beneficial for me” (F 18–30). Another participant explained how she felt ‘protective’ of her mother:

I learned that I needed to do all I could to protect Mum because we would never be able to manage without her. I learned to be invisible. I learned empathy, advocacy and compassion. Responsibility was front and centre of everything we undertook. (F 51–70)

Many participants stated they had provided physical care for their sibling with intellectual disability while they were growing up. One participant said, “My brother is nine years younger than me, so I looked after him a lot growing up” (F 31-50). Another said:

No one understood that before school I had been up for hours doing medications, suctioning, seizure management or resussing [sic] her and calling an ambulance. Took a lot of time off school to help my parents with her. (F 18–30)

One participant said she took responsibility for her sibling with intellectual disability’s health needs; from a young age, this participant knew how to respond to her brother’s seizures.
These data extracts illustrate the demands placed on siblings regarding the care or support of their sibling with intellectual disability and the acknowledgement by many of the participants that they felt these extra demands resulted in greater independence and maturity while they were growing up.

Experiences while growing up themes 3 and 4—Psychological and emotional impacts

Many of the participants wrote that having a sibling with intellectual disability had a psychological or emotional impact on themselves or their family. One participant said that their parents’ marriage ended in divorce as a result of the stress on the family. Another participant described the psychological and emotional impact:

There were certainly times when I experienced negative feelings because of my brother. These included feelings of guilt (why was I normal? Why wasn’t he normal?). As well as guilt over being frustrated at him, and feeling guilty when I imagined a life without a brother with a disability, or with a “normal” brother, anger (it wasn’t fair that he doesn’t get to live “normally”), frustration, great sadness, and a sense of questioning the world / God / the universe / whatever driving force you believe in for why he was born the way he was and why he had to be different. These are feelings I eventually worked through in my teenage years, but it was difficult at the time. (F 18–30)

Some participants described experiences that were grouped into several of the themes for this question:

The biggest toll was on my mother physically and mentally, resulting in a nervous breakdown. We didn’t get to do a lot of extracurricular activities like holidays, play dates and extra energies were spent on dealing with illness or outbursts [of violence]. (F 31–50)

Another participant stated:

I didn’t feel like an individual who was valued. My parents were not emotionally present, but provided a safe, routined life that was physically safe and secure. (F 31–50)
These extracts are pertinent because they illustrate the range of psychological and emotional impacts on parents and siblings growing up in a family where one of the children has intellectual disability.

Experiences while growing up theme 5—Positive experiences

Participants reported a range of experiences that were both positive and negative. One participant described the experience of growing up with a sibling with intellectual disability: “Overall I consider my experiences positive as he is part of the family and I’m very family orientated” (F 31–50). Another participant stated, “My experiences in this situation were largely positive. For me, growing up with a sibling with a disability was simply ‘normal’ to me” (M 18–30). Another participant felt that the family had become remarkably close and supportive of each other as a consequence of having a sibling with intellectual disability.

One participant reflected on both the positive and negative aspects of having a sister with ID:

My early childhood experience growing up with an older sister with disabilities was overall a positive one as my parents tried to keep life as normal as possible and love my brother and I equally. Not being able to connect with my sister emotionally was the hardest as I wanted to play with her and be her friend but I remember feeling sad when my mum explained this was not possible—this a sadness that I still carry today of the sister I will never have. (F 31–50)

Another participant stated:

Overall it was a positive experience for me as my family were very caring and supportive of my brother and taught me to do the same. (M 18–30)

Experiences while growing up theme 6—Negative experiences

Participants expressed many of the challenges growing up with a sibling with complex needs and challenging behaviours. These included physical outbursts of violence and aggression, embarrassment about sibling’s behaviour in public, and damage of childhood possessions. One participant mentioned feelings of resentment, embarrassment and humiliation. A brief excerpt has been included here to illustrate the complexity of family life:
I fully understand now that they love me infinitely and were doing the best they could … but as a child I felt unloved and neglected. From as early as I can remember in our family I took on the role of the ‘good girl’, the one who never rocked the boat, tried to care for everyone and do nice things for them to cheer them up, and never to cause more stress for my parents if I could help it … I internalised everything instead of confiding in my parents. I was 11 when I began self-harming and thinking of suicide. (F 31–50)

Another participant said:

Disabled child had more attention, disabled child required more help, care and support, and disabled child made me feel self-conscious. (M 31–50)

While a similar response from another participant was:

Anxiety, guilt, sense of responsibility, scared of behaviours by sibling. (F 18–30)

One participant described the challenging times growing up, the loss of friendships and contact with extended family, and disruptions in the household; however, this participant stated that as a result of their experiences they were a very close family.

*Experiences while growing up theme 7—sibling with intellectual disability main focus in family*

There was an underlying expression from participants that the sibling with intellectual disability was the focus of the family. However, sometimes this was mixed with feelings of gaining independence and maturity from necessity (owing to parents’ focus being on the sibling with intellectual disability), or sometimes mixed feelings were evident of feelings of resentment or love for participants’ sibling with intellectual disability. Participants described their experiences:

It wasn’t too difficult, I had very understanding parents who never wanted me to feel left out or ignored. There were definitely still moments of being the other child. I had to be older and mature to help
look after my sister. I grew up faster than I probably should have. (M 18–30)

The majority of my parent’s attention was directed towards my sister, but it meant that I had to grow up and mature which has been beneficial for me. (F 18–30)

The role I assumed in my family was to be my handicapped sister’s guide and protector while growing up. As is common in families with a disabled child, the parental focus was largely centred on the needs of my handicapped sister. My overall sense was that I was expected to be responsible and to cope with life without placing further demands on my parents. I became a parentified child in some ways. I cared deeply for my sister but also felt resentment that she took up most of the available ‘oxygen’ in our family. (F 51–70)

Other participants recalled their feelings about differential parental treatment:

As a child there was not much time for me because my brother’s condition took up most of my parent’s time and effort. (F 51–70)

Many memories of my mum being so absorbed in my brother’s care that she seemed to forget about me. (F 31–50)

Another participant reflected on her mother’s recollection of her childhood:

Mum reports she was busy looking after my brother and so I “raised myself”. (F 31–50)

Two further questions explored experiences growing up. These questions are presented together in Figure 4.9.

The two questions were:

a) Did you experience bullying or teasing from other children as you were growing up as a result of having a sibling with disability?

b) Do you think that having a sibling with disability affected (limited) some of your childhood experiences? For example—limited weekend or holiday outings.
A small difference was evident in the number of participants who reported bullying or teasing; however, nearly twice as many participants reported that having a sibling with intellectual disability limited some of their childhood experiences than reported this resulted in no limitations on childhood experiences.

### 4.3.3 Participants’ access to support services

The following section describes the responses to the question “Have you ever accessed support services for yourself in regards to your sibling with disability, such as counselling or peer support?” Most of the participants had not accessed support services for themselves in relation to having a sibling with intellectual disability (n = 49), although several reported having attending ‘sibs camps’ as children. Some participants expressed experiencing difficulty either accessing or knowing about what services might be available to them. This included responses that were a reflection of the era, such as “When I was young, there was nothing around” (F 31–50). Another participant said:

I always figured that everyone else had tough times throughout their childhood for various reasons and I was no different. I’m not sure these services were available when I was a kid. (F 31–50)

One participant explained the barriers she felt to accessing services for herself:

No, I haven’t sought formal support as I am still trying to work out what I would discuss with a counsellor. I do speak with people in my...
friendship network, but there is a part of me that feels disloyal to my brother to “complain” about the burden I feel. (F 51–70)

Twenty-one participants had accessed some form of support or counselling, and one person did not answer this question. The question was not asked of the six participants whose sibling with intellectual disability was no longer living.

4.4 Information and understanding of sibling’s disability

The questions in this section were intended to consider the information siblings had been provided with regarding their sibling’s disability, their understanding of disability while growing up, and about their current contact and relationship with their sibling with intellectual disability.

4.4.1 Understanding sibling’s disability

This question asked participants to describe their understanding of their sibling’s disability while growing up, and if they were provided with the information they wanted or needed about their sibling’s disability. The responses to this question were analysed using the same method as the other open-ended questions described earlier (Table 4.4 and Table 4.5). For the initial coding of this question, descriptive and in vivo coding was used (Creswell, 2013), presented in Table 4.6.

<table>
<thead>
<tr>
<th>Initial codes/subthemes</th>
<th>Frequency</th>
<th>Main themes</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes/Fully understood</td>
<td>22</td>
<td>Provided with information and understood disability</td>
<td>37</td>
</tr>
<tr>
<td>‘Parents explained everything’</td>
<td>13</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Enough information</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>‘Knew no different’</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not until older/adulthood</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Knew they were ‘special’/’different’</td>
<td>9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Limited information</td>
<td>4</td>
<td>Some understanding</td>
<td>21</td>
</tr>
<tr>
<td>‘Believe so”—no memories of wanting to know more</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some information but it wasn’t discussed</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>10</td>
<td>No information or understanding</td>
<td>16</td>
</tr>
<tr>
<td>Not really—linked to diagnosis</td>
<td>6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Received counselling</td>
<td>1</td>
<td>Received support</td>
<td>1</td>
</tr>
<tr>
<td>Worse when SWD was older</td>
<td>1</td>
<td>Decline in abilities of SWD</td>
<td>1</td>
</tr>
<tr>
<td>No response</td>
<td>1</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Note: SWD is used to represent sibling with intellectual disability in this table.*
Of the total 77 participants, 48% reported that they had been provided with enough information and understood their sibling’s disability when they were growing up (n = 37). Several responses were highly positive, stating that they felt very clear about or aware of their sibling’s disability, and 13 participants stated that their parents were their main source of information and discussed their sibling’s disability with them.

The responses that indicated that participants were provided with sufficient information and understood disability were also analysed by age group (see Figure 4.10). This was to allow an interpretation of this data based on the era in which the participant grew up and the amount of information available to them, or their parents, at the time.

![Figure 4.10 Age groups of participants who were well informed about their sibling’s disability](image)

Sixty-two per cent of participants in the 18–30 year age group, 45% of participants in the 31–50 year age group, and 37.5% of the participants in the 51–70 year age group (there was only one participant in the 70+ age group, who is represented in this chart) described being provided with enough information and understanding their sibling’s disability. Varying degrees of detail were provided in the answers for this question, and two answers appeared only once (Received counselling while growing up and It was worse when the sibling with intellectual disability was older). Since these answers did not directly correlate to the main themes, I have included them as separate responses. One participant did not answer. Participants’ responses were counted only once for this question. The participant responses for each theme are described below.
Understanding and information about sibling’s disability theme 1—Provided with information and understood disability

Some participants responded to this question simply with “yes”, while others provided more detail. Some participants explained how their understanding was enhanced by their involvement in their sibling’s medical, hospital or therapy appointments:

Yes, my parents were very open with his disability in terms of what had happened physically. I received information from the hospital and rehabilitation units. I understood why and how his disability was caused. (F 31–50)

[My sibling] attended [therapy] a few days a week, which I would visit with Mum, and there would often be therapists in the house. [My sibling] had a heart defect so we were always going to the hospital. Through these things I was able to get a clear picture about his needs and the ways in which his disability impacted him. Mum and Dad were always open to questions and I would attend lots of his appointments with her so I got a pretty clear picture. (F 18–30)

Many participants stated that their parents were extremely open and discussed their sibling’s disability with all members of the family. Two participants explained how they felt comfortable with the information provided by their parents when they were growing up:

My parents were the main source of information, but they did a good job in explaining any issues that arose because of my sister’s disability. I can’t remember ever receiving information from another source, but also can’t remember ever needing information from another source. (M 18–30)

Because my brother was older than me, I always knew him to be different. My parents would answer any and all of my questions, they would teach me the correct “labels” I could use to talk to him, but they would also explain to me what the labels meant. For example, I knew my brother had epilepsy, I knew what seizures looked like, and my mother had given me a very basic explanation as a child as to how
they occurred. Likewise, with other labels such as “intellectual disability”, “autistic tendencies”, and so on. When I got older, I would conduct online research to learn more. I have always been able to describe my brother to others. (F 18–30)

The two single statements from participants included in this theme were, “Yes—I knew no different, it just became a part of my life” (M 18–30), and “Yes, I understood it, and I felt like I had enough information” (F 31–50).

**Understanding and information about sibling’s disability theme 2—Some understanding**

Responses included in this theme demonstrated some understanding of participants’ sibling’s disability, which was often related to an ‘unclear’ diagnosis or reflected their parent’s lack of information about their sibling’s disability while they were growing up. Other responses indicated that participants understood more as they grew older:

I had a basic understanding of his condition but only understood fully as I got older. He isn’t typical autistic or Down syndrome … My dad provided me this information as I got older and could understand. Around the age of 13,14. (M 18–30)

I think that information and understanding about autism has greatly increased in the last 20 years. My mother had to gain a lot of knowledge from the USA via internet and journals in the 1990s as the local knowledge and support had not really developed. (M 18–30)

Others stated that while they were not given clear information, they knew that their sibling needed assistance, one stating that she “knew they were special”:

I don’t ever remember as a young child being told what my sibling had. I was always a part of their care and I just grew up with knowing their strengths and limitations. As I grew, I came to know the name of [the] syndrome and the finer details. As I said I just always knew they were special. (F 31–50)

He caught a special bus to school. I knew that he was different. (F 51–70)
Three participants also explained that while they were given some information, their parents did not discuss their sibling’s disability.

*Understanding and information about sibling’s disability theme 3—No information provided*

This theme represents the participants who explained that they did not have an understanding of their sibling’s disability while they were growing up.

No. I was not included in anything to do with planning his life.
Parents don’t think that one day they may not be there—so unfair.
This is not resentment but rather frustration for what could have been.
(F 51–70)

Did I understand it, certainly not. It was not talked about. We simply lived around [sibling’s] circumstances. (F 51–70)

Some responses in this theme were also linked to diagnosis of participants’ sibling’s disability:

No, he was lumped into a classification of special needs, which covered every disability under the sun and we were never provided with any other support option than stick him into this special school and he will be looked after. (M 51–70)

I don’t remember we were given any information or support aside from when he went to school and he was never formally diagnosed. (F 31–50)

The final two coded responses were unique. While neither of these responses answered the question, which would have allowed them to fit easily within one of the themes, they provided an insight into the challenges of growing up with a sibling with intellectual disability. One participant responded, “We had some counselling when we were teenagers” (self and other sibling/s; F 31–50).

Another stated:

As my brother got older his condition worsened as his brain didn’t develop and his ability to fit in with people his own age started to fail … mates moved on with their life. (F 31–50)
4.4.2 Contact with sibling with intellectual disability

This question asked participants how often they contact their sibling with intellectual disability currently to assist with ‘building the picture’ of the current relationship between siblings. It was also assumed that responses from this question would correlate closely to the following question about the current relationship between siblings.

![Figure 4.11 Current contact with sibling with intellectual disability](image)

It was assumed that if a sibling with intellectual disability lived with the participant their contact would be regular and probably daily. Only a small number of participants answered that they had contact with their sibling with intellectual disability once per month or less (n = 16). All other participants had contact, either by phone, email or in person, as regularly as every week.

4.4.3 Current relationship with sibling with intellectual disability

Since this study was undertaken from a life-span perspective, it was important to ask participants how they perceived their current relationship with their sibling with intellectual disability. In the analysis for this question, in addition to using descriptive codes, I also used in vivo coding (Creswell, 2013). Participants’ responses were counted only once for this question. As this question was only relevant to participants whose
sibling with intellectual disability was still living, this question was not asked of the participants whose sibling with intellectual disability had deceased.

Table 4.7 Describing the current relationship with sibling with intellectual disability

<table>
<thead>
<tr>
<th>Initial codes/subthemes</th>
<th>Frequency</th>
<th>Main themes</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Close—SWD lives with participant</td>
<td>2</td>
<td>Close relationship</td>
<td>33</td>
</tr>
<tr>
<td>Close / very close / frequent contact</td>
<td>10</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Good/excellent</td>
<td>11</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Awesome</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Loving/wonderful relationship</td>
<td>7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Better as SWD matures</td>
<td>2</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Limited owing to sibling’s disability</td>
<td>6</td>
<td>Limited relationship</td>
<td>23</td>
</tr>
<tr>
<td>Limited owing to commitments</td>
<td>5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Limited owing to location</td>
<td>8</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Limited—upsetting</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Limited—other</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Provides support—legal guardian</td>
<td>2</td>
<td>Relationship</td>
<td>6</td>
</tr>
<tr>
<td>Provides support—contemplating guardianship</td>
<td>1</td>
<td>involves care</td>
<td></td>
</tr>
<tr>
<td>Provides some support</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No relationship</td>
<td>1</td>
<td>Not a close</td>
<td>8</td>
</tr>
<tr>
<td>Distant/strained/poor</td>
<td>4</td>
<td>relationship</td>
<td></td>
</tr>
<tr>
<td>Difficult / requires effort / frustrating</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No answer</td>
<td>1</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: SWD is used to represent sibling with intellectual disability in this table.

The greatest proportion of participants perceived that they had a close relationship with their sibling with intellectual disability (n = 33), or a limited relationship owing to a range of circumstances (n = 23). Six participants answered this question in relation to the care they provided, and a further eight reported that they did not have a close relationship with their sibling with intellectual disability.

Current relationship with sibling with intellectual disability theme 1—Close relationship

Participants’ responses included in this theme indicated a close relationship with their sibling with intellectual disability. Two participants responded to this question stating they were close to their sibling with intellectual disability because they lived with them. Examples of responses indicating a close relationship are:

We have a wonderful relationship. We speak daily and I enjoy taking her out occasionally on weekends. I know I am also a good support person for her if she is ever upset. (F 31–50)

Awesome, we have never had a bad relationship, if anything he behaves better when I’m around. I see him nearly every day. (F 18–30)
Two participants explained that while their relationship was close, it had changed since they had left the family home:

Good relationship though not as close as when I was living at home. We have common interests in technology, television and movies, which we discuss. I have a very close relationship with my parents and see my brother once a fortnight if not weekly. (M 18–30)

I have recently moved out of home which has changed it a lot. My sister was very dependent on me at home and took advantage of the fact I would do a lot of things for her. I thought when I moved out she would call me every few days to catch up with me, like she would do when I went on holiday or we were away. But since moving out my interactions with her have changed. If I go home, she sometimes wants to engage with me, other times she just doesn’t show much interest. (M 18–30)

For one participant, the parent was currently ageing, so the contact with her sibling with intellectual disability was regular, mostly to attend to the sibling’s needs:

Because my mother is no longer driving, I am taking him to all his medical and other appointments, attend meetings with service providers, read all his mail … and speak with him about any issue he is concerned about. He relies on me to solve his issues. (F 51–70)

Current relationship with sibling with intellectual disability theme 2—Limited relationship

A broad range of reasons presented regarding why relationships were limited between the participants and their sibling with intellectual disability. Many reported that their sibling’s disability affected the relationship. Examples of this include, “I have a limited relationship with my sister as she is unable to have a conversation” (M 31–50) and “My brother is non-communicative so it is extremely difficult to have a relationship with him” (F 31–50). Another participant explained how communication limited their relationship:

My brother is profoundly disabled, I know I love and care deeply for him but he can’t tell me or express how he feels about me.
Interpretation is subjective but at least I don’t think he dislikes me. (F 31–50)

While a limited relationship with a sibling is understandable when location is a factor, some also stated that their sibling’s disability added to their difficulty because of communication. Some participants explained that their sibling with intellectual disability could not use the telephone owing to hearing or communication difficulties; hence, being unable to communicate in this way limited their relationship. One participant said, “Not very close because I live away and it seems difficult for us to connect without meeting up” (F 31–50). Another said, “He is non-verbal so I can’t email him or phone him. Our relationship can only be face to face. As we live [in different cities], this is difficult” (F 31–50).

Some participants explained how regular contact was difficult with their sibling with intellectual disability owing to other family commitments:

I’m busy with my own family and work but I try to catch up with my parents and brother as much as I can. (F 31–50)

It is hard to give him the amount of attention he wants as I have three children and a FIFO [fly-in fly-out employment] husband. I also wanted to have more of a career and my relationship with my brother has limited my chances. I guess I resent this a bit. I feel an obligation to make sure he is looked after. (F 31–50)

Another participant stated that their relationship was not as close as it used to be because of her commitment to her young family:

Not as close now that I have children and I am not able to care for her as much. Still very involved in her life, my children are also very involved and love her. (F 18–30)

_current relationship with sibling with intellectual disability theme 3—Relationship involves care_

In response to this question, some participants explained that their relationship was mostly based on care:
I remain concerned about the challenges he faces. We have a solid relationship and deeply care for one another. However, I feel much of our relationship is about me supporting him and helping him with his disability—emotionally. [As] opposed to the types of relationships I see other siblings have. (F 18–30)

As my father has passed away and my mother is ageing, I am moving into a more carer and manager of their care. (F 31–50)

Current relationship with sibling with intellectual disability theme 4—Not a close relationship

Eight participants described a relationship that reflected this theme. These responses included those who stated that they did not have a relationship with their sibling with intellectual disability at all. Some examples of these statements include “No relationship”, “Distant, my brother has isolated himself” and “Our relationship is strained”.

4.5 Guardianship

The purpose of including a question about guardianship was to ascertain the number of siblings who acted as legal guardian or power of attorney for their sibling with intellectual disability.
The largest percentage of siblings did not act as legal guardian or hold power of attorney for their sibling with intellectual disability (n = 46). Twenty-four (54%) of the siblings with intellectual disability included in this number currently still lived at home with parents or a parent, which could explain why the participant was not currently acting as legal guardian or with power of attorney. Only four of the participants who reported that they were a legal guardian or held power of attorney for their sibling with intellectual disability stated that their sibling with intellectual disability lived at home with their parents (16%).

4.6 Developing the interview guide and research questions for stage two

To develop the research question for the second stage of this study and to develop the interview guide, I revisited the research questions, sub-questions and purpose statement to ensure that the interviews would provide added depth to the data collected in the first stage or explain phenomena that emerged. The central research question is, What are the family characteristics and lived experiences that influence sibling relationships and decision-making across the life span when a sibling has intellectual disability?

In the introduction, a preliminary overarching research question for the second stage of this study was suggested as, How do the selected experiences identified in stage one contribute to the current relationship between siblings? Therefore, to develop the interview questions for the second stage, I needed to select an experience or variable that required further exploration from the analysis of the first stage of this study. I also needed to consider the research sub-questions, and the depth at which I felt that these questions had been explored in the initial survey. In addition, I identified in Chapter 1 that the mixed methods research question would emerge at the development of the second stage of this study.

The purpose statement also provided guidance for the development of the interview guide. The purpose of this sequential explanatory mixed methods study was to gain a greater understanding of the experiences that influence relationships and connectedness between siblings when one has ID and how family characteristics and childhood experiences influence decision-making across the life span. Table 4.8 presents the process and the rationale that I used to develop the purposive selection criteria for participants and the development of the interview guide.
Table 4.8 Process for selection of participants and question development for stage two

<table>
<thead>
<tr>
<th>Research sub-question topics</th>
<th>Data collected in the survey</th>
<th>Possible further exploration/explanation</th>
<th>Influence case selection</th>
<th>Interview question</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Individual and family</td>
<td>a) Gender of both siblings</td>
<td>Gender roles / same gender dyads</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>characteristics</td>
<td>b) Was their SWD younger or older than themselves?</td>
<td>The pertinence of birth order</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>c) Other siblings in the family besides the SWD and themselves.</td>
<td>Number of siblings in the family</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>d) What is their sibling’s disability?</td>
<td>Disability type and characteristics</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td>Describing experiences growing up with an SWD</td>
<td>Impact on family dynamics</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>2. Experiences</td>
<td>The information and understanding of sibling’s disability while growing up</td>
<td>Impact on relationship with SWD</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>3. Information and understanding</td>
<td>Provision of future support and why</td>
<td>This question has been answered in the survey</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>4. Future care</td>
<td>Current or most recent job role</td>
<td># and % working in a helping or service role influenced by experiences</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>5. Decisions and choices</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: SWD is used to represent sibling with intellectual disability in this table.

4.6.1 Developing the interview guide

A process of elimination was required to select the participants to interview to ensure that the interview stage selected information rich cases that could answer the research questions. As Table 4.8 illustrates, two criteria could influence participant selection and serve as criteria to select interview cases. These are the birth order in the family and the number of other children in the family. The effect of having a sibling born or diagnosed with disability on the dynamics of the family (e.g. a sibling with intellectual disability being born after the participant) would have required an adjustment to family life with the needs of a sibling with intellectual disability to consider. In addition, selecting participants who had other siblings in the family (in addition to their sibling with intellectual disability and themselves) would also provide an opportunity to explore relationships with siblings without disability in the family.

A further two criteria could benefit from the phenomenological perspective of an interview. Research sub-question 3 focuses on the how the information provided to
participants contributed to an understanding of their sibling’s disability, and how this affected sibling relationships. This is a subjective experience; therefore, while it is acknowledged that the data collected in the interviews would not be a representation of the 77 participants who completed the survey, the benefits of including this in the interview questions could provide an opportunity to explore the emotions that are attributed to these memories. In addition, the participants in the survey were asked what their current or most worked career role was, however, there was no explanation why this type of data were being collected. The interview questions could explore the link between experiences of having a sibling with intellectual disability and career choice.

4.6.2 The qualitative and mixed methods research questions

As a result of the development process for the interview guide and selection of participants, it was possible to construct the research question for the second stage of this study and the mixed methods research question that integrated the two stages of this study. The research question for the second stage of this sequential study was developed as a result of the findings emerging from the first stage and re-examining the research questions in the light of those findings as this study progressed. According to Tashakkori and Creswell (2007), mixed methods studies benefit from this “dynamic process” (p. 210). The mixed methods research question is presented here as an explicit question to explain how the findings from each stage relate to the other (Tashakkori & Creswell, 2007), addressing the overall intent of the study (Plano Clark & Ivankova, 2016).

The qualitative research question for the second stage of this study is:

*How do older siblings perceive family dynamics are affected following the birth or diagnosis of a younger sibling with intellectual disability?*

The mixed methods research question is:

*What are the implications for policy and practice in the disability sector as a result of this study?*

4.6.3 Interview question guide

A full copy of the interview questions and guide are attached as Appendix 2. All participants were advised that they were selected for interview because they were older than their sibling with intellectual disability and they had other siblings in the family. The interviews also provided the opportunity to further explore the correlation between the experience of having a sibling with intellectual disability and the effect on other
aspects of life as an adult—in this instance, the choice of a career. I felt that this needed further exploration because the survey results suggested that a greater number of the participants in this study (43%) worked in helping or service professions compared with the general population (11%).
Chapter 5  Findings—Stage two

Forty-four participants in the survey answered that their sibling with intellectual disability was younger than they were, plus one additional participant who said they were the same age. Of those 45 participants, 35 had at least one other sibling in the family. Of those 35 participants, 24 had provided their details consenting to be contacted for interview. All 24 participants were contacted and asked if they were still interested in participating in an interview, by phone or in person. One participant declined to be interviewed, and five did not respond to the email (or follow-up email four weeks later). This left a total of 18 interviewees. All other participants in the survey who had left their details consenting to a follow-up interview and were not selected for interview were contacted and thanked for their participation in the survey.

At the time of arranging the interview with one of the participants, this participant requested whether a second sibling could also attend the interview and was happy that the second sibling’s responses would be recorded as individual responses, so that their experiences could be considered separately from one another. The second sibling also met the criteria for interview, and this request was granted. In addition, one other potential participant contacted me after the closure of the survey and expressed an interest in participating in an interview. This participant also met the criteria, and a total of 20 interviews were conducted.

5.1 Demographic analysis

Demographic data were collected at the time of the interview. All participant quotations (verbatim extracts from the data) were coded in the same manner as the survey data, identifying participants only by their gender and generational age group. Table 5.1 provides the demographic details of the interviewed participants, in no particular order.
Table 5.1 Demographic details of the interviewees

<table>
<thead>
<tr>
<th>Gender</th>
<th>Age</th>
<th>Gender of SWD</th>
<th>Age of SWD</th>
<th>Children in Family</th>
<th>Guardian</th>
</tr>
</thead>
<tbody>
<tr>
<td>Female</td>
<td>65</td>
<td>Male</td>
<td>60</td>
<td>4</td>
<td>yes</td>
</tr>
<tr>
<td>Female</td>
<td>65</td>
<td>Female</td>
<td>63</td>
<td>3</td>
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<td>56</td>
<td>6</td>
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<td>60</td>
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</tr>
<tr>
<td>Female</td>
<td>23</td>
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<td>6</td>
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</tr>
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<td>Female</td>
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<td>Male</td>
<td>50</td>
<td>3</td>
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<td>Female</td>
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<td>Male</td>
<td>55</td>
<td>5</td>
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<td>Male</td>
<td>35</td>
<td>9</td>
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<tr>
<td>Female</td>
<td>45</td>
<td>Male</td>
<td>34</td>
<td>4</td>
<td>yes</td>
</tr>
<tr>
<td>Male</td>
<td>56</td>
<td>Male</td>
<td>54</td>
<td>5</td>
<td>no</td>
</tr>
<tr>
<td>Female</td>
<td>27</td>
<td>Female</td>
<td>18</td>
<td>6</td>
<td>no</td>
</tr>
<tr>
<td>Female</td>
<td>20</td>
<td>Female</td>
<td>18</td>
<td>6</td>
<td>no</td>
</tr>
<tr>
<td>Female</td>
<td>59</td>
<td>Male</td>
<td>52</td>
<td>3</td>
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<tr>
<td>Female</td>
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<td>62</td>
<td>4</td>
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<td>67</td>
<td>Female</td>
<td>57</td>
<td>3</td>
<td>yes</td>
</tr>
</tbody>
</table>

Note: SWD is used to represent sibling with intellectual disability in this table.

To enable exploration of the ‘gender commonality’ theory in sibling dyads when care is a factor, all participants were asked for their gender and the gender of their sibling with intellectual disability. Figure 5.1 shows the genders of the siblings in the dyads from the interview participants.
Figure 5.1 Genders of the sibling dyads who were interviewed

More than half of the participants in the interviews were over the age of 50 years, and no participants were aged under 20 years of age (Figure 5.2). Participants came from a family of three to six siblings, with one family of seven children and one family of nine children. Age gaps between the sibling with intellectual disability and the participant varied from two years to 23 years, although only four participants had an age gap of 10 or more years between themselves and their sibling with intellectual disability. Nine of the 20 participants were legal guardians, acted as an administrator or held power of attorney for their sibling with intellectual disability.

Figure 5.2 Ages of participants interviewed in stage two
5.2 Thematic analysis process

5.2.1 Initial theme development

The interviews were analysed using a thematic analysis process described in Chapter 3, employing Braun and Clarke’s six-phase framework (Braun & Clarke, 2006). With the use of computer-assisted software for analysis (Nvivo), initially five potential themes were identified, which were named attitude, knowledge and understanding, responsibilities, ways of coping and sibling with intellectual disability influential. I used these themes as working themes that still needed refining and defining (Braun and Clarke’s fourth and fifth phases in the thematic analysis framework).

Guided by Braun and Clarke’s belief that themes should not be constructed based on their frequency of occurrence within the data, thereby rendering them quantifiable, I chose not to report on the frequency of themes. I also wanted to ensure that themes were constructed with the research questions in mind. According to Braun and Clarke (2006), the themes need to “capture something important about the data in relation to the research question” (p. 82). In addition, because this study utilised a social constructionist ontology, it was important I ensured that the final themes captured the meaning of the participants’ experiences to allow for a greater depth of understanding (Denzin & Lincoln, 2011). In support of the social constructionist approach, Braun and Clarke (2006) suggested that the final themes needed to “go beyond the semantic content of the data” to explore the latent meaning that was underlying in the participants’ responses (p. 84). Finally, I wanted to identify themes that were ‘data-driven’ and not coded into a pre-existing framework, while still considering the theoretical framework, bioecological theory, in which this study was developed (Braun & Clarke, 2006). The theoretical framework would not influence the final names of the themes; however, recognising the significance of the theoretical framework at this stage of the analysis would be helpful in the discussion stage of the thesis to explore the participants’ experiences relational to the environment around them. Since these themes were large and quite complex, I identified several subthemes within the main themes to provide them with structure (Braun & Clarke, 2006).

5.2.2 Refining and defining the themes

For this phase of the thematic analysis process, I reverted to a manual method of analysis by printing and cutting up the themes, subthemes and research questions on coloured paper. I arranged the themes and subthemes beneath the research questions
that I felt they answered sufficiently. I also referred to Saxena and Adamsons’s (2013) bioecological framework to explore the influence of systems theory and the relationship within and between the environments in which the participants lived. This process led to a reduction and renaming of the initial five themes to four final themes, and the reorganisation of the subthemes within them. The final four themes constructed were *relationships, knowledge and understanding, siblings as carers, and consequences for family* (see Table 5.2).

This process also identified where I had potentially omitted to code latent meaning in the data (for example, the coding of the effect of having a partner or children on the current relationship with participants’ sibling with intellectual disability, and the participants’ role of teacher or advocate for their sibling with intellectual disability). The final step was to write a descriptive passage that identified the essence of each theme with a title that was sufficiently concise to endow the theme with a sense of the meaning (Braun & Clarke, 2006).

<table>
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<tr>
<th>Main themes</th>
<th>Subthemes</th>
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<td><strong>Relationships</strong></td>
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<td>Leaving home</td>
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The following paragraphs provide a description of each theme.

*Interviews theme 1—Relationships*

This theme describes how the participants’ experiences influenced relationships with their sibling with intellectual disability within the family, with extended family and with peers. Elements in this theme include how family dynamics and circumstances changed when the sibling with intellectual disability was born, including experiences of ‘life revolving around the sibling with intellectual disability’, and parental stress. A subtheme, *fitting in the family*, was included in this theme to describe the importance, from the participants’ point of view, attributed to partners or others fitting in the family and to their acceptance of disability.

*Interviews theme 2—Knowledge and understanding*

The theme describes the experiences of participants regarding the knowledge and information with which they were provided (if any) about their sibling’s disability while they were growing up and their understanding of the impact of their sibling’s disability. The subtheme *learned over time* also captures the participants’ memories of hospitals and the health issues of their sibling with intellectual disability while they were growing up, including the diagnosis of their sibling’s disability, which was often a source of information.

*Interviews theme 3—Siblings as carers*

This theme captures the experiences of the sibling’s role as a carer while they were growing up and currently, and expectations of care in the future. Participants also described feelings of protection and responsibility and roles that included teaching, leading by example or acting as advocate for their sibling with intellectual disability. This theme also encompasses how having a sibling with intellectual disability and their role as carer or protector influenced participants’ life choices (decision to marry and/or have children, or choice of career).

*Interviews theme 4—Consequences for family*

This theme describes the participants’ perception of the consequences of having a child with disability in the family. Subthemes capture the family’s access to support, expressions of having ‘missed out’ on things while growing up or statements like ‘it was normal for us’. Other elements captured in subthemes include parent involvement in parent advocacy groups, the influence of religion on the family and relocation of the family attributed to the sibling with intellectual disability’s needs. I have also included
in this theme a subtheme of leaving home. This was in response to participants stating that either they or their siblings left the family home, sometimes when they were quite young, as a consequence of having a sibling with disability.

5.2.3 Presenting the findings

The following sections present each main theme and their subthemes and include data extracts (verbatim comments from the participants) that provide examples of the theme. The main purpose of providing verbatim comments in this chapter is to provide evidence of participant’s statements that illustrate the themes and subthemes, and to provide the reader with a deeper understanding of the construction of the meaning (Corden & Sainsbury, 2006). As described in Chapter 3, some of the subthemes are expressed in vivo (in the participants’ own words). The purpose of this is to give the participants a ‘voice’ by using their own words. It should also be noted, as explained in Chapter 3, that the frequency of occurrence of themes and subthemes is not reported here, nor does the following order of themes and subthemes reflect the frequency or importance (perceived or otherwise).

Below are some notes on the presentation of the findings:

- The in vivo subtheme titles are expressed using single quotation marks (for example, ‘normal for us’).
- When participants have used their sibling’s name in the quote, or the name of another family member, or when identifying age or gender may make it possible to identify the participant, the text has been removed and replaced with a generic term using square brackets.
- The participants are presented in Table 5.1 without pseudonyms. Similar to the presentation of verbatim quotes from the survey, the code used is [gender] and [age group]. Any information in the quote that would otherwise identify the participant has been changed to maintain confidentiality.
- Not all statements that support the subtheme are presented. A selection of statements was used that best illustrate the theme.
- The transcriptions and statements presented here have received minor editing to remove the ‘ums’ and ‘ers’ and repetitive words, and to add punctuation where required to enhance readability (Corden & Sainsbury, 2006).
5.3 Theme 1: Relationships

Participants described their experiences of the effect of having a sibling with intellectual disability on their relationships with their sibling and others. This was an important component of this study and provided evidence to answer the research questions. Participants’ descriptions of their experiences, all unique, provide an insight into the circumstances that influence relationships.

5.3.1 Subtheme: Relationship with sibling with intellectual disability

A range of statements from participants described their relationship with their sibling with intellectual disability while they were growing up, and now as adults. There were expressions of mild jealousy caused by the focus on the sibling with intellectual disability while they were growing up, and some expressions of guilt for the lack of current contact with their sibling with intellectual disability. One participant described how her responsibilities to provide care for her sibling with intellectual disability were a reflection of their relationship while growing up:

When we were younger, it was quite a difficult relationship because I was like the second mum, so it was, there was a lot of me telling him what to do, and me having to make him do stuff, and me being in charge. So, I was left in charge a lot, and now, it’s pretty similar … But it was more of a kind of parent–child relationship rather than a sibling relationship. (F 31–50)

Another participant described a feeling of not having an option regarding the care relationship with her sibling with intellectual disability now as an adult:

… and I’m now stuck with overseeing everything for [sibling with intellectual disability], which is really not, I never thought I would be in this situation, I just never thought. And I find that hard. (F 51–70)

The provision of care or support for their sibling with intellectual disability was a common response when participants were asked to describe the relationship between themselves and their sibling. One participant provided a clear description of the constantly evolving relationship between siblings over the course of their lifetime:

[I am] closer to him now than perhaps I was or have been for a long, long time. We were close growing up, but when I left the family home
all that got quashed. And now we’re quite close and I’m always hovering around him making sure that he gets treated correctly and he enjoys a good life. (F 51–70)

5.3.2 Subtheme: Relationships within the family

There was a strong sense of life ‘revolving around the sibling with intellectual disability’ in the participant interviews, resulting in a change in dynamics of the family when participants’ sibling was born or diagnosed with disability. Examples of statements include “I was the centre of the universe for the first four and a half years until my brother came along” (M 51–70), “I don’t remember too much before [sibling with intellectual disability], because when he was born, everything was focused on him” (F 31–50), and “I can remember 18 months after [sibling with intellectual disability] was born my parents were non-existent, and me and my older brother looked after ourselves for a long time” (F 18-30).

Participants described a feeling of loneliness or isolation, despite the size of the family:

I think that little nine-year-old girl, her needs were secondary to, and I think in fact all four of us learned that what we needed and what we wanted was second place to anything that happened to [sibling with intellectual disability]. In some ways I think I felt invisible and that, to some extent, has carried into my adult life, where I can be very wounded if I feel that I’m invisible. I think, I’m not conscious of ever having resented [sibling with intellectual disability] in my childhood. (F 51–70)

I think what changed was just we became more isolated. We were literally put into a corner. (F 51–70)

Then it became me and [sibling with intellectual disability], yeah. Cause I remember when I was young there was obviously no things as kindergarten or anything, I’d play by myself. (M 51–70)

A common theme that emerged for participants was the positive impact of having a sibling in the family with disability on relationships with other siblings. The following data extracts describe how these participants felt that growing up with a
sibling with intellectual disability strengthened the relationships with their other siblings:

It’s probably made us closer. I think it’s affected us positively. Because I can remember going through high school … I couldn’t understand what all my friends were going on about how they hate their sister, and oh, their sister’s so annoying and they hate their mum. (F 31–50)

I think having [sibling with intellectual disability] in our family made us a very strong family, and I think it made us, as siblings, it made us very tight. (F 51–70)

Some participants described how having a sibling with intellectual disability affected their other siblings more than it did themselves:

My brother didn’t cope with it as, well, he was a lot older, so he found it hard and he still finds it hard. He doesn’t have very much to do with my sister. (F 51–70)

I think that probably because there was such a big age gap, it didn’t affect me as much as it affected my younger brother, and I do remember him having some concerns, and having some issues, and stuff like that … (F 31–50)

Several responses described less positive relationships with participants’ other siblings, which some attributed to the experience of having a sibling with intellectual disability or to the different views about the future care or support of their sibling with intellectual disability:

My relationship with my sister is dreadful. We are estranged. We don’t speak. We both have very different views about what we think is the best for our brother. (F 51–70)

Well they’ve decided I’m too bossy, so they don’t relate to me at all. It’s much easier that way. (F 51–70)

I think maybe it made us closer, because we had to, Mum was so focused on [sibling with intellectual disability], we were sent outside
to go play and stuff. [It] made us a little bit closer, but now not so much because we’ve got different opinions. (F 31–50)

One participant recalled a sense of competitiveness with her other sibling (without disability) and searching for a ‘big sister’ relationship that was not forthcoming.

5.3.3 Subtheme: Relationships with extended family

Responses grouped under the subtheme of ‘extended family’ include reflections on how the extended family had been part of the family’s support network. Examples of this include “I think if the family wasn’t so supportive it would be more difficult” (F 8–31), and “We were all close, so there was extended family we couldn’t have done it without” (F 51–70). One participant described the presence of their extended family:

Not so much support, but I suppose socially we all did a lot of things, just as families do. I think they would have done it anyway. I don’t think they were thinking they had to support us. (F 51–70)

Other participants reflected on how they felt isolated from their extended family while growing up, either physically (by location) or psychologically. Isolation due to distance from extended family was reported by several of the participants. One participant explained how distance from extended family exacerbated the feeling of isolation:

We were a migrant family from [another country] … a young family with no other support family network around us, so it was very difficult for migrant children losing that connection with grandparents and extended family trying to fit into a different country. Even though we were from [another country], the culture was very, very different. (F 51–70)

Another participant explained that despite living in close proximity to some extended family members, her relationship with them was not close, which she attributed to her sibling with intellectual disability:

We lived next door to [extended family], and [another extended family member] lived down the road, but I don’t remember them having too much to do with [sibling with intellectual disability], I
think they felt a bit awkward about him and how to help him. (F 31–50)

5.3.4 Subtheme: Peer relationships

Many of the participants described the impact of having a sibling with intellectual disability and the difficulty of making friends. Examples of statements include “It was so bad, trying to make new friends” (F 31–50) and “Making friends was always a bit tricky, with a brother who had an intellectual disability” (F 51–70). One of the difficulties expressed by several participants related to the care that they needed to provide to their sibling with intellectual disability when they were at home, even when with friends:

So you couldn’t just be with your friends in your room, you had to be available. And then if you didn’t hear her choking you would get yelled at in front of your friends. And your friends would just be standing there thinking “what on earth”. (F 18–30)

Other participants recalled feeling embarrassed about their sibling’s behaviour or the characteristics of their disability. Many stated they went to friends’ houses in preference to their friends coming to theirs, and they expressed the difficulty they experienced trying to explain their sibling’s disability to other children to prepare them for what to expect.

This subtheme is closely linked to the subtheme missed out under the main theme of consequences for family. Several participants reflected on their relationships with peers and the perception of missing out on things that other children could do.

5.3.5 Subtheme: ‘Fitting in the family’

The interview guide did not specifically focus on the presence of a partner or children and the subsequent effect, if any, on the relationship with participants’ sibling with intellectual disability. However, several participants discussed how their partners needed to ‘fit in with their family’, including interacting with their sibling with intellectual disability. One participant discussed meeting his son’s partner for the first time:

And my son … he came home with his partner for Christmas last year and, a great test to see if people are going to fit in the family, and she was there … no worries. (M 51–70)
Other participants described how their sibling with intellectual disability remained a part of their lives even after they married:

And I was lucky enough that my husband is fully supportive and has always been like, open and happy to help too. (F 51–70)

[sibling with intellectual disability] always came on a weekend to my place with myself and my current partner, but also, I’ve been married before, so also with them she came. (F 51-70)

Another participant expressed how she did not want her partner to feel burdened with the care of her sibling with intellectual disability:

But the other thing I have to balance is, I’m married and my husband’s not somebody who’s a natural carer, and I never want him to feel burdened. I know he would deeply resent it if she became too much of a feature in our lives. (F 51–70)

5.4 Theme 2: Knowledge and understanding

Responses from interview questions that asked participants to recall their knowledge and understanding of their sibling’s disability while they were growing up were grouped into three subthemes. These are memories of being excluded, learning over time (described by some participants as ‘learned by osmosis’) and being well informed.

5.4.1 Subtheme: Excluded

When reflecting on their understanding of their sibling’s disability, or the information they were provided with about their sibling’s disability, some participants expressed a feeling of being excluded, or ‘pushed away’ by parents. One participant explained:

Mum became very protective of her, so if we did anything wrong like, like we would just go and play or whatever, we would get corrected, so we eventually, over time, stepped back. (F 51–70)

Some participants stated that their parents had never discussed or explained their sibling’s disability. One participant said, “To this day they haven’t” [discussed her sibling’s disability] (F 18–30). Statements that reflected regret that participants were not
involved more with their sibling with intellectual disability as a child were expressed as, “It was a closed shop. It was like they [parents] were living in denial” (F 51–70), and from another participant, “We were never allowed to be a part of it, to take the weight off Mum, ’cos she just carried it 24/7” (F 51–70).

One participant in the older generational age group also thought that the information available and the way disability was discussed might have been a reflection of the era:

… it was always adults talking in the corner, and we were never part of it. And that’s the time as well, “seen and not heard”. (F 51–70)

Another participant felt that her sister’s disability was more complex because of the lack of understanding at the time:

She probably was born 20 years too soon, because I often wonder, what would [sibling] have been, had she been born 20 years later. Because I don’t believe that her intellectual disability was as enormous as it became, because of her lack of communication. (F 51–70)

5.4.2 Subtheme: ‘Learned over time’

The data extracts coded under this subtheme included participants who stated that they discovered their sibling’s disability by themselves, ‘learned by osmosis’ (an in vivo code) and learned by listening to adults.

One participant reflected on overhearing conversations about her sibling with intellectual disability:

So, in a way, just because the conversations that we heard between our parents, and the conversations that we heard when other people visited, or whatever, that’s where we got our information from. (F 51–70)

And another stated:

You just slowly learn about it, you hear the language … you just sort of, just by being around the adults and listening to them and talking. (M 51–70)
Participants described how they thought their parents were protecting them from knowing the full extent of their sibling’s disability:

I think they did talk about it, but I think they talked about it in a way that they thought was protective of us, as opposed to letting us know. So, I think there was less understanding at times. (F 51–70)

They only spoke about it, and my parents are very British, like stiff upper lip, push it in a cupboard ... So you really had to pry it out of them. And as I got older, I just used to ask the doctor in the hospital outright. (F 31–50)

Many participants reflected on the health or medical complexities of their sibling with intellectual disability, with some focusing on the actual diagnosis of their sibling’s disability. Some participants mentioned their familiarity with the hospital environment; this was explained by one participant in the following terms: “It sort of became our second home” (F 51–70). Another participant said, “So I heard a lot, I went to a lot of the doctor’s appointments” (F 31–50). Many talked about attendance at medical appointments and assisting with therapy (these data extracts have been included in the theme siblings as carers). The participants often reflected on the information they received from people outside the family, mainly medical staff, as an additional source of information.

5.4.3 Subtheme: Well informed

Despite the examples provided above, most of the participants who were interviewed had been provided with information about their sibling’s disability, though in varying depth. Often, participants explained that as a potential contributing aspect to their acceptance of their sibling with intellectual disability, the depth of information they received was not important. The following extract illustrates this:

I don’t recall asking very much, they must have told me that she would always need help and they would always look after her. I can’t remember it being a big thing. (F 51–70)

Some participants felt that their parents provided all the information they had at that time. One participant expressed this as follows:
[We] could always ask questions. But I don’t know if my parents knew a lot, because she didn’t have a syndrome or a name, they couldn’t really look things up or find out about the future, they didn’t really know. We used to come to Perth a couple of times a year to the clinic at [children’s hospital] to see a couple of specialists but there was never anything new that would happen. (F 51–70)

Participants referred to the language used for their sibling with intellectual disability; however, it should be noted that the language used in these data extracts reflects the language used in that era (usually pre-1970s). Some examples of comments that reflect the use of language are presented below:

We just got told he was a slow learner. Back then, that was the words. He belonged to the Slow Learning Children’s Group. That was the bus he caught. It was—he was just a slow learner. And that’s how I’ve always pictured him. (F 51–70)

Mum always used the term “he’s special”. That was Mum’s language. My dad’s language always was, “he’s a slow learner”. Because that was the term, he wasn’t using it to be derogatory that was just the term. So that was his way of explaining, if anybody asked, where’s [brother], what school’s he going to? What’s he doing? He’s a slow learner, he’s going to a slow learning school. Mum would say, “he’s special, he’s going to a special school”. (M 51–70)

Overall, the depth of information provided to the participants depended on the knowledge their parents possessed regarding the impact of their sibling’s disability, the age of participants at the time of birth or diagnosis of their sibling’s disability, and the accepted language of the era when their sibling was born or diagnosed.

Three participants described seeking further information about disability through other means, such as online or through books:

… both mum and dad were always people that did research. Found stuff out. Didn’t know the answer to that, we need to find out. And we always had encyclopedias in our home, we always had, if it wasn’t in the encyclopedia we went to the library and we found out. (F 51–70)
When I got older, I would conduct online research to learn more. (F 18–30)

So the first thing I did was start reading. And there are not a lot of books on that either. (F 18–30)

5.5 Theme 3: Siblings as carers

The theme of siblings as carers was constructed as a result of responses from the participants that described experiences growing up with a sibling with intellectual disability and the responsibility of providing physical care and protection for their sibling. This theme also captures the experiences of teaching or advocating for their sibling with intellectual disability, the future plans for their sibling’s care, and the influence of the provision of care and sense of responsibility on later life decisions and choice of career.

5.5.1 Subtheme: Physical caring

Participants described the care they provided for their sibling with intellectual disability while they were growing up, including participating in therapy for their sibling. Some physical caring tasks described seemed quite advanced for young children to perform. One participant described knowing how to set up a nebuliser for her sibling at age 6 or 7, and another described changing a tracheostomy tube for her sibling at a young age.

Participants reflected on the expectations of providing support to their mothers for the care of their sibling with intellectual disability:

Mum would always turn around, “now clean up all the toys [participant]”. And I always felt like all I’m doing is doing the care, and I didn’t know cognitively until I was much older, I was always the one following around doing the washing, following Mum doing all the clean-up, really. (F 51–70)

I was my mother’s back-up plan, if you like, so I did a lot of caring for and supporting my younger sister while my mother’s struggling to cope, and that … I grew stronger as I, kind of, got older in childhood, such that, as I was in my late teens, the only future I could imagine was that I would be unmarried and the carer for my sister. It didn’t seem there were any other options. (F 51–70)
Several participants described caring for their sibling with intellectual disability and the impact on their social lives and school life:

… the neighbours in the street used to play with each other but we wouldn’t because we were looking after [sibling with intellectual disability], even as kids, we would help look after [sibling with intellectual disability] ’cos we’d play with her. (F 31–50)

I used to miss a lot of school so that I could go to appointments with Mum or if Mum was so exhausted from being up with her all night I could stay home and look after her. (F 18–30)

School was non-existent. I couldn’t run the risk of people pointing out that I had a brother like him … and when they did, they were exceptionally cruel. So I stopped going to school. (F 18–30)

One participant described how the role of being a carer to her sibling with intellectual disability continued as she grew up:

But I used to, as a ritual I used to give her a bath every night, that was my thing, it gave my parents half an hour to have a rest and that was something I did until I got married actually. It was just something I could do that gave them 20 minutes or so. (F 51–70)

There was a good deal of data coded to this theme. Participants saw themselves as carers, both while they were growing up and now as adults. This was not always depicted in a negative way.

5.5.2 Subtheme: Protection and responsibility

This subtheme was separated from the previous subtheme of caring to differentiate between actual physical care and the role of protector with increased responsibility. Some examples from the data include:

It wasn’t that we were always defending him, which we did, many a fight in the school yard has happened, because you’ve got a slow learning brother and they picked on him and you’d stand up for your brother. (M 51–70)
I do recall times in shopping centres and people walking past, and I might have been 8 or 9, and people staring at the oddity, 'cos she was in a wheelchair, or not a wheelchair in those days, a stroller, Mum used to use a stroller, a large push chair … and people would stare and I can remember doing it—‘what are you staring at, she’s my sister’.

(F 51–70)

So, we were the barricade, you had to get past us, to get to [sibling with intellectual disability]. We were her protectors; we were a team in that sense. (F 51–70)

Three participants described how their parents provided a level of ‘protection’ for them, to ensure they did not feel ‘burdened’ by having to protect or care for their sibling with intellectual disability:

The only difference being she went to a different school, and that was about protecting us from having to protect her at school … (F 51–70)

My parents didn’t want me to take responsibility and didn’t want it to be an extra burden … they wanted to do that themselves. (F 51-70)

I think Mum did, and Dad did, such a good job at perhaps keeping us a little bit protected, but also isolating us at the same time, if you get what I mean. (F 51–70)

The role of a guardian was also included in this theme. Nearly 50% (n=9) of the interview participants explained that they were currently guardian for their sibling with intellectual disability, or that they expected to be in the future. This included the management of financial affairs.

5.5.3 Subtheme: Sibling as a teacher or advocate

Many of the participants commented on the potential for their sibling with intellectual disability to have learned more as they were growing up, often relating this to the options for schooling available in the era. One participant said:

We grew up just knowing he didn’t fit into this school, but we also knew he didn’t fit into that school. So, but there was no other option, there was nothing. (M 51–70)
Another participant described how her sibling with intellectual disability had demonstrated the potential to learn as they had grown older:

I feel that, given how he’s learning now and the advances that he’s made, probably in about the last five or six years … We’ve just seen him almost have like a bit of a maturity spurt. If he’d maybe had that in his mid to early teens, what might have been different? (F 51–70)

Another participant described her sibling with intellectual disability’s frustration at not being ‘heard’:

I don’t think anyone really stopped for five minutes to even have a conversation with her … I said to her one day, I’m here and I’m going to find you the best people who can be with you and support you, what would you want them to know? And she said, “they have to listen to me, I’m not stupid.” (F 51–70)

While participants’ responses coded in this theme were few, they were often powerful, describing regret that their sibling with intellectual disability had not reached their full potential, or that their sibling’s ‘voice was not heard’.

5.5.4 Subtheme: Future planning

The future planning for their sibling with intellectual disability was described by many of the participants. Some participants described explicit future planning that had been done, and some described implicit future plans not yet in place formally. This subtheme was included in the theme of siblings as carers since many of the future plans involved some level of care or support by the participant. One participant said that there was an expectation that as the eldest she would be responsible for the future care of her sibling with intellectual disability. Another participant, who holds power of attorney for her sibling with intellectual disability, described how future plans had been put in place by her parents:

Mum and Dad have put everything in place so that, should something happen to them, [sibling with intellectual disability] will pretty much continue on as he is. We will all have responsibilities like taking him on holidays once a year, or whatever, and I do that now. But, it’s so that it doesn’t fall to one of us, they don’t want him to become a
burden on us, they want us to be involved in his care, as … as a sibling, rather than as a carer. (F 31–50)

One of the participants described the reciprocal care existing between his sibling with intellectual disability and mother and the need to consider the future when their mother is no longer living:

So he’s the man of the house, so to speak. He offers her that support for protection and does the jobs around the house that the male normally is doing, especially for an elderly woman. But that’s the main issue that we have, of course, is that she is getting older and there’s the care factor, because he will always need to be—even if he can live alone, he’s quite capable of living alone, but he’s always going to need that support, coming around for paying bills, etc. (M 51–70)

There was little evidence in the data of the use of short-term accommodation to assist with transition to independent or supported housing. This topic is related to future planning because options for permanent independent or supported housing in the future were discussed in the interviews. One participant explained the difficulty that her brother with intellectual disability experienced when he left home for the first time in his late 40s:

They never had any respite. I don’t know if they would have accepted it. But I think if they had learned to start using it early on, it might have made things easier, because as it went on and on and on, and he didn’t leave home until he was 47/48 … (F 51–70)

One participant also explained that her parents were having difficulty securing funding for permanent supported accommodation for her sibling with intellectual disability; she wished to have this in place before her parents were no longer able to care for her.

5.5.5 Subtheme: Career and life choices

Of the 20 participants who were interviewed, 18 worked in a helping or service profession. Three of those 18 stated that their career choice was not influenced by their experiences growing up with a sibling with intellectual disability. One participant stated that her choice of career had nothing to do with her sibling with intellectual disability
yet had a core value for her of ‘natural justice’ (F 51–70: Social worker). Another stated:

Now, whether I’d linked it directly to [sibling with intellectual disability] … it could well be, I’ve never really thought of it, it was just, I always wanted to help other people. (M, 51–70: Law enforcement).

One participant, a nurse, explained that while she had always wanted to be a nurse, she was unsure if her sibling with intellectual disability had been that influence, and she did not want to work in the disability sector:

I have to do that at home, why would I want to do that as my job? But I just always wanted to do care stuff, and yeah, I don’t know if [sibling with intellectual disability] influenced that. Mum was a nurse before she had us, so that might have been more that influence there, and it was also, again, that era, we girls didn’t go off and be scientists. (F 51–70: Nurse)

Some participants acknowledged that their choice of career in what is considered a helping or service profession was definitely influenced by their experiences having a sibling with intellectual disability. Examples of the data extracts from interviews where participants described direct influence on career choice are provided below:

Having a brother with disability has definitely impacted on my career choice. It made me an empathetic person. (F 18–30: Special education teacher)

Oh, I think it was because of him. It was the time we spent in the hospital. I know it was for me. It was either that or become a nun because I went to a catholic school. But yeah, it was always nursing for me from when I was a girl visiting him in hospital. (F 51–70: Nurse)

I was always really set on something on the medical side of things, because I think of our involvement with [sibling with intellectual disability]. (F 18–30: Disability support worker)
I’d already decided before I got to high school that I was going to be a nurse and save babies like [sibling with intellectual disability]. So I’d already decided I’d be a nurse, so nobody ever took me to one side, and said what I might be suited for, or what I might like to do, or what my options might be. I was a child that already had direction and knew where she was going, so I probably would have chosen OT [Occupational Therapy] right from the word go if I’d known about OT. (F 51–70 : Nurse who later trained as an OT)

Some participants were also working in volunteer roles related to disability, and they attributed this to their experiences growing up with their sibling with intellectual disability. The following two examples describe their volunteering roles in the disability sector:

It is exciting and I would never have done that if I hadn’t had that experience with my brother. It wouldn’t have been on my radar. (F 51–70)

[sibling with intellectual disability] is the big influencer, because I’ve always enjoyed working with her, working with her peers … In my gap year, I actually volunteered for hydrotherapy, which was with kids, former students, of her school. (F 31–50)

Participants remarked on other life decisions that were influenced by their experiences growing up with a sibling with intellectual disability. One participant stated that she had made a decision not to have children because the sibling’s disability was genetic, and another participant stated that her brother had made a decision not to have children.

Other decisions participants noted concerned where they had decided to live. For example, one participant described the ‘pull’ to stay close to her sibling:

I think there has been lots of times that we have wanted to move away, or I know other siblings have wanted to move away, and [sibling with intellectual disability] has kept us all here … (F 18–30)
5.6 Theme 4: Consequences for family

The subthemes in this theme were constructed to capture the consequences for the family of having a sibling with intellectual disability. This includes access to or involvement with services and support while growing up, the latent meanings that were constructed from the data regarding moving out of home, expressions of ‘missing out’ or circumstances being ‘normal for us’, religion, and relocation to enable greater access to services for participants’ sibling with intellectual disability.

5.6.1 Subtheme: Access to support

Some participants’ memories of growing up included a network of friends or community that supported their parents and family. One participant stated:

I know my parents got a lot of support from their neighbours and they [neighbours] supported us as kids, and they were wonderful, their neighbours. Yeah, neighbours were fantastic, but it was back again in the days when you knew everybody in the street. (F 51–70)

Other participants noted the support from close-knit communities in towns in rural areas of WA. One participant stated that she had “great memories of community and belonging”, and another stated that by living in a small community, “everyone just pulled together”.

Some participants discussed their family’s involvement with parent advocacy groups, often mentioning their participation in fundraising events and their parent’s participation in committees. There was also evidence that some parents acted as mentors, providing support and information to other families with a child with disability:

My mum would sometimes mentor other mums who actually had [a child with] Down syndrome. So they would be given her name and they would get in contact with her as a support and they quite often would become friends. (F 51–70)

Another participant stated:

They were the go-to people, they’d become the go-to people. So if someone had a baby that was clearly disabled in the hospital, the
hospital rang Mum and Dad. And Mum and Dad were the people that gave out that information to other parents. (F 51–70)

The involvement with formal care or health services in the lives of participants was evident. Most of the responses related to attendance at hospitals, medical appointments and therapy services. One participant reflected on the lack of privacy in her parents’ home owing to the need for carers to assist with the care of her sibling with intellectual disability:

That is a big thing with having the carers, because I don’t have privacy at Mum and Dad’s house. Even in the night-time there is no privacy. (F 18–30)

5.6.2 Subtheme: Leaving the family home

Several of the participants discussed leaving home while still in their teens, with one participant stating that the reason for leaving home young was “to get away”, while another stated:

I left home very early … I needed to do that in terms of finding who I was … (F 51–70)

Some participants recalled that their other siblings were affected in different ways from themselves. One stated that her other siblings stayed at home a decade longer than she did, and another recalled her older brother leaving home not long after their sibling with intellectual disability was born, so her brother had not had the same experience at home.

5.6.3 Subtheme: ‘Missed out’

The perception of having missed out as a consequence of having a sibling with intellectual disability was a dominant theme in the interviews, similar to the first-stage surveys. This included participants’ feeling that they had missed out on social events, holidays, friendships and having a ‘normal’ relationship with their sibling with intellectual disability. One of the statements used in the construction of this subtheme was “life revolved around [sibling with intellectual disability]”, which was a common expression, or congruent to an expression, used by several of the participants. One participant reflected on being the youngest in the family, “I was the centre of the universe … until my brother came along” (M 51–70). The following data extracts
reflect the participants’ notion of ‘life revolving around’ their sibling with intellectual disability:

… a lot of things then revolved around him and they tried their best to give us a life … (F 51–70)

I don’t remember too much before [sibling with intellectual disability], because when he was born, everything was focused on him. (F 31–50)

In addition, participants often expressed sentiments relating to the ‘loss of a parent’ owing to the focus on their sibling with intellectual disability. These feelings are evident in the extracts presented below:

I can remember 18 months after [sibling with intellectual disability] was born my parents were non-existent, and me and [siblings without disability] looked after ourselves for a long time. (F 18–30)

… you then realise you haven’t got a mother, she’s just totally focused on keeping this child from choking, from, you know, every hour of the day is focused on this little child in a cradle. And you just realise you just haven’t got a mother anymore. (F 51–70)

Similar to the findings in the first stage of this study, several of the participants recalled the impact that having a sibling with intellectual disability had on their friendships and the ability to have friends over to play or for ‘sleepovers’. Participants reflected on the difficulty in explaining their sibling’s disability to their peers, with one saying that it was easier not to have friends visit than to have to explain her sibling’s behaviours.

Sleepovers and friends coming over to play was a common topic in the interviews. Many of the participants talked about the difficulty of having friends in the house or recalled not having friends over at all. Some extracts from participants include:

We used to play with the neighbours, but I don’t remember having friends come over, because, no, I don’t remember. (F 31–50)
I couldn’t have friends for sleepovers or things like that, because my sister would cry a lot at night and my parents didn’t get much sleep … (F 51–70)

… and then you would miss out on having sleepovers or just going to friends’ houses because you had to look after her. (F 18–30)

So there wasn’t a lot of children coming into the home, we didn’t do sleepovers in those days. (F 51–70)

Some participants expressed their excitement prior to the birth of their sibling, followed by a feeling of loss when they learned, or realised, that their sibling had a disability. This included the regret expressed that they could not have a ‘normal relationship’ with their sibling with intellectual disability:

I was [age] and my [other sibling] was older, and I thought, this is going to be great, I’m going to have a little brother or sister, but it didn’t work out. That was probably my first reaction, because I had all these plans in my mind of what we were going to do. (F 51–70)

One participant expressed it as having ‘missed out’:

I feel that I’ve missed out on having a normal family relationship because it wasn’t a brother–sister relationship like that somehow or other, it just wasn’t. (51–70)

While the perception of having missed out, as illustrated by the quotations from the participants, had a broad meaning for the siblings who grew up with a sibling with intellectual disability, many of the participants placed greater emphasis on missing out on family events and holidays. Numerous quotes can illustrate this, such as “we never went out”, “we didn’t really have very many holidays” and “we couldn’t go on holidays”. Many perceived that their sibling with intellectual disability ‘controlled’ the family’s social and recreational activities.

5.6.4 Subtheme: ‘Normal for us’

The subtheme of ‘normal for us’ and other congruent statements, such as ‘grew up thinking it was the norm’ and ‘part of the family’, were prominent in the interviews.
Quotations from participants that illustrate this include, “She was just my sister”, and “It was normal because that was our normal”. For example, one participant said:

> We just grew up thinking that our family situation was all the norm. It’s really not until I was, probably as late as a teenager, that I started thinking that things were so different to the household next door, if you like. Yeah, I just didn’t know there’s any difference. (F 51–70)

> We’ve always treated him as normal, like we’ve always treated him as part of the family. (F 31–50)

One participant stated that her sibling with intellectual disability did not affect the family’s social lives and friendships, and that having a child with disability in the family was ‘normal’ for them:

> I don’t think he had any impact. We were restricted from doing a lot of things, just because my parents were a little bit old-fashioned. But it was nothing to do with him. So we actually had quite a good social life. We could go out, see our friends. We all had hobbies that we would go out for. We went to school things. It was nothing to do with him, the things that we could or couldn’t do. (F 51–70)

The same participant later in the interview said, “I think being part of a big family, he, despite all his quite significant problems in the amount of time and attention he got, he sort of just melded in as well”.

Another participant said that her sibling was always ‘present’ in the family and did not affect her social life and friendships:

> I had girlfriends come and sleep over, I went to girlfriends’ places and slept over … I know there were families where, if people came to visit, the disabled child was locked away in another room. That never ever happened in our home, [sibling with intellectual disability] was always front and centre. (F 51–70)

Two participants described the realisation that their sibling had a disability, and how until that moment they had not understood the impact on their lives. This is captured in the following statements:
I don’t really know when I twigged that he was different. It’s just something that grows on you, I guess. And then you realise that he’s not the same and you sort of accept it, you know. (M 51–70)

I don’t think we really called it disability. I don’t think that was in our language. It was just, this is the youngest and it’s the one that needs the most attention. It was never, well no discussion anyway, I don’t think we ever, I ever labelled her “disabled”. Just, things aren’t working, it’s a child’s way of, this is just an 11-year-old, but I can’t remember the whole disability thing until I well and truly left home, and it’s like you look back, and that’s when I realised. (F 51–70)

One participant recalled the moment that she felt her sibling realised she was different from other children:

She was standing there, there was some kids playing out the front in the street who would have been a similar age to her, and she was standing in the lounge room window looking out watching those kids play, and sobbing. And I felt broken-hearted for her. Because it was at that point, I felt she knew she was different. She recognised that she was different, and that was really heartbreaking. (F 51–70)

References to circumstances being ‘normal for us’ in the interviews were prevalent. Many participants discussed this throughout their interview, often reflecting positively on their life with their sibling with intellectual disability.

5.6.5 Subtheme: Religion

The influence of religion was not a targeted question; however, many participants recalled memories that included experiences that encompassed church, church groups or a religious upbringing. Participants attributed a religious influence to feelings of ‘looking for a family’ (in the church), a sense of nurturing and being accepted. One participant explained attending a church youth group as a teenager for social interaction and acceptance.

Another participant described how her mother felt a sense of responsibility for her sibling’s disability and attributed that to her mother’s religious upbringing. The following extract has been edited to ensure confidentiality for the participant:
She felt guilty because his disabilities were as a result of some birth trauma, which she felt responsible for, and she couldn’t shake that guilt. She’d been brought up [in a religious environment]. I think that [religious] guilt, sense of guilt for her and that sense of responsibility. (F 51–70)

One participant felt that religion contributed to the acceptance of her sibling with intellectual disability in the family:

I think that it was probably part of their religious beliefs as well, and the way we were brought up in some ways, that we had that kind of nurturing stuff and we never really felt jealous so much, or any of that sort of stuff. (F 51–70)

Another participant reflected on her sibling with intellectual disability’s acceptance by the church community:

Mum and Dad were heavily involved in the church as well, so we had Christian friends as opposed to secular friends, and most of those people were warm and accepting and happy for their children to come. [sibling with intellectual disability] was very much a part of the church life. She came to church, people fussed over her, she was just there. Mum and dad never ever hid her away. (F 51–70)

5.6.6 Subtheme: Relocation

Several participants discussed their family’s relocation to a larger regional city, or to Perth, to receive the support or education that their sibling with intellectual disability needed. The impact on the family included a parent seeking a new career or new role because of relocation, fitting into larger schools, and extensive regional travel for the family to seek medical or therapeutic support, ultimately resulting in a move. One participant described the impact of moving to a new school:

… entry into a school here, with my confidence shattered, was not easy. I picked up the pieces and then high school was good for me, but that first, maybe six months in the new school wasn’t good, and that felt, as I think back, was an impact of having a handicapped
sister. That transition where how I was responding to all of this change was not even remotely considered. (F 51–70)

One of the eligibility criteria for this study was that the participant and his or her sibling with intellectual disability had lived, or were now living, in Perth. All participants who discussed earlier childhood experiences living in country areas ultimately lived in Perth later in their lives, either as children or as adults.

5.7 Conclusion to this chapter

The findings for the second stage of this study, informed by the first-stage surveys, have been presented in this chapter. The data from this stage provided a deeper understanding of the experiences of the participants and added depth to the data collected in the first stage. The two-phase process of thematic analysis and the themes that were developed as a result of the thematic analysis process assisted with understanding of the phenomenon. Devising the final themes, and the subthemes within them, have enabled an analysis of the data and the discussion presented in the following chapter to describe the essence of participants’ experiences. The following chapter provides a discussion to answer the research questions while considering the theoretical framework of this study.
Chapter 6  Discussion

This chapter provides a discussion and interpretation of this study’s findings to answer the research questions. The findings are juxtaposed with previous literature and contextualised within the theory selected to underpin this study: Bronfenbrenner’s ecological systems theory applied to sibling research regarding disability (Saxena & Adamsons, 2013), CDT (Pothier & Devlin, 2006) and family life cycle theory (Whiteman et al., 2011).

The central research question was, What are the family characteristics and lived experiences that influence sibling relationships and decision-making across the life span when a sibling has intellectual disability? Two stages of data collection were implemented for this study. The first stage comprised an online survey completed by a convenience sample of individuals who had a sibling with intellectual disability. The sample of participants for the second stage of this study were purposefully selected from the survey participants following analysis of findings in the first stage. The focus of the second stage was the change in family dynamics that participants described in stage one as a result of having a child in the family with ID. For participants older than their sibling with intellectual disability, this change in family dynamics might have occurred at the time of birth of their sibling or the time of diagnosis of their disability. For participants who were younger than their sibling with intellectual disability, the realisation of ‘difference’ might only have occurred when they were old enough to notice that they had ‘overtaken’ their sibling’s development or milestones or that their sibling needed additional care or support. Since it was possible to select participants most likely to have experienced a change in family dynamics as an older sibling, the second-stage research question was How do older siblings perceive family dynamics are affected following the birth or diagnosis of a younger sibling with intellectual disability?

The discussion presented in this chapter is structured by the research sub-questions, with specific focus on dominant concepts that answer the research questions. The mixed methods research question posed at the end of Chapter 4, What are the implications for policy and practice in the disability sector as a result of this study? is discussed in the final section of this chapter.
6.1 What individual and family characteristics influence relationships in childhood and adulthood?

In both stages of data collection, demographic information was gathered to answer this research sub-question and to assist with analysis of the other research sub-questions. This section provides a discussion of the individual and family characteristics that affect the relationship between siblings when one has ID. These factors include the influence of gender on sibling relationships, family structure, extended family and how the characteristics of participants’ sibling’s disability has influenced relationships with sibling/s and peers.

6.1.1 The influence of gender on sibling relationships

The greatest proportion of participants in this study were female (79%) and the greatest proportion of siblings with disability were male (62%). Previous studies (e.g., Arnold et al., 2012; Doody et al., 2010; Heller & Kramer, 2009) also reported a low rate of male participants (siblings without disability) and a higher percentage of male siblings with disability. An explanation for the lower percentage of male participants in this study could be the social pattern of gendered caregiving, which predisposes females to a caregiving role. Several earlier studies (Burke et al., 2012; Greenberg et al., 1999; Griffiths & Unger, 1994; Heller & Kramer, 2009; McGraw & Walker, 2007; Orsmond & Seltzer, 2000; Sonik et al., 2016) also found that sisters were more likely to have involvement with or provide caregiving to their sibling with intellectual disability than were brothers, and also to have higher expectations that they would provide care in the future. For the female participants in this study, the expectation that they will undertake a caregiving role for their sibling in the future suggests a gender-stereotyped pattern of family caregiving that is often grounded in childhood. Similar patterns of gendered caregiving were also found in earlier studies with mothers as informants (Pruchno et al., 1996; Seltzer et al., 1991) and studies concerning parents who were nominating legal guardianship in the future (Griffiths & Unger, 1994).

Akiyama’s (1996) principle of ‘femaleness’ (refer to Chapter 2, literature review) states that the closest relationship is a female–female dyad, and a male–male relationship the most distant. The femaleness principle can be used to explain how gender influences adult relationships. The findings in this study support findings in earlier research (Greenberg et al., 1999; Orsmond & Seltzer, 2000) that suggests that the principle of femaleness influences the sibling relationship based on the likelihood that sisters provide more care or support to their sibling with intellectual disability while
they are growing up and are more likely to predict future caregiving. However, owing to the small sample size of male participants and the predominantly female participants in this study, it is unlikely that this finding is generalisable. Additionally, the participants self-selected to participate in this study and the sampling strategy did not focus on participants who provided care or support to their sibling with intellectual disability. It is also possible that sisters, as the most likely sibling to provide caregiving to their sibling with intellectual disability, are more likely to respond to a study such as this current one. As previous authors have suggested (Begun, 1989; Doody et al., 2010), it is possible that a controlled sampling process and active recruitment of male participants in future studies will validate findings in relation to gender influences on the sibling relationship.

An explanation for the higher percentage of male siblings with disability in this study could be attributed to the higher rates of ID for males than females in the Australian general population (Australian Bureau of Statistics, 2014). This can be attributed to the fact that males have higher rates of conditions that are associated with ID than females and higher rates of ASD than females (more than 3.6 times as likely in the 0-14 years age group; Australian Bureau of Statistics, 2014). Previous earlier studies (Arnold et al., 2012; Doody et al., 2010; Greenberg et al., 1999; Heller & Kramer, 2009) also reported a greater number of male siblings with intellectual disability.

Sixteen males participated in this study. Twelve had a brother with intellectual disability and four had a sister with intellectual disability. Fifteen of the male participants indicated that they provided some form of care or support for their sibling with intellectual disability currently (the sixteenth male participant explained that his sibling with intellectual disability lives in supported accommodation, and he felt he did not need to provide any further care or support for him). Two of the male participants who had a sister with intellectual disability reported that there was only the sibling with intellectual disability and themselves in the family; therefore, the responsibility to provide care or support for their sister may have fallen to them as the only other sibling. However, nearly half of the male participants (n = 5) with a brother with intellectual disability were also the only other sibling in the family; therefore, it is difficult to draw any conclusions in this regard.

Akiyama’s (1996) alternative theory to explain sibling relationships is the gender commonality theory. This hypothesis predicts that same gender sibling dyads have stronger emotional ties of affection than mixed gender dyads. The findings of this
study appear to support the gender commonality theory since 12 of the 16 male participants in this study had a brother with disability (75% of male participants) for whom they currently provided support or expected to provide support in the future. However, there was insufficient evidence that gender influenced the provision of care or support when the sibling without disability was female; 25 of 60 female participants (42%) were in female–female dyads and 35 of 60 female participants (58%) were in female–male dyads. This is consistent with previous studies (Burbidge & Minnes, 2014; Greenberg et al., 1999; Orsmond & Seltzer, 2000) that also found limited evidence to support the gender commonality theory when the sibling without disability was female.

From a theoretical perspective, the variables that influenced the relationships of the participants in this study are evident in the bioecological framework (Saxena & Adamsons, 2013). Factors that influenced the gender of siblings who provided care or support for their sibling with intellectual disability are represented in the macrosystem and the chronosystem within the bioecological framework. Family life cycle theory (Whiteman et al., 2011) is also relevant. For example, the family’s culture and ethnicity may predispose females to undertake a caring role for their sibling with intellectual disability, and beliefs or life stage may also influence the gender propensity to provide care or support to a sibling with intellectual disability (Seligman & Darling, 2007). Some evidence was found to support the notion of the gendered nature of family caregiving, noted by Burke et al. (2012) and Sonik et al. (2016) and the self-expectation to provide future care or support based on gender.

Exploring the influence of gender on the quality of sibling relationships presents challenges. As Stoneman (2005) suggested, sibling relationships change over the life span, which renders the analysis of the influence of gender on the quality of sibling relationships problematic using a cross-sectional data set from one moment in time (see also Arnold et al., 2012; Whiteman et al., 2011). Data in this study were collected using self-reported measures concerning how often participants contacted their sibling and questions asked participants to describe their current relationship with their sibling, what support they provided to their sibling with intellectual disability currently and what support they expected to provide in the future. No data were collected from the sibling with intellectual disability, so the concept of ‘quality relationship’ was explored from the viewpoint of the sibling without disability (the participant) only.
Ages, birth order and number of siblings in the family have been considered together in this discussion because they were linked with sibling relationships in earlier studies (Begun, 1989; Breslau, 1982; Burke et al., 2016). In addition, birth order and number of siblings in the family were the criteria for selection of participants for the second-stage interviews. The generational age groups of the participants who responded to the survey were comparatively similar: however, when the selection criteria for interview were developed for stage two of this study (older than their sibling with intellectual disability and other siblings in the family), more than 50% were in the 51–70 years age group, with the largest percentage being 60+ years. There could be two explanations for this: a) because of retirement, participants over 60 years of age may might have more time to participate in interviews and therefore be more likely to volunteer for the interview stage; and b) the average family size since the mid-1900s has nearly halved (from an average of 3.2 children per family in 1955 to 1.7 children per family in 2000; Australian Institute of Family Studies, 2012). Since a criterion for selection was three or more children in the family for the second stage of this study, it was statistically more likely participants would be in the 60+ age group.

Participants in this study assumed different levels of involvement, care and support of their sibling with intellectual disability regardless of their age or the number of siblings in the family. There was no evidence in this study of the benefit of a wide age gap between siblings when one has ID, contrary to the findings of previous research (Begun, 1989; Breslau, 1982). The needs of siblings in the family must be considered separate, unique experiences that are redefined over the life span (Atkin & Tozer, 2013), and relationships with individuals’ sibling with intellectual disability remain reliant on the family and social space—the microsystem—in which they occur.

Saxena and Adamsons (2013) suggested that family life and parental favouritism, a contextual element in the microsystem of bioecological theory, affect the individual outcomes of children growing up in a family with a sibling with intellectual disability. Findings in both stages of this study were dominated by participants’ recollections of parental differential treatment as a result of the demands of caring for a child with disability, loss of ‘importance’ in the family and life ‘revolving’ around their sibling with intellectual disability. Bioecological theory explains how an event that occurs within the family affects all family members (Saxena & Adamsons, 2013; Stoneman, 2001), as evident in parental differential treatment when a sibling is born or
diagnosed with disability. Parents treat children within the family differently, and favouritism is not uncommon (Stoneman, 2001); however, when a child in the family has disability, it is expected that there will be increased levels of differential treatment between the children in the family, which favour the child with disability. This finding concurs with my assumptions prior to commencing this study.

However, not all participants in this study reflected on parental differential treatment of children in the family in a negative way. Some responses were quite positive, demonstrating an understanding of the participants’ sibling’s increased need for their parents’ attention. It is possible that expressions of understanding parental differential treatment could be attributed to a greater sharing of knowledge regarding participants’ sibling’s disability by their parents, thereby leading to a greater understanding of the need for parental differential treatment. In a review of the available literature that focused on youth adjustments to having a sibling with autism spectrum disorder, McHale et al. (2016) concluded that if siblings are supported to understand the reasons their parents show differential treatment to their sibling with intellectual disability, sibling relationship and adjustment problems are reduced. It is difficult to draw conclusions that a greater knowledge of their sibling’s disability contributed to an acceptance of parental differential treatment for the participants in this study; nevertheless, it raises the question of relationship between the two.

The findings from this study also provided further insight into the relationship between positive childhood bonds within the family and positive, connected relationships as adults when one sibling has ID. This contributes to the evidence that strong emotional family bonds as children are growing up predisposes them to warmer, quality relationships (Greenberg et al., 1999) and a commitment to their sibling with intellectual disability (Dew et al., 2014; Tozer & Atkin, 2015) in adulthood. For the participants in this study, the presence of other siblings in the family often elicited a strong bond between siblings as they were growing up, and siblings felt united as children and adults. This is consistent with findings from earlier literature (Orsmond et al., 2009) reporting that in adolescence, siblings engaged in less conflict when they came from a larger family. However, family size is not always a defining factor for sibling harmony. Five participants in this study described feeling lonely in childhood despite family size, and they lamented the loss of their (and their other siblings’) ‘importance’ in the family as the focus shifted to their sibling with intellectual disability. It was this expression of loss of ‘importance’ in the family that prompted the
focus on the change in family dynamics in the second stage of this study (see further discussion in section 6.2 in this chapter).

This study has shown that the number of other siblings in the family did not overtly predispose siblings to an equal sharing of responsibilities for their sibling with intellectual disability while they were growing up and as adults. Consistent with the findings of Burke et al. (2016), participants in this study felt that sibling disagreements regarding their sibling with intellectual disability’s current or future care or support had caused tension or estrangement amongst siblings in the family. However, this was not always consistent since several participants in this study reported an equal sharing of responsibilities and decision-making regarding the care or support of their sibling with intellectual disability. In addition to this, and contrary to the earlier study by Burke et al., (2016), the sibling closest in age to the sibling with intellectual disability was not always the sibling who provided care or support, or felt responsible for the care or support, of their sibling with intellectual disability. For older siblings, the pattern predisposing them to the provision of care or support could be grounded in childhood (Saxena & Adamsons, 2013), when the sibling closest in age would not have been able to provide practical or emotional support. An older sibling might have been able to provide care that a younger child would not have been capable of. This predisposition could explain the role of primary carer or support person for a sibling with intellectual disability into adulthood. As previously mentioned, the gendered nature of family caregiving may also contribute to the role of primary carer or support person when the closest sibling in age to the sibling with intellectual disability is male.

### 6.1.3 Relationships with extended family

The participants in this study were not asked directly about the role of extended family in the care or support of their sibling with intellectual disability, the presence of extended family, or any support provided by extended family to their parents. However, during the interviews (second stage of this study) 12 of the 20 participants discussed their extended family while they were growing up.

Saxena and Adamsons (2013) provided a helpful definition of the influence of extended family members in the context of the bioecological framework. When extended family provide direct care to siblings, they form part of the microsystem (the immediate environment), and if they provide support to the parents (and therefore a more indirect influence on the siblings), they form part of the exosystem. With this
definition in mind, it is possible to consider the participants’ responses regarding their extended family support in these contexts.

Participants in this study reported on the presence of extended family at social events and close relationships with cousins. When extended family had been available as an emotional support for either their parents or themselves, participants responded positively, with a sense of feeling supported. When extended family had not been present, participants felt that their childhood was difficult, and that the presence of extended family may have helped. According to Saxena and Adamsons (2013), the value of the support of extended family is under researched; however, this study provides some evidence that parents and siblings may benefit from the support of extended family. It was not the intention of this study to explore the influence or impact of the involvement of extended family in the lives of siblings with a sibling with intellectual disability; therefore, it is difficult to draw conclusions regarding this. It is also reasonable to conclude that the omission of the discussion of extended family in the interviews was not an indication that extended family were not present because the participants were not directly asked about extended family. Nevertheless, the findings provide new insight into the importance that siblings may place on extended family support.

6.1.4 Peer relationships

In both stages of this study, difficulties with peer relationships emerged as a consequence of having a sibling with intellectual disability. Participants described the difficulty of making friends, having friends over to play, friends understanding their sibling’s disability, or explaining their role as a ‘carer’. Earlier research (Mulroy et al., 2008; Smyth et al., 2011) found that children who have a sibling with intellectual disability may feel isolated and ‘different’ from their friends, which could affect their social connectedness, psychological and physical health and wellbeing, and peer relationships. The findings in this study support Mulroy et al.’s (2008) and Smyth et al.’s (2011) findings, demonstrating difficulty establishing friends resulting in limited after school activities, and for some, evoking memories of missing out, embarrassment and isolation. During the thematic analysis, ‘relationships with peers’ and ‘missing out’ were closely linked. There is further discussion in the following section that considers the perception of having missed out on activities and experiences as a consequence of growing up with a sibling with intellectual disability.
6.1.5 Disability characteristics and sibling relationships

The final individual and family characteristic to be considered is the type of disability and characteristics of disability that the participants’ siblings experienced. Data were collected throughout both stages of the study regarding disability type, but this was not to provide a comparison between two or more disability types. The purpose behind the collection of this data was twofold: firstly, asking a question about this in the first-stage survey ensured that the participants’ siblings all had a ‘decision-making disability’ (see Chapter 1.2 Scope of the study), since this study focused on siblings with intellectual disability. Secondly, the question was asked to elicit discussion with participants in the second-stage interviews about how the characteristics of their sibling’s disability affected their relationship.

Behavioural issues as a result of their sibling’s disability negatively affected sibling relationships for the participants in this study. This was particularly true when participants described difficult behaviour or other behaviours considered ‘anti-social’ (such as ‘having a tantrum’, physical violence or aggression and ‘making loud noises’). Behaviours appeared to have even more impact on relationships in childhood. The legacy of childhood memories and social and emotional difficulties while growing up also affected the relationship with participants’ sibling with intellectual disability as adults, consistent with findings from previous research (Orsmond & Seltzer, 2007).

In both stages of this study the inability for participants to physically communicate with their sibling with intellectual disability affected their relationship with their sibling, most evident when telephone communication was required (owing to physical distance), when it was a preferred method of communication (owing to other commitments), or when their sibling’s disability characteristics prevented, or limited, oral communication. This supports findings from earlier research (Dew et al., 2014) that when communication is difficult, the problem of keeping in touch with a sibling with intellectual disability is intensified, and the closeness of the relationship may be affected...
When participants lived in close proximity to their sibling with intellectual disability, and therefore had the option to communicate face to face, their sibling’s difficulty with oral communication had less of an impact on their relationship. The uniqueness of the individuals within a relationship, and their physical and psychological characteristics, determine the impact of the characteristics of disability on the relationship between siblings. This perspective supports Saxena and Adamsons’ (2013) interpretation of the bioecological framework for siblings of people with disability, which encompasses psychological characteristics along with other characteristics of the individual and family.

6.2 How do the participants perceive having a sibling with intellectual disability affect the family?

Findings from this study highlighted the perception of a change in family dynamics as a result of having a child with disability in the family. During the analysis of the data, concepts of ‘missing out’ or life being ‘normal for us’—conflicting opinions of impact on the family unit—were identified. This section also considers the importance of ‘belonging’ and ‘community’ to family adjustment to and acceptance of a sibling with intellectual disability.

6.2.1 Changing the family dynamics

Following the analysis of data from the first stage of this study, the phenomenon that could benefit from examination in greater depth was the concept of the change in family dynamics. This section synthesises the data from the initial research sub-question, How do the participants perceive having a sibling with intellectual disability affect the family? and the question for the second stage of the study How do older siblings perceive family dynamics are affected following the birth or diagnosis of a younger sibling with intellectual disability?

The significance of these findings are discussed here.

The selection criteria for the purposeful sampling process for stage two of this study enabled a closer exploration of the change in family dynamics occurring when a sibling was born or diagnosed with disability, from the older sibling’s perspective. A prominent finding in relation to a change in the family dynamics was participants’ expression of things having changed in the family when their sibling was born or diagnosed, and the child with disability becoming the ‘centre of attention’, described by participants as ‘missing out’. As discussed earlier, any event or change within the
family is likely to affect the entire family; this is a basic tenet of bioecological theory. In addition, family life cycle theory can assist our understanding of the impact on all family members as participants’ parents and sibling with intellectual disability age and their needs change, consequently requiring other siblings to take on more of a caregiving role.

Participants in this study acknowledged that they missed out on regular childhood experiences that their peers were able to enjoy, such as holidays, going out or sleepovers with friends. Participants described a sense of loss in regard to the ‘way things were’ or a sense of loss in regard to an ‘expected’ typical sibling relationship. Others focused on the sense of loss of a parent because of the increased care needs of their sibling and the focus on the child with disability. Similar to findings in previous studies, participants in this study described effects on the family and adjustment to having a child with disability, such as disharmony and conflict between parents (Stoneman, 2001), grief (Brown et al., 2017) and isolation due to increased care duties or responsibilities (Smyth et al., 2011).

The lack of formal support for the family may have contributed to a sense of missing out, affecting the time that parents had to devote to themselves or other siblings in the family. When participants in this study recalled formal services, these were medical or therapy-based services; only a few described formal support in the home (paid support), social support or support for siblings. Only 7% (n = 8) of participants stated that they attended sibling camps while they were growing up. When asked what might have helped when growing up, participants expressed that services to help their parents, including short-term accommodation (respite services), may have reduced the burden on their parents and allowed more ‘family time’, potentially reducing the sense of social exclusion the participants felt. Having conducted research exploring disability services in WA in the middle to late twentieth century (Simpson et al., 2019), I had expected that for participants growing up in this era the access to formal support services for their family and themselves would have been limited.

During analysis of the data from the interviews, the subthemes of ‘missing out’ and ‘normal for us’ were collectively represented under the theme of consequences for family. Earlier authors (Saxena & Adamsons, 2013) argued that perceptions that having a child with disability in the family negatively affects the family unit may be presumptuous. Participants may have felt they missed out on experiences as a child yet they still spoke of their experiences as a sibling in a positive way. This included
expressions of ‘grew up thinking it was the norm’, ‘part of the family’ and ‘I wouldn’t change the experience’. The participants in this study who expressed that it was ‘normal’ for their family had a positive outlook on disability and believed that their sibling’s limitations or additional needs were an accepted part of their life. The findings from this study support those of earlier studies (Greenberg et al., 1999) that positive relationships and strong emotional bonds within the family may predispose siblings to a positive relationship as they age.

A sense of ‘normalcy’, positive outlook and acceptance may also be attributed to the provision of information about participants’ sibling’s disability while growing up. The benefits of providing information to participants about their sibling’s disability to alleviate stress (Ying Li, 2006), to help adjust to the reality of their sibling’s disability (Brown et al., 2017) and to enhance their ability to provide support (Heller & Arnold, 2010) have been well documented in the literature. Previous studies (Pollak, 2008; Seltzer et al., 1997) described open and clear communication within the family as a contributing factor to a greater acceptance of their family situation. Further discussion about the provision of information to siblings is presented in the following section of this chapter.

6.2.2 The broader social context

In the broader social context, the findings emerging from this study demonstrated that the informal support the family received from others, the support groups they participated in (such as church groups and parent advocacy groups) and the sense of community in the neighbourhood, contributed to coping with and acceptance of participants’ sibling with intellectual disability. Community resources and support networks are the distal influences in the ‘exosystem’ of the bioecological framework (Saxena & Adamsons, 2013; Stoneman, 2005) that can affect the wellbeing of siblings.

Available community resources for the more than 30% of the participants in this study who were born in the mid-twentieth century may have been limited. Since the 1970s, disability services in Australia and around the world have undergone significant reform (Simpson et al., 2019); therefore, the impact of having a child in the family with ID may have been intensified by the era in which they grew up. Participants in this age group (51+) reflected on this and acknowledged that their experiences were ‘a sign of the times’ and that these difficulties may not be experienced by those growing up in Australia in the twenty-first century. The change in community attitudes and the social construction of disability, the effect of deinstitutionalisation and the rise of availability
of services and support since the mid-to-late twentieth century (Heller & Arnold, 2010; Simpson et al., 2019) will have influenced the experiences of the older participants in this study.

It is also possible that findings from this study about religion represent a societal manifestation of the era because there has been a decline in the reporting of an affiliation with a religious group in the Australian census over the last 60 years (especially Christian religions; Australian Bureau of Statistics, 2016b). Most of the participants who described affiliation with church or church groups while they were growing up were born in the mid-twentieth century. Religion was not a focus in the research questions nor the purpose of this study; however, eight of the 20 interviewed participants in stage two described their family’s or their own involvement with church or church groups while they were growing up. Participants described a feeling of belonging, a sense of ‘other family’ or the non-judgemental attitudes of church groups. Since the study did not include a specific question regarding religion, it is possible that participants underreported their families’ involvement with church or church groups, and this number may be higher.

In the review of the literature for this study using the key search terms as described in Chapter 2, no previous studies were found that had explored religion in families with a child with disability. However, following the findings from the second stage of this study regarding participants’ association or involvement with church or church groups, I conducted a further literature search using new key terms of ‘disability’, ‘religion’, ‘siblings’ and ‘families’. The literature available was extremely limited with relevance to this study because of the difference in religious profiles in the country of research origin.

One study (Marshall et al., 2003) was conducted in the US state of Utah, with 16 families with a child with disability, all of whom were members of the Church of Jesus Christ of Latter-Day Saints (Mormon). Marshall et al. (2003) found that “the power of religion and spiritual meaning” assisted families to deal with the challenges of having a child with disability (p. 70). Religious belief was found to provide a personal and family philosophical context that contributed to a positive meaning of life (Marshall et al., 2003). Another study was conducted in Korea (You et al., 2019) with 242 mothers of children with ID, of whom 36.8% were Protestants, 17.4% were Catholics, 11.6% were Buddhists and 33.5% had no religious affiliation. You et al. (2019) found that religion and spiritual meaning helped families deal with the challenges of having a child with
disability, thereby supporting Marshall et al.’s (2003) earlier finding. You et al. (2019) argued that mothers in their study demonstrated higher levels of life satisfaction when they had higher intrinsic religious orientation.

In the Australian Census 2016, Christianity was the most common religion reported in Australia (52%), followed by Islam (2.6%) and Buddhism (2.4%), with 30% of the population reporting that they had no religion (Australian Bureau of Statistics, 2016b). A similar percentage of the population in Australia and Korea follow a Christian faith; however, Australia’s percentage of people who follow Buddhism is much lower than Korea’s (You et al., 2019). While the difference in religious profiles in the country of research origin limits generalisability of the findings of previous studies by You et al. (2019) and Marshall et al. (2003), the findings from this current study provide further evidence that families may seek religion or religious communities for support when they have a child in the family with disability. Further research is required to explore how religion is beneficial for families with a child with disability.

Functions of social interaction and support are often met through association with families experiencing similar challenges. Several participants in this study described their family’s involvement with parent advocacy groups, especially the Slow Learning Children’s Group (SLCG). Established in WA in the 1950s, the SLCG was founded by parents with a child with disability following concerns regarding the inadequacy of existing service provision (Simpson et al., 2019). Over time, the SLCG expanded to provide assessment, therapy and support for families and children with intellectual disability (Gillgren, 1996), and in the 1990s it became Activ, an organisation that still exists in WA today. More than 20% of the participants in this study grew up in the 1950s and 1960s in Perth when the SLCG was prominent in disability advocacy in WA. Several of these participants recalled their family’s involvement with the SLCG, and the support their parents provided to other families, with a sense of pride. These positive parental attitudes to disability seemed to lay the foundation for a positive family environment while participants were growing up. In a similar way to the findings in regard to religion, families’ association with parent advocacy groups or other parents with a child with disability was not targeted by a research question, and generalisability is therefore limited. Nevertheless, the findings raise a question about how families utilise resources available to them and possibly seek out a community of support.
Participants also described a sense of community and belonging defined by location, in the context of the neighbourhood. For participants’ families living in a country town or regional area when their sibling with intellectual disability was born, the need for access to appropriate services necessitated a move to a larger regional town and/or Perth. Owing to the limited resources available in rural and remote areas of WA, it was expected that for some participants in this study a move to Perth or a larger regional location would be necessary to access medical or allied health services, education services and support. My assumptions that access to disability services would be limited in rural or remote areas of WA prior to commencing this study informed my decision to limit participant recruitment to Perth residents. The findings from this study concur with my assumptions prior to commencing data collection. Participants reflected on the changes and impact on the family when a move was required, describing a sense of loss of community, an increased sense of loneliness or difficulty making new friends, all attributed to having a sibling with intellectual disability. This broader social context of community, acceptance within their local community and the availability of appropriate services influenced the lives of the participants in this study in many ways, thus reinforcing findings from earlier research (Giallo et al., 2012).

This section has provided some insight into the consequences of having a child with disability in the family and the impact on other siblings. The findings of this study support earlier literature that highlights the importance of social support, access to services, positive attitudes, acceptance within the local community (Giallo et al., 2012) and support groups and networks (Arnold et al., 2012; Heller & Kramer, 2009) in the contribution to positive outcomes for people with a sibling with intellectual disability. The findings of this study reinforce findings from previous research identifying that siblings’ personal qualities, such as empathy and understanding, may be a result of a positive family environment (Chambers, 2007), appropriate family support systems (Saxena & Adamsons, 2013) and positive parental attitudes (McHale & Gamble, 1989).  

6.3 How did the provision of information to participants about their sibling’s disability affect sibling relationships and connectedness?

This study focused on the experiences of the participants, all siblings with a brother or sister with intellectual disability: the individual at the centre of the bioecological framework. Each individual plays a unique role that affects their environment, just as an environment affects the roles of the individuals within it (Saxena & Adamsons, 2013). This is especially true when considering the knowledge
and information that participants were provided with regarding their sibling’s disability. This section provides a discussion of the understanding of participants’ sibling’s disability as they were growing up and the possible relationship to sibling connectedness.

### 6.3.1 Learning about their sibling’s disability

Half of the participants (n = 37) in the first stage of this study responded that they had limited or no information or understanding about their sibling’s disability while they were growing up (eight in the 18–30-year age group, 15 in the 31–50-year age group, 14 in the 51–70-year age group). Participants stated that they experienced feelings of resentment (sibling with intellectual disability focus of family; obligation to care provides limited career prospects), frustration (difficulty in communicating) and sadness (for not having a relationship like ‘other’ siblings have; not being involved in decisions made for the future).

The remaining participants (n = 37) reported that they were provided with sufficient information and understood disability while they were growing up (13 in the 18–30-year age group, 14 in the 31–50-year age group, and nine in the 51–70-year age group). These participants spoke of maturing early and having greater empathy for others, and they acknowledged their parents’ challenging role caring for a child with disability. This is congruent with findings from similar studies (Begum & Blacher, 2011; Brown et al., 2017; McHale & Gamble, 1989; McHale et al., 2016). Participants in this study said they accepted the differential treatment from their parents while they were growing up and justified the extra time their parents needed to spend with their sibling with intellectual disability—a similar finding to McHale and Gamble (1989). Furthermore, participants described learning more about their sibling’s disability as they grew older, either from parents or through other sources, acknowledging that the information they were provided with as they were growing up was ‘enough’ and appropriate for their developmental level and age. Earlier studies had also highlighted the benefit of providing age-appropriate information to siblings (Brown et al., 2017; Orsmond & Seltzer, 2007; Seligman & Darling, 2007) to alleviate any anxieties in relation to their sibling’s disability. There was no evidence to support findings from earlier studies (Edward, 2011) that the provision of information may address unwarranted concerns and fears regarding genetic causes of disability.

An additional finding from this study was the relationship between participants receiving information about their sibling’s disability and the generational age group.
The lowest number of participants who reported that they received enough information about their sibling’s disability growing up were in the 51–70-year age group (n = 9), and the lowest number (n = 8) who reported that they had limited or no information while they were growing up were in the youngest age group, 18–30 years. This could be explained by the era in which the participants grew up and the consequent availability and accessibility of information.

This study found that the information siblings were provided with about their sibling’s disability, or their understanding of their sibling’s disability while they were growing up, did not appear to influence the quality or the relationship with their sibling with intellectual disability as adults. The participants who stated they did not have information provided to them, or had little or no understanding of their sibling’s disability, still often stated that they currently experienced a good relationship with their sibling with intellectual disability, saw them often, acted as legal guardian or expected to take on guardianship in the future. There was limited evidence in this study to associate the provision of information and understanding of participants’ sibling’s disability to positive sibling relationships found in the literature review by McHale et al. (2016). However, there are notable differences between this current study and McHale’s (2016) review. McHale’s review focused on the experiences of youth whose siblings had diagnoses of ASD, thereby narrowing the findings within the parameters of sibling-disability research. This current study was from a life-span perspective; therefore, an assumption could be made that the provision of information while growing up with a sibling with intellectual disability had less significance for or influence on the sibling relationship in adulthood. This is especially relevant considering the recent advances in technology and the accessibility to information may not have been available to the participants in this study while they were growing up. Additionally, since this study focused on the broader definition of ID, it would be difficult to compare the results to earlier studies that had a narrower focus on ASD only, owing to the wide-ranging characteristics of disability dependent on diagnosis. Indeed, a lack of diagnosis of their sibling’s disability was something that participants in this study felt limited the information that their parents had available to them.

6.3.2 Accessing information

As previously discussed, it is important to consider the era in which many of the participants in this study grew up and the changes to disability support since the mid-twentieth century. Owing to the large number of participants from the older generational
age groups, it was not surprising that they reflected on the era as having influenced the amount of information available about their sibling’s disability at the time. Changing practices and the changing social construction of disability since the mid-twentieth century influenced the language used, the diagnosis and treatment of many of the participants’ siblings in this study. This was evidenced by the higher percentage of participants in the youngest age group who reported having been provided with sufficient information and understanding about their sibling’s disability.

Technological advances since the beginning of the twenty-first century mean that children and young adults now have access to web-based information more readily, possibly filling the void of information left by parents who are unable, or unwilling, to share. In a study by Graff et al. (2012), adolescents sought additional information about their sibling’s disability by “doing their own research” (p. 189), a response that is likely to reflect the availability of online information. As this ‘self-help’ access to web-based information was not available to more than 70% of the participants in this study while they were growing up, similar findings may be difficult to replicate in future studies. There was limited evidence in this study that participants conducted their own research into their sibling’s disability.

The need for ongoing conversations about their sibling with intellectual disability while they were growing up was highlighted by participants in this study as an important way for them to understand the limitations of their sibling’s disability and any issues that arose. This supports the findings in Skotko and Levine’s (2006) study that surveyed children who had a sibling with Down syndrome. Skotko and Levine (2006) found that children preferred ongoing discussions that addressed their concerns as they emerged. Participants in this current study who identified that they did not receive ongoing information as they were growing up felt regret, disappointment or a sense of ‘unfairness’. It is possible that access to information via the internet that would be available to siblings now may have ameliorated some of these feelings.

However, having open access to unlimited health information available on the internet may not always have a positive outcome. Parents who did not share information about their child’s disability with the other children in the family may have been concerned about a negative reaction (Skotko & Levine, 2006). Indeed, as one of the participants in this study identified, parents may have been trying to protect other children in the family from the full knowledge of the extent of their sibling’s disability. Several of the studies reviewed for this study highlighted the need for factual
information for siblings of people with disability (Arnold et al., 2012; Burbidge & Minnes, 2014; Greenberg et al., 1999; Heller & Kramer, 2009). However, the inability to interpret health or medical information, or misinformation, may lead to inaccurate assumptions about their sibling’s future and the impact of disability on their lives.

6.4 How has the participants’ experience of growing up with a sibling with intellectual disability influenced decisions and choices across the life span?

In this study, participants described the decisions they have made over their lifetime that were influenced by having a sibling with intellectual disability. These decisions include when they would leave home or where they would live, what their choice of career would be and whether to have children. Decisions relating to current or future care of participants’ sibling with intellectual disability is discussed in section 6.5.

6.4.1 Career choice

The findings of this study have shown that growing up with a sibling with intellectual disability is likely to increase the probability that siblings will choose a career that is considered part of the helping or service professions. This is a strong finding that supports the evidence in the literature (see Chambers, 2007; Davys et al., 2016; Ferraioli & Harris, 2009; Martins, 2007; Seligman & Darling, 2007; Seltzer et al., 1997) that life experiences of growing up with a sibling with intellectual disability may influence an individual’s choice of career. The participants in this study were approximately four times more likely to work in a helping or service profession than were the general population of Australia (Australian Bureau of Statistics, 2019a), with most participants directly attributing their career choice to their experiences. In addition, some participants in this study stated that they volunteered in roles related to disability and attributed their experiences to the reason they volunteered.

An interesting finding in this study was that some participants who worked in a helping or service profession did not attribute this to their experiences growing up with a sibling with intellectual disability. The participants who were interviewed were asked if their career choice was influenced by their life experiences, and despite working in a helping or service career, three participants stated that their experiences did not influence their career choice. These participants used descriptive statements such as “I wanted to help other people” (F 51–70), “I have a core value around natural justice” (M 51–70) and “I just always wanted to do care stuff” (F 51–70). This would suggest that personal qualities, such as wanting to help other people, were a result of their sibling experience. This is similar to findings by Chambers (2007), whose research examined
siblings’ perceptions of motives for entering into employment in the disability field, and despite stating family connection to disability was not the primary reason, they recognised the importance of the sibling experience in their career choice. Self-realisation of personal qualities may be reflected upon over time, hence the importance of considering the impact of sibling experiences over the life span. This supports Saxena and Adamsons (2013), who suggested that a life-span approach to sibling-disability research can support understanding of the influence of early life experiences on life choices, such as choice of career. However, for some siblings their experiences growing up with a sibling with intellectual disability may lead them to undertake careers outside of the helping professions (Seligman & Darling, 2007).

6.4.2 Other life decisions

This study did not focus on decisions regarding leaving home or where to live in either the survey or interviews; however, such decisions were included in the analysis of the interview transcriptions because they were discussed by the interview participants. Despite only five of the 20 interview participants stating that they left the family home early, and only three of those specifically stating that this was because of difficulties at home, their actions did raise the question of life altering decisions based on having a sibling with intellectual disability. There is evidence in the literature (Atkin & Tozer, 2013; Dew et al., 2014; Orsmond & Seltzer, 2007) that siblings make decisions regarding where they might live based on close proximity to their family home or their sibling with intellectual disability; however, the minimal amount of data collected in this study would make it difficult to generalise any of its findings.

Participants in this study described other life choices that were influenced by experiences growing up with a sibling with intellectual disability. Only one participant related that a decision not to have children was based on the hereditary nature of her sibling’s disability. However, this study did not focus on the decision to have children, nor did it explore the hereditary nature of the participants’ siblings’ disabilities. Nevertheless, there is evidence in the literature (Davys et al., 2016; Ferraioli & Harris, 2009; Orsmond & Seltzer, 2007; Seltzer et al., 1997; Taylor et al., 2008) of a correlation between growing up with a sibling with intellectual disability and decisions about having children owing to concerns about passing on genetic conditions. Further research to explore decisions regarding having children based on these concerns would strengthen this correlation.
6.5 What are the participants’ expectations regarding the future care and support of their sibling with intellectual disability?

When asked about growing up with a sibling with intellectual disability, participants in this study described experiences that included parent-ascribed roles as carer, an expectation to care or an assumed role of protector. These findings reinforce those of earlier studies (Bigby, 1997; Greenberg et al., 1999) that siblings often fulfil the expectations of their parents to be involved or provide care or support for their sibling with intellectual disability in the future, motivated by familial obligation (Dew et al., 2014; Taylor et al., 2008) and shared family responsibility (Stoneman, 2005).

Familial obligation and shared responsibility were recognised by participants from an early age. A third of the participants in this study acknowledged that during their childhood they understood the expectation placed on them of care and/or support for their sibling with intellectual disability, and they felt they were more mature, ‘grew up quickly’ or were more independent than their peers as a result. Being a ‘young carer’ was often associated with positive outcomes for participants in this study, similar to findings of Moore and McArthur (2007). The findings also support those of earlier studies (Graff et al., 2012; Hodapp & Urbano, 2007; Orsmond & Seltzer, 2007; Tozer & Atkin, 2015) that siblings growing up with a sibling with intellectual disability often took on greater responsibilities than their peers and were consequently more mature (Mulroy et al., 2008; Saxena & Adamsons, 2013). There was limited evidence in this study of a close relationship with a sibling with intellectual disability in a mutually beneficial way that did not have elements of care, protection or a sense of obligation attached. This is congruent with the findings of Taylor et al.’s (2008) study. However, previous research (Bigby, 1997; Stoneman, 2001; Tozer et al., 2013) has provided evidence that when siblings took on a strong advocacy and care role for their sibling with intellectual disability when they were younger, they were more likely to have a closer emotional relationship as adults.

Only three of the participants in this study discussed feeling some resentment towards their sibling with intellectual disability as they were growing up. Similar to the findings from previous studies (Atkin & Tozer, 2013; Seligman & Darling, 2007), participants in this study described their childhood experiences and often implied that their additional duties (care of their sibling with intellectual disability or home chores) as a child, or their sibling with intellectual disability being ‘the main focus of their family’ while they were growing up, elicited feelings of resentment about how this
affected their lives. Only one participant stated being “stuck with overseeing everything” for their sibling with intellectual disability as an adult, implying that there was currently a feeling of resentment about providing care or support. Nevertheless, participants in this study often justified the need to assist their parent/s, expressing an understanding of the challenges their parents faced bringing up a child with intellectual disability. As earlier research has suggested (McHale & Gamble, 1989; Moore & McArthur, 2007), the provision of sibling care at a young age is not necessarily associated with negative outcomes.

As discussed previously, gender may have an influence on the ascribed or assumed role of carer. In this study, only female participants commented on the provision of physical care for their sibling with intellectual disability or an increase in household chores while she was growing up, suggesting a social pattern of gendered caregiving. However, while none of the male participants in this study described the provision of care for their sibling with intellectual disability while they were growing up, most male participants stated that they expected to provide care or support for their sibling in the future. The findings in this study support claims in earlier research (e.g., Cicirelli, 1995; Stoneman, 2001) that there is a disproportionate expectation for female siblings to provide care for their sibling with intellectual disability or support in the family home. The gendered aspect of care, a reality for many of the female participants in this study, highlight a structural inequality; a ‘reality’ for sisters who have a sibling with intellectual disability. As this study is approached through a critical realist lens, it acknowledges that perceptions of reality may be distorted by one’s social, cultural and biological formation, and operates independently of knowledge or awareness (Crotty, 1998).

6.5.1 Intention to care versus actual provision of care

Over 90% of the participants in this study reported providing care or support for their sibling with intellectual disability currently, and over 70% stated that they expected to provide care for their sibling in the future. The prediction of care in the future by the participants in this study is similar to the figure reported by Greenberg et al. (1999), yet much higher than the 38% figure reported by Heller and Kramer (2009). However, participants in this current study were asked about the care or support that they expected to provide in the future, which incorporated a broader range of elements of care or support than those included as elements of care in Heller and Kramer’s (2009) study (Heller and Kramer asked participants if they expected to be the primary caregiver
This current study asked participants whether they expected to provide any support with daily living or transport, practical home support, financial planning support, emotional support or any other kind of support. The rationale for this was informed by the literature review (discussed Section 2.5).

Construal theory was introduced earlier in the thesis, described by Burke et al. (2012). Construal theory can explain the difference between intention to care versus actual care in the future. As Burke et al. (2012) explained, events that are more imminent may be thought of in context, and events that are some distance away may involve more abstract reasoning. Therefore, older participants, for whom a care role is more imminent, may judge their capacity to provide future care with greater accuracy.

As discussed earlier, over 70% of the participants in this study stated they expected they would provide some form of care or support in the future for their sibling with intellectual disability, yet Heller and Kramer (2009) reported that 38% of participants in their study expected to be the primary caregiver in the future. As the mean age of participants in Heller and Kramer’s study was 37.16 years of age, it is likely that their expectation to be the primary caregiver in the future was judged by more abstract reasoning. Demographic data in the first stage of this study collected generational age groups; therefore, the mean age could not be calculated. However, the mean age of participants in the second stage of this study was 50.35 years—13 years older than the mean age of participants in Heller and Kramer’s (2009) study, yet a higher percentage of participants in this study expect to provide care or support for their sibling with intellectual disability in the future. This difference could be explained by the language used (primary caregiver) and the broader range of options that participants in this study were asked to describe in regards to care or support in the future.

Additional unforeseen commitments and events may also affect the ability to provide care in the future, despite every intention to do so at another stage in their lives. Data collected in the first stage of this study included information about other commitments that may affect the relationship and amount of contact with a sibling with intellectual disability. Other commitments may include having a spouse or partner, having dependants (children or grandchildren), providing care or support for others, or work commitments. These factors are present in the chronosystem of Saxena and Adamsons’s (2013) model of the bioecological framework, which is conditional on time and ‘sociohistorical’ events over the life span. Participants were aware of the changing needs of their sibling with intellectual disability, and the need to provide care or support
in the future because of the increased needs and reduced capabilities of ageing parents. The likelihood of needing to provide care or support may not be relevant in the immediate future; therefore, the context of participants’ intention to care may be more abstract (Burke et al., 2012). Nevertheless, the recognition that participants’ sibling with intellectual disability will require additional care or support in the future and that they were prepared to provide it, was a prominent finding of this study.

For some participants, other demands on their time, such as partners, family or work, combined with the desire to maintain contact with their sibling with intellectual disability led to feelings of guilt for not having as much contact as they would like. Competing family responsibilities and commitments often took precedence over ongoing contact with their sibling currently, similar to findings from earlier studies (Cuskelly, 2016; Dew et al., 2004).

6.5.2 Sharing support with service providers

Participants in this study expressed a lack of confidence or trust in service providers to provide the quality or level of care that their sibling required. Therefore, they assumed they would need to provide care or support in the future to fill this void. Since parents are usually the main contact with service providers for their child with disability until they are no longer able to provide care or support, and siblings may only take over this role once they have become adults, service providers’ contact with siblings in the family may be limited (Tozer & Atkin, 2015). Participants in this study described the support they provided to their sibling with intellectual disability as additional to formal support services, often because of perceived feelings of service inadequacy, poor quality of formal services or previous negative experiences with service providers. This finding is similar to findings from earlier studies (Atkin & Tozer, 2013; Davys et al., 2016). Participants in this study felt that they needed to provide ongoing ‘monitoring of services’, ‘oversee service providers’ or provide advocacy for their sibling with intellectual disability throughout their lifetime.

According to Bigby et al. (2015), through regular contact and advocacy siblings may be able to influence the quality of care their sibling receives, to “safeguard the wellbeing of their brother or sister” (p. 464).

Findings in this study revealed that siblings often felt ‘disconnected’ from their sibling with intellectual disability when formal support services were in place, sometimes leading to discord between service providers and siblings regarding the nature of support for their sibling. This was even more difficult when siblings were not
living in a geographically close location. To improve understanding of the importance of a life-span approach, and to enable siblings to maintain contact when distance is a factor, service providers need to be cognisant of the mechanisms that support strong sibling relationships into adulthood. These findings reinforce those from earlier studies (Arnold et al., 2012; Bigby, 1997; Dew et al., 2014; Rawson, 2010; Tozer & Atkin, 2015). Service providers may unwittingly undermine the extent to which sibling relationships can contribute to the holistic context of ‘family’ (Atkin & Tozer, 2013), and there is currently no imperative for agencies to address the current gaps in service provision by recognising sibling relationships (Siblings Australia, 2017).

6.6 What are the implications for policy and practice?

6.6.1 Implications for policy

The findings of this study can guide policymakers in the development of policy that recognises siblings in the support network for people with disability. There is a lack of recognition of siblings in current governmental policy as part of the family support network unless they are recognised as carers. In addition, the definition of care and support needs to include all support provided by people to their sibling with intellectual disability, including advocacy, transport, financial advice, and emotional support.

Three key pieces of legislation in Australia guide disability policy: the National Disability Strategy 2010–2020 (NDS), the National Disability Agreement 2008 (NDA), and the NDIA Act, the legislation that underpins the NDIS. The NDS outlines and provides guidance on the principles that underpin the United Nations CRPD, ratified in Australia in 2008. The NDA is an agreement between the Australian Commonwealth and state governments relating to services for people with disability, and is a mechanism for accountability and achievement of outcomes within the disability services sector (Productivity Commission, 2019). Introduced into Australia in 2013, the NDIS is an insurance scheme that funds individualised services for people with disability (Kendrick et al., 2017), moving away from a welfare-based model for service delivery (Reddihough et al., 2016). These key documents fail to mention the role of a sibling as a part of the natural network in the lives of their sibling with intellectual disability, despite the legislation that specifically tasks the NDIS to “strengthen, preserve and promote positive relationships between the child and the child’s parents, family members and other people who are significant in the life of the child” (Commonwealth of Australia, 2013, p. 8). Key NDIS documentation fails to
acknowledge the importance of relationships, and focuses on the role of informal support for people with disability, potentially to mitigate costs (Meltzer & Davy, 2019).

In 2019, the Productivity Commission undertook a review of the NDA and recommended the inclusion of an additional outcome acknowledging the role of carers and families in the lives of people with disability (Productivity Commission, 2019). This outcome focuses on carer and family wellbeing yet fails to acknowledge that siblings may not consider themselves as carers. In addition, these key documents only specifically name parents when referring to families. The participants in this study, despite more than 90% of them acknowledging that they provide some form of care or support to their sibling with intellectual disability now and more than 70% stating they expected to provide care or support in the future, did not specifically state they were their sibling’s carer. This is consistent with findings from the literature (Meltzer, 2017).

Earlier studies (Meltzer, 2015; Siblings Australia, 2017; Smyth et al., 2011) also reflected on the apparent ‘invisibility’ of siblings in governmental policy unless they identified as carers. Furthermore, since one of the most important and long-lasting relationships in a person’s life is with their siblings (Cicirelli, 1995), people with disabilities may not want to categorise a sibling as their carer because it undermines the sibling relationship and suggests that the relationship is one of ‘carer’ and ‘care recipient’ (Meltzer, 2017; Siblings Australia, 2017). The challenge to policy development is to address structural inequalities, particularly in consideration of the gendered nature of family care, and the barriers that siblings experience by identifying as a carer or care recipient and shift the focus onto the support required to suggest an equal relationship based on familial norms and a “whole of family approach” (Smyth et al., 2011, p. 158).

A key finding from this study and earlier work (Siblings Australia, 2017) is that people with disability are now outliving their parents, and siblings are likely to provide some form of care or support for their sibling with intellectual disability, or advocate for them, in the future. The evidence in this study supports the findings of the US study by Arnold et al. (2012) and suggests that siblings encounter consistent experiences in regards to inclusion in policy change and the advocacy movement in similar Anglophone countries. The sibling relationship should be acknowledged, and siblings should be recognised as contributors to the wellbeing of their sibling with intellectual disability across the life span. In addition, sibling support needs should be
acknowledged within the NDIS Act and other disability legislation. This will have a flow-on effect for disability practice.

### 6.6.2 Implications for practice

This study has significance for service providers who provide support for people with intellectual disability. An understanding of the experiences of growing up with a sibling with intellectual disability gained from this study can assist disability service providers when working with families to ensure that all members of the family are considered. The findings support evidence from earlier studies (Atkin & Tozer, 2013; Bigby, 1997; Graff et al., 2012; Siblings Australia, 2017), that suggest service providers need to understand the importance of holistic family inclusion and the needs of other siblings in the family. By becoming aware of the contributions of siblings in the lives of people with disability, support services can leverage siblings as a valuable resource to enhance supported decision-making for their sibling with intellectual disability across the life span, especially when planning for the future. Disability service providers need to introduce inclusive early invention services for siblings of people with intellectual disability to enhance the value of sibling relationships within the support network for a person with disability, predisposing them to positive relationships and shared decision-making into adulthood.

While other studies (Atkin & Tozer, 2013) described similar findings about life revolving around the sibling with intellectual disability and high levels of stress in the family (Giallo et al., 2012; Graff et al., 2012), few earlier studies described the concept of missing out as a child as prominently as participants did in this study. Findings in this study associated with the perception of having missed out on experiences in childhood are important because they highlight the impact that formal support services can have when supporting families with a child with disability. Participants expressed regret that services were not available for them or their families, and that parents often went without appropriate short-term accommodation (respite) or support for their child with disability, which resulted in the other children in the family missing out on ‘normal family life’. A large percentage of the participants in this study grew up in the mid-to-late twentieth century. Since then, Australia has witnessed profound changes in service provision and community attitudes towards disability, however, expressions of missing out because of a lack of other support were not limited to participants in the older age brackets, since participants in the 18–30-years age group also articulated this concern. Similarly, Tozer et al. (2013) found that siblings in the younger age groups expressed
frustration with the lack of support available to them as they were growing up. This leads me to question how successful service providers have been since the inception of the NDIS in 2013 to effectuate the changes to service provision and to acknowledge and respect the roles of family and natural networks, as legislated by the *NDIS Act* (Kendrick et al., 2017). According to Meltzer et al. (2019), the NDIS appears to place little importance on the value of relationships beyond the benefit of functional support and mitigating costs of the scheme. Long-term generational change is required to realise the benefits of a conscious investment in families from an early intervention and relational perspective (Kendrick et al., 2017).

Children with a sibling with intellectual disability need to be provided with factual and age-appropriate information about their sibling’s disability. Technological advances may mean that children now have access to online information sources at a younger age, nevertheless, families must have access to support services that meet the needs of all family members. The provision of age-appropriate information regarding their sibling’s disability may alleviate concerns about their sibling’s health, genetic causes of disability or inherent feelings of anger as a consequence of their parent’s differential treatment towards their sibling with intellectual disability while growing up. Factual information provided by trained disability support staff, especially in adolescence when stigma about their sibling’s disability may have the greatest impact, may help siblings develop an understanding of their sibling’s experiences and equip them to better support their sibling as they age.

This study has contributed to the understanding of the importance of sibling relationships and the vital role they play in the lives of their sibling with intellectual disability (Heller & Arnold, 2010; McHale et al., 2016; Walker & Ward, 2013). The sibling relationship is the longest lasting family relationship (Cicirelli, 1995), articulated by one of the participants in this study as “the longest life journey together”; therefore, sibling involvement early in life is going to be the best way to enable positive sibling relationships across the life span. Service providers must implement policies and practices to provide opportunities for, and recognise the importance of, family inclusion and natural relationships in the lives of people with disability, working in a collaborative, non-conflicting way. This is similar to recommendations made by Taylor (2011) and Bigby et al. (2017). According to Kendrick et al. (2017), service provision has long been seen as “having a greater importance than relationships and community belonging”, and paid staff are often considered a manageable way to provide support for
people with disability, ‘circumnavigating’ more complex natural relationships (p. 12). There is currently little recognition of the role and needs of siblings and their contribution to positive outcomes for their sibling with intellectual disability (Siblings Australia, 2017). As Taylor (2011) suggested, “the benefit of family inclusion would then flow to people with intellectual disabilities, families and service providers” (p. 17).

To improve understanding of the implications of communication difficulties with individuals’ sibling with intellectual disability, especially when distance is a factor, service providers should consider ways to facilitate involvement and contact between siblings. Service providers can contribute to sibling connectedness through facilitated communication methods and assistive technology. The importance of maintaining contact between siblings when one has disability and the role of augmentative and alternative communication (AAC) have been highlighted in earlier work (Dew et al., 2008, 2011; Rossetti & Hall, 2015). Participants in this study felt that communication difficulties were a barrier for regular communication with their sibling with intellectual disability, especially when they were not able to maintain face-to-face contact on a regular basis, yet none had been offered alternative ways to communicate with their sibling. The use of AAC options should be explored by service providers, even when families have not utilised AAC in the past. Specialist practitioner services (such as speech pathology and occupational therapy) need to be accessible for all people with disability because new ways of enhancing communication, such as through the use of AAC, may improve connectedness between siblings and strengthen the sibling relationship throughout their lives. The use of other technology, such as messaging, email, videoconferencing (using platforms such as Skype and Zoom) and social media are all new ways to keep connected. With support from service providers, barriers to the use of these technological forms of communication can be overcome to enable a greater connection to siblings when face-to-face communication is not possible (Burbidge & Minnes, 2014).

6.7 Summary of major findings

The individual and family characteristics that influenced relationships in childhood and adulthood largely supported the earlier literature. While the influence of gender was not a strong finding, there was evidence that the gendered nature of family caregiving was present for the participants in this study. For the female participants, the gender of their sibling with intellectual disability did not appear to influence their decision to provide care or support now or into the future. Family structure, including
age when a sibling with intellectual disability was born or diagnosed, birth order and number of siblings in the family, did not appear to influence sibling relationships nor predispose siblings to ‘share the responsibilities’ of their sibling with intellectual disability into adulthood. However, a strong finding was the focus in the family on the sibling with intellectual disability and parental differential treatment while growing up, which supported findings in the literature. Disability characteristics and the difficulty, or inability, to communicate face to face with their sibling with intellectual disability, affected the participants’ relationship with their sibling. Likewise, while growing up, it was found that challenging disability characteristics affected participants’ peer relationships.

There was a strong finding that following the birth or diagnosis of a sibling with intellectual disability, the family dynamics changed considerably for the participants in this study. Family life cycle theory assisted with the explanation of how a change in the family affects all family members. A perception of having missed out on experiences in childhood was a prominent finding in this study, exacerbated by the lack of formal support in the home. However, families met the need for support in other ways. This included contact with families experiencing similar challenges, and involvement with churches and church groups, parent advocacy groups and other community-based resources.

This study found that the provision of information about their sibling’s disability was important to the siblings in the family. However, because of the dominant older age groups participating in this study (older than 50 years of age), experiences related to the provision of information could largely be affected by the era in which these participants grew up. Owing to technological advances, information is now more readily accessible; therefore, responses from a younger age group may alter findings in future studies.

This study has provided a significant contribution to knowledge that associates a career in the service or helping professions and the experiences of growing up with a sibling with intellectual disability. Findings from this study also supported earlier literature that suggests that positive personal qualities, such as empathy and understanding, may be a result of earlier experiences assisting with the care or support of their sibling with intellectual disability.

An expectation to provide care or support for their sibling with intellectual disability in the future was also a prominent finding. Expectations of their parents, familial obligation and sharing of responsibilities were recognised as defining factors
that influenced decisions to provide future care or support for their sibling with intellectual disability. However, from a life-span perspective it is difficult to conclude that any intention to provide care in the future will translate to actual care when the time comes. Construal theory assists in the understanding of distant or imminent events that influence the ability to provide care; despite every intention to care in the future, when the time comes, it just may not be possible. Finally, this study found that despite service providers supporting their sibling with intellectual disability, participants often felt the need to oversee formal care and provide advocacy for their sibling across the life span, and they often felt excluded from decisions about their sibling, reinforcing findings from previous studies.

The final section of this chapter discussed the implications for policy and practice: the topic of the mixed methods research question. The findings from this study highlight the importance of holistic support for people with disability, that is, the inclusion of all family members in policy, legislation and early intervention practices to ensure siblings with a sibling with intellectual disability are supported and sibling relationships are encouraged across the life span.
Chapter 7  Conclusion

The impetus for this study was borne out of earlier research undertaken for my Master’s degree: a qualitative study exploring the experiences of families with an adult child with intellectual disability. I had also worked in disability organisations in WA, and therefore was familiar with the challenges that families and service providers sometimes face to ensure that people with intellectual disability have the support they require and relationships that they value throughout their lives, thus enabling them to realise a greater level of independence and participation in social and economic life. With the introduction of the NDIS in Australia in 2013, and the recognition of the natural networks that families and siblings can offer to a brother or sister with intellectual disability, it was timely that I continued on my research path and considered siblings’ experiences and the contributions to positive relationships between themselves and their sibling with intellectual disability.

My assumption as I began this study was that the importance of the sibling relationship is often disregarded by service providers, even from a young age. The review of the literature and the findings from this study provided evidence to support this assumption. The discussion in Chapter 6 and the recommendations to follow focus on inclusive early invention services to enhance the value of sibling relationships within the support network for a person with disability, and the opportunities for further research to explore some additional concepts identified in this study.

Stoneman (2005) explored the themes of research focused on siblings of children with disabilities and posited a research model that placed the sibling relationship at the centre, with issues that were proximal considered first, followed by more distal influences thereafter. Person-centred planning, one of the key principles of the United Nations CRPD (2006) places the person with disability ‘at the centre’ of the planning process that identifies the person’s goals and support. According to Meltzer and Davy (2019), person-centred planning is a fundamental element in the NDIS.

When Saxena and Adamsons (2013) considered the application of theoretical frameworks to understand research related to siblings of individuals with developmental disability, they identified that sibling-disability research is often atheoretical, therefore challenging when considering the multiple influences on the lives of people who have a sibling with disability. They also sought to contribute to future sibling research by identifying the contexts and aspects of sibling-disability research that needed further
investigation; this framework was utilised in this study. Saxena and Adamsons (2013) suggested that to enhance an understanding of the multiple influences on the lives of people who have a sibling with disability, a theoretical framework is crucial “as it has implications for supports available to siblings and families, as well as for research, programs, and policy” (p. 300). They used Bronfenbrenner’s ecological (they called it bioecological) framework to ‘reframe and organise’ current sibling-disability research. It was therefore appropriate that I used the bioecological framework as an underpinning theoretical framework for this study, following the guidance from the earlier work of Stoneman (2005) and Saxena and Adamsons (2013).

7.1 Contributions to sibling-disability research

This study adds to the knowledge of the experiences of growing up with a sibling with intellectual disability, and relationships across the life span, from the perspective of siblings without disability in WA. Previous studies have relied on accounts from parents or carers (e.g., Begum & Blacher, 2011; Carr, 2005; Mulroy et al., 2008; Pruchno et al., 1996; Seltzer et al., 1991), or compared specific diagnoses, such as ASD or DS (e.g., Hodapp & Urbano, 2007; Mulroy et al., 2008; Ormond & Seltzer, 2007; Tomeny et al., 2017). It is important to acknowledge the differences between the states of Australia with respect to disability service access. The WA Disability Services Commission had already been providing self-directed, individualised support prior to the introduction of the NDIS in WA, yet there is a dearth of evidence that has explored the experiences of siblings of people with disability in WA. This study fills this gap. Many of the families in this study lived in rural or regional areas of WA and only moved to Perth to access disability services. It is likely this is not unique to WA, but reflective of living in a non-urban area with limited services for families with a child with disability, certainly in the era that many of the participants in this study grew up in.

This study adds to knowledge about the importance of holistic family inclusion and early intervention strategies that include siblings. The evidence in this study builds on the evidence found in earlier studies that individual and family characteristics affect the relationship between siblings across the life span, and that experiences differ depending on the era in which study participants grew up. The need to include all family members in future planning for their sibling with intellectual disability was highlighted by the participants in this study. An assumption that they would be providing care or support for their sibling with intellectual disability when parents were
no longer able to was a concern for the participants because they felt a sense of responsibility to their sibling, especially when no formal plans were in place. The sense of concern regarding future care was often felt simultaneously with concern for ageing parents. This study demonstrated the importance of including all siblings in future planning, at a time when joint decisions with parents can be made about the support and future care for their sibling with intellectual disability. Decision-making at a time of great stress or grief may not produce the results that are optimal for all family members. This study provides evidence that disability service providers need to work in harmony with families to achieve the best possible outcomes for all family members, especially as they age.

Throughout the discussion chapter it has been acknowledged that the older age groups of participants in this study and the contemporary and changing attitudes regarding disability since the mid-twentieth century may have affected the findings. The context of care, deinstitutionalisation and the longer life expectancy of people with disability have all produced dramatic effects on service provision over the last several decades. Nevertheless, the findings from this study contribute to the understanding of having a sibling with intellectual disability from a life-span perspective and the experiences that have shaped relationships in childhood and adulthood, from the perspective of adults living in WA in the early part of the twenty-first century.

7.2 Limitations of this study

Some potential limitations to this study should be identified. In the study design I did not allow time for a pilot of the survey to be conducted prior to the commencement of data collection. Piloting the survey may have strengthened the survey responses by ensuring that the questions were relevant and would be generally understood, and it may have picked up the ‘skip logic’ error in the survey and corrected it prior to participants completing the survey. The siblings in this study self-selected to participate; therefore, there is a possibility that some of the responses in the survey may be an exaggeration of the amount of contact and closeness between siblings, since participants may have wished to ‘present a good impression’ for the researcher. Since this study did not collect data from the sibling with intellectual disability, the accounts of the connectedness and relationships were provided only from the viewpoint of the sibling without disability.

The research design and recruitment process did not address the difficulty in engaging harder to reach populations such as Aboriginal and Torres Strait Islander people, those who are non-English speaking and those who have poor literacy. There
were no responses from Aboriginal or Torres Strait Islander people in the study sample. The survey and interview questions also did not collect data from the participants regarding their culture (except for identification as Aboriginal or Torres Strait Islander), limiting the generalisability of the results to other cultures. It was also identified in Chapter 6 that the study sample contained a gender imbalance, which potentially could have influenced the findings. All participants needed to be able to write in English with some competency to complete the survey, and as the majority of recruitment was conducted via social media and access to a computer was required, this may have restricted participants with low literacy, or with no access to a computer or a stable internet connection.

It was identified in Chapter 6 that the older age groups of the participants in this study could potentially have influenced the responses to questions relating to experiences with service providers and the provision of information while they were growing up. As a result of disability reform and the introduction of rights-based legislation both internationally and nationally since the mid-to-late-twentieth century, experiences of people in a younger cohort may differ. It is also not unreasonable to conclude that responses from the participants in the older age groups in this study are likely to have been influenced by the passage of time, and recollections of some of their experiences influenced by the lack of service provision in the decades in which they grew up and the changing social construction of disability over time.

In spite of these limitations, the findings from this study provide evidence of the individual and family characteristics and lived experiences that influence sibling relationships and decision-making across the life span when a sibling has ID. The findings from this study provide evidence to support recommendations for policy, practice and further research.

7.3 Recommendations

7.3.1 Recommendations for policy and practice

The implications for policy and practice were presented in Chapter 6 as discussion relating to the mixed methods research question. Practice in the disability services sector has been heavily legislated to protect human rights, especially since the mid-twentieth century with the introduction of rights-based legislation internationally (Chenoweth, 2000) and the introduction of the National Disability Services Standards in Australia in the late-twentieth century (Simpson et al., 2019).
As a result of the literature review, findings and analysis of the data collected for this study, recommendations can be made regarding policy and practice in disability services. A summary of the recommendations for policy and practice include:

a) Policy and legislation specifically acknowledge siblings as family members, a part of the ‘natural network’ in the lives of their sibling with intellectual disability. The NDIS must be made accountable to the families the scheme was intended to serve to ensure that siblings are included in early intervention strategies, future planning and advocacy throughout the life span.

b) Disability service providers recognise siblings as integral to the family unit and understand the sibling relationship and the importance of the role of siblings when parents are no longer able to provide care. Policymakers need to consider the evidence from research, such as this study and others (Becker, 2007; Meltzer, 2017; Moore & McArthur, 2007; Smyth et al., 2011) that highlight the importance of the sibling relationship.

c) Disability service providers actively engage and involve siblings, utilising them as a valuable resource for supported decision-making for their sibling with intellectual disability across the life span, especially when planning for the future.

d) Early intervention services consider what the family needs as support and include the other children in the family in this equation. The evidence from this study highlighted the importance of all children having access to ‘normal family life’, something that many siblings in this study felt they missed out on because of lack of appropriate support for the family.

e) Augmentative and alternative communication (AAC), assistive technology and access to related allied health practitioners must be made available to all people with disability if required, to enable clear communication between service providers, siblings and other family members. This will support decision-making and provide a voice for people with disability who have limited means of communication, and support sibling relationships across the life span.

7.3.2 Recommendations for further research

The findings from this study and other previous studies (Begun, 1989; Doody et al., 2010) support a controlled sampling process and active recruitment of male participants to validate assumptions in respect of relationship quality and the influence of gender on the sibling relationship when one has ID. Owing to the disproportionate
gender balance of participants and siblings with intellectual disability in this study, the generalisability of the findings is limited regarding gender influence on sibling relationships. From reviewing the literature and analysing the findings of this study, I also recommend that future research and analysis of the influence of gender on sibling relationship quality collect data from the other person in the sibling dyad, the person with disability. This is a core tenet of critical disability studies. A further benefit of a gender-balanced sampling strategy would be to improve understanding of the relationship between gender and the provision of care and support for a sibling with intellectual disability when the sibling without disability is male. This study illustrated that male siblings are most likely to provide care and support to brothers with disability; however, future studies could test the hypothesis that when the only other sibling in the family is male (other than the sibling with intellectual disability), the care relationship is more likely to be based on a sense of responsibility, and gender does not influence the care relationship.

This study has also raised questions about the intention to provide care or support for a sibling with intellectual disability in the future and the translation into actual care when that time arrives. Longitudinal studies could consider the factors that influence the ability to provide care or support and how future caregiving expectations change over the life span from a bioecological perspective. This recommendation aligns with recommendations from earlier studies (Burke et al., 2012; Heller & Arnold, 2010). Future studies could also examine construal theory (Burke et al., 2012), introduced in Chapter 2 and further discussed in the presentation of this study’s findings in Chapter 6, and consider mechanisms to provide support for siblings who intend to provide care for their sibling with intellectual disability when their parents are no longer able to. Since people with disability are now outliving their parents, other support networks are required to ensure that people with disability are given the support they require throughout their lifetime, to realise a greater level of independence and participation in social and economic life. The values and ideals of the NDIS recognise the contribution of siblings to the natural networks of a person with disability, and the importance of the role of siblings as advocates to make enduring and positive change for people with disability (Kendrick et al., 2017). Further research is required that continues to ‘monitor’ the progress of the ideals of the NDIS, so that siblings are supported to ensure that their sibling with intellectual disability has access to ‘reasonable and necessary’ support throughout his or her lifetime (Kendrick et al., 2017).
The findings from this study indicated that families utilise various networks and groups to facilitate social support, assist with access to services and seek communities with positive attitudes and acceptance of a child with intellectual disability. There was evidence to support a premise that the presence of, and support from, members of the extended family may lessen the impact on siblings growing up with a sibling with intellectual disability. The findings in this study regarding extended family were unanticipated, and the generalisability of the findings is limited. I agree with Saxena and Adamsons (2013) suggestion that further research is required to draw conclusions regarding positive outcomes for siblings as a result of support from extended family. Similarly, the findings from this study and earlier research (Marshall et al., 2003; You et al., 2019) support the premise that families with a child with disability may find solace in religious belief, and support from church or church groups. Further research is required to explore this notion.

This study provided evidence that siblings make life decisions as a result of having a sibling with intellectual disability, including about leaving home early and where to live (to stay within close proximity to the family home to support parents or their sibling), and decisions regarding having a family. It is difficult to describe these findings as generalisable in the broader context; however, to improve understanding of their implications, further research could explore these variables to provide a greater understanding of the impact on decisions that siblings make as a result of having a sibling with intellectual disability.

The aim of this study was to gain a greater understanding of siblings’ experiences and the individual and family characteristics that influence relationships and decision-making when they have a sibling with intellectual disability. This study focused on the WA experience, a previously under-researched population in sibling-disability research. Owing to WA’s previous investment in the disability sector, and the established self-directed, individualised support for people with disability under the administration of the WA Disability Services Commission prior to the introduction of the NDIS in Australia in 2013 (Kendrick et al., 2017; Reddihough et al., 2016), the experiences of siblings living in WA were likely to have varied from the experiences of siblings in other states on Australia. Hence, it was important that the voices of WA siblings were heard. This study was able to capture the experiences of siblings who grew up in the mid-to-late twentieth century and in the early twenty-first century in WA, a time of great change and reform for disability services in Australia. The findings
from this study contribute to sibling-disability research by guiding evidence-based
disability practice and policy supporting holistic family inclusion that considers siblings
as intrinsic members of natural support networks for people with intellectual disability.
References


https://www.abs.gov.au


https://www.abs.gov.au


[https://doi.org/10.1177/1468018107073892](https://doi.org/10.1177/1468018107073892)


[https://doi.org/10.1016/j.ridd.2011.01.056](https://doi.org/10.1016/j.ridd.2011.01.056)


[https://doi.org/10.3310/phr04080](https://doi.org/10.3310/phr04080)


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https://doi.org/10.1097/01.mrr.0000191845.65198.d7

Appendices
Appendix 1 — Survey

**Siblings with intellectual disability: Relationships and decision-making**

**Researcher** – Wendy Simpson, PhD Candidate, Edith Cowan University

**Supervisors**

- Dr Vicki Banham, Associate Dean, School of Arts and Humanities, Telephone: 6304 5530, Email: v.banham@ecu.edu.au
- A/Prof Trudi Cooper, School of Arts and Humanities, Telephone: 6304 5637, Email: t.cooper@ecu.edu.au

**What is the study about and who will take part?**

This research project is being undertaken as part of the requirements of a PhD at Edith Cowan University. We want to know about the relationships between adult siblings when one has an intellectual/cognitive/developmental disability or autism. Siblings may have a coexisting physical disability. The study is open to residents of the Perth metropolitan area and the Peel region of Western Australia. Your sibling with disability may be living or deceased.

**Why is the study important and who will benefit?**

The study is important because it adds to previous research about adult siblings. We want to understand how siblings can contribute to the life of a sibling with disability. This will benefit all families and siblings who have a family member with disability.

**What will I need to do?**

Complete the online survey. If you are interested in a follow-up interview, please give your name and contact details at the end of the survey. Participation in the study is voluntary.

**Are there any risks to participating?**

If you become distressed at any stage during the survey you are able to stop at any point and continue at a later date. You may withdraw from the study at any time and any information gathered will not be used in the study. If you feel that you need someone to talk to about your distress, you can contact RUAH COMMUNITY SERVICES on 9485 3939 for access to counselling services in your location.

**How is my privacy guaranteed and what happens to the results?**

You do not need to provide your details to complete the survey. If you do provide your name and contact details for the purpose of the follow-up interview, your responses will be confidential. All survey and interview data will be deidentified following transcriptions of the follow-up interviews. All data will be destroyed after a period of 7 years. The results of the study will be included in the PhD thesis, and may be used at conference presentations and published in academic journals.

**Who has approved the study?**

The study has been approved by the Human Research Ethics Committee at Edith Cowan University. If you have any concerns or complaints about the study, please contact Research Ethics Officer, Edith Cowan University, Phone: 6304 2170 Email: research.ethics@ecu.edu.au

**Who do I contact for further information?**

If you have any questions regarding the study, please contact the Researcher on 0403 355 114, or by email at ecudisabilitystudy@gmail.com
Continuing with this survey indicates that you have read and understood the above information, and consent to participating in this survey.

Please provide your postcode ____________________

Q1. Aboriginal or Torres Strait Islander status
   - I identify as Aboriginal
   - I identify as Torres Strait Islander
   - I identify as Aboriginal and Torres Strait Islander
   - I do not identify as Aboriginal or Torres Strait Islander

Q2. My age
   - 18 - 30 years of age
   - 31 - 50 years of age
   - 51 - 70 years of age
   - over 70 years of age

Q3. My sibling with disability age. If you have more than one sibling with disability in your family, answer the survey about your eldest sibling with disability.
   - 18 - 30 years of age
   - 31 - 50 years of age
   - 51 - 70 years of age
   - over 70 years of age

Q4. My sibling with disability is
   - older than me
   - younger than me
   - same age as me

Q5. Other siblings in my family (other than my sibling with disability and me)
   - none
   - 1
   - 2
   - 3 or more
   If any of your other siblings also have a disability, please indicate how many
Q6. My gender
- male
- female
- transgender
- prefer to self-describe
- prefer not to answer

Q7. My sibling with disability gender
- male
- female
- transgender
- prefer to self-describe
- prefer not to answer

The following questions will give you an opportunity to tell us about your sibling.

Q8. Briefly state the type of disability your sibling has. (i.e. autism, intellectual disability, Down syndrome with intellectual disability etc).

__________________________

Q9. Does your sibling have the ability to make reasoned/informed decisions for themselves?
- definitely yes
- probably yes
- might or might not
- probably not
- definitely not

Q10. My sibling with disability lives most of the time
- at home with parents
- in supported group home accommodation
- in supported accommodation by themselves
- independently without paid support
- without paid support with one or more other people (with or without disability)
- with me
- with another family member (other siblings, grandparents, aunt or uncle, or other relatives)
- with a partner
- other (for example in aged care, foster care or hospital)
The following questions will give you an opportunity to tell us about you.

Q11. Your relationship status

- I am in a relationship and my partner lives with me
- I am in a relationship but I do not live with my partner
- I am not in a relationship
- I am divorced or separated from my partner
- I would rather not say

Q12. Your children, dependants or other people you provide care for (You can choose more than one).

- I do not have any children or dependants who live with me
- I have children or dependants who live with me
- I provide care for others
- I have an adult child/children but they are not dependants
- I have an adult child/children who do not live with me but require some form of support from me
- I have grandchildren but do not provide permanent or long term care for them
- Other ________________________________________________

Q13. Your work status -

- I am not in the paid workforce (unemployed)
- I work part time or casual
- I work full time
- I am retired
- I am studying
- Other ________________________________________________

Q14. Briefly describe your job title/role, or if you no longer work, what was your most worked job title/role?

________________________________________________________________
________________________________________________________________
________________________________________________________________
These questions allow you to tell us about your experiences and write your answers in the box. Please be open and honest with your answers.

Q15. Briefly describe your experiences as a child growing up with a sibling with disability.
____________________________________________________________________
____________________________________________________________________

Q16. Did you experience bullying or teasing from other children as you were growing up as a result of having a sibling with disability?

- no
- maybe, I don’t remember
- yes

Q17. Do you think that having a sibling with disability affected (limited) some of your childhood experiences? For example - limited weekend or holiday outings.

- no
- maybe, I don’t remember
- yes

Q18. While growing up, did you understand your sibling’s disability? Were you provided with information you wanted or needed about your sibling’s disability?

____________________________________________________________________

Q19. Have you ever accessed support services for yourself in regards to your sibling with disability, such as counselling or peer support? If so, please indicate which services.

____________________________________________________________________

These questions give you an opportunity to tell us about your relationship with your sibling with disability at the moment.

Q20. How often do you contact your sibling? This may be by phone, email or in person.

- more than once per week
- about once per week
- once or twice per month
- once per month or less
- my sibling lives with me
Q21. Briefly describe your relationship with your sibling at the moment.

________________________________________________________________
________________________________________________________________
______________________________________________________________

Q22. What sort of support do you provide to your sibling? Select as many that apply to you.

- physical support with daily living, including personal care
- physical support with transport, outings
- practical home support (for example - housework, shopping)
- support with financial planning, booking of appointments, legal support
- my sibling didn’t require any physical or practical support
- emotional/mental support
- any additional support

Q23. Does your sibling with disability access paid support from service providers? 

- Yes
- Maybe
- Not sure (skip the next question)
- No (skip the next question)

Q24. Select the type of support your sibling currently receives from paid service providers. Select as many that apply.

- physical support with daily living, including personal care
- physical support with transport, outings
- practical home support (for example - housework, shopping)
- support with financial planning, booking of appointments, legal support
- support in the workplace or supported work (sheltered workshop)
- unsure

Q25. Do you expect that you will need to provide physical, emotional or practical support to your sibling with disability in the future?

- yes
- probably yes
- unsure
- probably not (skip the next question)
- no (skip the next question)
Q26. Please explain why you think you will need to provide future care. For example, your sibling currently lives with parents, or your siblings care needs are increasing.
__________________________________________
__________________________________________

Q27. Do you or another of your siblings act as Power of Attorney or Legal Guardian for your sibling with disability?

- [ ] yes
- [ ] no
- [ ] unsure
- [ ] the Office of the Public Advocate acts as the legal guardian for my sibling

Thank you for participating in this survey.

If you have any questions regarding the study, please contact the researcher on 0403 355 114, or by email at wsimpso0@our.ecu.edu.au

If you are interested in participating in a follow-up interview, please provide your name, phone number and email address (if you have one). You DO NOT need to complete this if you do not wish to be interviewed. Not all people who provide their contact details will be interviewed. Your privacy is guaranteed. If you do provide your name and contact details, your responses will be confidential.

Name ______________________________________
Phone number __________________________ Email address ____________________
Appendix 2 — Interview Guide

Siblings with intellectual disability: Relationships and decision-making

Interviewer – Wendy Simpson, PhD Candidate

Thank you for meeting with me today. As you recall, you completed an online survey as a part of the research I am doing about the experiences of siblings who have a sibling with an intellectual disability. You provided your details on that survey consenting to being contacted for this interview. This interview is the second stage of the research.

Interviewee is given a copy of the Information Sheet and Consent form. Once understood and signed, the following script begins -

Recording on

1. Firstly, can you tell me a bit about you and the siblings in your family?
   i. Prompt: How many children in the family?
   ii. Prompt: What are their genders; age gaps; where do you fit in the order?
   iii. Prompt: What is your relationship like with your brothers/sisters without disability?

2. Can you tell me a little bit about your sibling with disability?
   i. Prompt: Can you tell me if you remember life in your family before your sibling with intellectual disability was born?
   ii. If yes - Prompt: Can you explain how/if your life/family life changed when your sibling with intellectual disability was born?
   iii. If no – go to question 3.

3. In the survey, you answered a question about your experiences growing up with a sibling with an intellectual disability. For the purpose of this recording, would you like to tell me about your experiences?
   i. Prompt: Why does that stand out in your memory?
   ii. Prompt: How do you believe that your experiences affected your relationship with your brother/sister with disability? As a child? As an adult?
   iii. Prompt: Do you believe that having a sibling with intellectual disability in the family affected your relationships with your other siblings? How?
   iv. Prompt: Effect on schooling, social life?

4. You also answered a question in the survey about the information or knowledge you had when you were growing up about your sibling’s disability. Can you briefly tell me about your understanding of your sibling’s disability and the information you received while you were growing up? How did you get this information, at what age, who told you?
   i. Prompt: Do you believe that your knowledge/understanding affected your relationship with your brother/sister with disability? As a child? As an adult?
ii. Prompt: How do you believe it affected your relationship with sibling with intellectual disability?

iii. Prompt: How do you assess the relevance of the information you received? What would it be?

5. What did help, what do you think might have helped (with the benefit of hindsight)?

6. In the survey, you were asked to tell me what your job title/role is, or if you no longer work, what was your most worked job title/role?. **Can you tell me how you made your career choice?** (Ask what their career/job role is, and what industry/sector if not explained).

7. Is there anything else you would like to say?

*Recording off*

Thank you for agreeing to today’s interview. The recording will be transcribed by a qualified transcriber who has also signed a confidentiality agreement with me. This was a part of the ethics approval at the university.

Once transcribed, I will be in contact with you to provide you a copy of the transcription, to give you an opportunity to confirm that it is an accurate representation of the interview. Following this process, the transcriptions will be deidentified and coded so the transcriptions will no longer be identifiable.

Prior to transcription, if you choose to withdraw from this study, your recorded interview and any notes taken during the interview will be destroyed and will not be used in this study.
## Appendix 3 — Literature

<table>
<thead>
<tr>
<th>Topics</th>
<th>Subtopics</th>
<th>Main work</th>
</tr>
</thead>
<tbody>
<tr>
<td>Definitions of disability</td>
<td></td>
<td>Barnes &amp; Mercer, 1996, 2003; Murray &amp; Lopez, 1994; Pfeiffer, 1998; WHO, 1980, 2002; Bury, 1996; Berghs et al., 2016; Government of Western Australia, 1993; Owens, 2015; Department of Communities, 2018</td>
</tr>
<tr>
<td>Factors impacting relationships</td>
<td>Parenting</td>
<td>McHale et al, 1989 (McHale &amp; Pawletko, 1992 is the same data set); Davys et al, 2016; Kovshoff, 2017; McHale et al, 2016 (literature review); Orsmond et al, 2009; Orsmond &amp; Seltzer, 2000; Burke et al, 2016</td>
</tr>
<tr>
<td></td>
<td>Gender</td>
<td>Akiyama et al, 1996; Begun &amp; Blacher, 2011; Burbridge &amp; Minnes, 2014; Cuskelly, 2016; Doody et al., 2010; Griffiths &amp; Unger, 1994; Greenburg et al., 1999; McGraw &amp; Walker, 2007; Burke et al., 2012; Heller &amp; Kramer, 2009; Orsmond &amp; Seltzer, 2000; Burke et al, 2016</td>
</tr>
<tr>
<td></td>
<td>Characteristics of sibling’s disability</td>
<td>Greenberg et al, 1999; Rossetti &amp; Hall, 2015; Doody et al., 2010; Hodapp &amp; Urbano, 2007; Orsmond &amp; Seltzer, 2007; Orsmond et al., 2009; Tomeny et al., 2017; Burke et al, 2012; Seltzer et al, 1997; Mulroy et al, 2008</td>
</tr>
<tr>
<td></td>
<td>Family structure</td>
<td>Breslau, 1982; Begun, 1989; Burke, 2016; Mulroy et al., 2008;</td>
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<tr>
<td></td>
<td>Geographic proximity to SWD</td>
<td>Greenberg et al., 1999; Orsmond &amp; Seltzer, 2007; Doody et al., 2010; Tomeny et al, 2017; Burke et al., 2012; Heller &amp; Kramer, 2009; Dw et al., 2011; Perkins &amp; LaMartin, 2012</td>
</tr>
<tr>
<td></td>
<td>Young carers</td>
<td>Becker, 2007; Moore &amp; McArthur, 2007; Smyth et al., 2011; McDougall et al., 2018; Tozer et al., 2013; Meltzer, 2017</td>
</tr>
<tr>
<td></td>
<td>Expectation of future care</td>
<td>Davys et al., 2011; Bigby, 1997; Dew et al., 2014; Cuskelly, 2016; Burke et al., 2012; Doody et al., 2010; Greenberg et al, 1999; Tozer &amp; Atkin, 2015</td>
</tr>
<tr>
<td>The experience of having a SWD</td>
<td>Challenges</td>
<td>Seligman and Darling, 2007; Brown et al., 2017; Atkin &amp; Tozer, 2013; Giallo et al., 2012; Graff et al., 2012; Seltzer et al., 1997; Tozer and Atkin, 2015; Hodapp &amp; Urbano, 2007; Orsmond &amp; Seltzer, 2007; Ferraioli &amp; Harris, 2009; Taylor et al., 2008; Glasberg, 2000; Carr, 2005</td>
</tr>
<tr>
<td></td>
<td>The positive experiences</td>
<td>Cuskelly &amp; Gunn, 2003; Giallo et al., 2012; Greenberg et al., 1999; Seltzer et al., 1997; Tozer and Atkin, 2015; Graff et al., 2012; Rossiter &amp; Sharpe, 2001; Cuskelly et al., 2016;</td>
</tr>
<tr>
<td></td>
<td>Choice of career</td>
<td>Chambers, 2007; Davys et al., 2016; Marks et al., 2005; Martins, 2007; Seligman &amp; Darling, 2007</td>
</tr>
<tr>
<td></td>
<td>Learning about sibling’s disability</td>
<td>Seligman &amp; Darling, 2007; Skotko &amp; Levine, 2006; Love et al., 2012; Davys et al., 2016; Perkins and LaMartin, 2012</td>
</tr>
<tr>
<td></td>
<td>Formal services and support for siblings</td>
<td>Atkin &amp; Tozer, 2013; Davys et al., 2016; Tozer &amp; Atkin, 2015; Siblings Australia, 2017; Rawson, 2010; Orsmond et al., 2009; Ying Li, 2006; Arnold et al., 2012; Heller &amp; Kramer, 2009</td>
</tr>
</tbody>
</table>
Appendix 4 — Map of the Greater Perth Statistical Area

Perth (Greater Capital City Statistical Area)

The following map is a representation of the regions that will be included in the study. According to the ABS, the Greater Capital City Statistical Area of Perth encompasses the metropolitan area of Perth and the Peel region (Australian Bureau of Statistics, 2016a).

(Australian Bureau of Statistics, 2016a)
Appendix 5 — Information sheet for social media posts (Stage 1)


This research project is being undertaken as part of the requirements of a PhD at Edith Cowan University. Supervisors –

Dr Vicki Banham, Associate Dean       A/Prof Trudi Cooper,
School of Arts and Humanities,          School of Arts and Humanities
Telephone: 6304 5530                   Telephone: 6304 5637
Email:v.banham@ecu.edu.au            Email:t.cooper@ecu.edu.au

What is the study about and who will take part?

The study is to find out about the relationships between adult siblings when one has an intellectual/cognitive/developmental disability or autism. Siblings may have a coexisting physical disability. The study is open to residents of the Perth metropolitan area and the Peel region of Western Australia. Your sibling with disability may be living or deceased.

Why is the study important and who will benefit?

The study is important because it adds to previous research about adult siblings. We want to understand how siblings can contribute to the life of a sibling with disability. This will benefit all families and siblings who have a family member with disability.

What will I need to do?

Complete the online survey. If you are interested in a follow-up interview, please give your name and contact details at the end of the survey. Participation in the study is voluntary.

Are there any risks to participating?

If you become distressed at any stage during the survey you are able to stop at any point and continue at a later date. You may withdraw from the study at any time and any information gathered will not be used in the study.

How is my privacy guaranteed and what happens to the results?

You do not need to provide your details to complete the survey. If you do provide your name and contact details, your responses will be confidential. All data will be destroyed after a period of 7 years. The results of the study will be included in the PhD thesis, and may be used at conference presentations and published in academic journals.

Who has approved the study?

The study has been approved by the Human Research Ethics Committee at Edith Cowan University. If you have any concerns or complaints about the study, please contact Research Ethics Officer, Edith Cowan University, Phone: 6304 2170 Email: research.ethics@ecu.edu.au

Who do I contact for further information?

If you have any questions regarding the study, please contact the Researcher on 0403 355 114, or by email at wsimpso0@our.ecu.edu.au
Appendix 6 — Information sheet for Interviews (Stage 2)

**Research title:** Siblings with intellectual disability: Relationships and decision-making

**Name of researcher** — Wendy Simpson, PhD Candidate, Edith Cowan University.

This research project is being undertaken as part of the requirements of a PhD at Edith Cowan University

**Name of Supervisor/s** —

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Contact Information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dr Vicki Banham</td>
<td>Associate Dean</td>
<td><a href="mailto:v.banham@ecu.edu.au">v.banham@ecu.edu.au</a></td>
</tr>
<tr>
<td>A/Prof Trudi Cooper</td>
<td>School of Arts and Humanities</td>
<td><a href="mailto:t.cooper@ecu.edu.au">t.cooper@ecu.edu.au</a></td>
</tr>
</tbody>
</table>

**What is the study about and who will participate?**

The study is to find out about the relationships between adult siblings when one has an intellectual/cognitive/developmental disability or autism. Siblings may have a coexisting physical disability. The study is open to residents of the Perth metropolitan area and the Peel region of Western Australia. Your sibling with disability may be living or deceased.

**Why is the study important and who will it benefit?**

The study is important because it adds to the previous research that has been done to understand siblings and how they can contribute to the life of their sibling with disability. This will benefit all families and siblings who have a family member with disability.

**What will I need to do?**

The study requires you to participate in a face to face or telephone interview. If I meet with you face to face I will record the interview and transcribe later, or they will be transcribed by a third party. If the interview is by telephone, I will take notes as we talk. I will provide you with a transcript or notes of the interview so you can verify the content.

**How is my privacy guaranteed?**

The interview will be audiotaped and transcribed at a later date, or notes will be taken, however all documentation will be deidentified and information gathered will remain confidential. Responses will be coded in a number format, and will not use any names or addresses. All recordings and documentation will be stored in a secure location at the university, which will be destroyed after a period of 7 years.

**Are there any risks to participating?**

All interviews will be conducted sensitively and in confidence. If you become distressed at any stage you may discontinue the interview and continue at a later date. You may withdraw from the study at any time and any information gathered will be destroyed. In addition, I have information and contacts for counselling or support from independent community organisations. This information will be provided at the time of the interview.

**Do I have to take part, and what is involved?**

Participation is entirely voluntary and you may withdraw at any time without giving a reason. This research is not connected to service provision. It is expected that the interview will take approximately 1 hour. A second interview may be required.
Who has approved the study?
The study has been approved by the Human Research Ethics Committee at Edith Cowan University. If you have any concerns or complaints about the study, please contact -
Research Ethics Officer, Edith Cowan University, Phone: 6304 2170, Email: research.ethics@ecu.edu.au

Who do I contact for further information?
If you have any specific questions regarding the study, please contact me on [redacted] or by email at wsimpso0@our.ecu.edu.au

Can I see the final results of the study?
If you would like a copy of the results of the study, you can let me know at the time of your interview or by contacting me at any time. In addition to the thesis required for the PhD, the results of the study may be used for conference presentations or published in academic journals.

What do I do now?
Sign the consent form in my presence and I will also sign as the researcher.

Thank you for taking the time to learn about this study and your consideration to participate. Please keep a copy of this Information Sheet.

Kind regards,

Wendy Simpson
PhD Candidate
Appendix 7 — Consent form (for Interview)

Research title –
Siblings with intellectual disability: Relationships and decision-making

Researcher –
Wendy Simpson,
Contact wsimpso0@our.ecu.edu.au

Declaration –

- I have been provided with an information sheet explaining the research project, and I understand this.
- I have been given the opportunity to ask questions and all my questions have been answered satisfactorily.
- I am aware that I can contact Associate Professor Trudi Cooper if I have any further queries, or if I have concerns or complaints. I have been given contact details in the Information Letter.
- I understand that this project will involve participation in an interview.
- I am aware that the interview will be the audio-taped and will be transcribed by the researcher or a third party.
- It has been explained to me that audio recording and transcriptions of the interview will be stored securely on the university premises for 7 years after completion of the project with no identifying names.
- I understand that I may withdraw at any time without given reason and without prejudice.
- I agree that research data gathered for the study may be published, provided no names or other identifying information is used.

Name of participant ……………………………………………………………………

Participant signature …………………………………………… Date…………………

I ……………………………………… have explained the research study to be conducted, and the implications of participation and requirements of the study to the volunteer. I believe that the volunteer understands and has given consent to participate.

Name of researcher …………………………………………………………………

Researcher signature………………………………………………….. Date…………………
Appendix 8 — Survey Results

**Siblings with intellectual disability: Relationships and decision-making**

Notes:
- Options in the survey that had no responses are not shown (with the exception of Q3).
- Responses from qualitative (open text) questions (14, 15, 18, 19, 21 & 26) are presented in Chapter 4 of the thesis.
- Some questions were not shown to participants who had a SWD no longer living (21, 23, 24, 25, 26).
- Due to an early error in the survey ‘skip logic’, 9 participants did not see question 25 or 26.
- SWD is used as an abbreviation in this table for sibling with intellectual disability.

<table>
<thead>
<tr>
<th>Question</th>
<th>Number (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Q1 Aboriginal or Torres Strait Islander status</strong></td>
<td></td>
</tr>
<tr>
<td>I do not identify as Aboriginal or Torres Strait Islander</td>
<td>77</td>
</tr>
<tr>
<td><strong>Q2 My age</strong></td>
<td></td>
</tr>
<tr>
<td>18 - 30 years of age</td>
<td>21</td>
</tr>
<tr>
<td>31 - 50 years of age</td>
<td>31</td>
</tr>
<tr>
<td>51 - 70 years of age</td>
<td>24</td>
</tr>
<tr>
<td>over 70 years of age</td>
<td>1</td>
</tr>
<tr>
<td><strong>Q3 My sibling with disability age</strong></td>
<td></td>
</tr>
<tr>
<td>18 - 30 years of age</td>
<td>24</td>
</tr>
<tr>
<td>31 - 50 years of age</td>
<td>27</td>
</tr>
<tr>
<td>51 - 70 years of age</td>
<td>20</td>
</tr>
<tr>
<td>over 70 years of age</td>
<td>0</td>
</tr>
<tr>
<td>My sibling is no longer living</td>
<td>6</td>
</tr>
<tr>
<td><strong>Q4 My sibling with disability is/was</strong></td>
<td></td>
</tr>
<tr>
<td>Older than me</td>
<td>32</td>
</tr>
<tr>
<td>younger than me</td>
<td>44</td>
</tr>
<tr>
<td>same age as me</td>
<td>1</td>
</tr>
<tr>
<td><strong>Q5 Other siblings in my family (other than my sibling with disability and me)</strong></td>
<td></td>
</tr>
<tr>
<td>none</td>
<td>20</td>
</tr>
<tr>
<td>1</td>
<td>27</td>
</tr>
<tr>
<td>2</td>
<td>13</td>
</tr>
<tr>
<td>3 or more</td>
<td>17</td>
</tr>
<tr>
<td><strong>Q6 My gender</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>16</td>
</tr>
<tr>
<td>Female</td>
<td>60</td>
</tr>
<tr>
<td>Preferred not to answer</td>
<td>1</td>
</tr>
<tr>
<td><strong>Q7 My sibling with disability gender</strong></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>47</td>
</tr>
<tr>
<td>Female</td>
<td>29</td>
</tr>
<tr>
<td>Preferred not to answer</td>
<td>1</td>
</tr>
<tr>
<td><strong>Q8 Briefly state the type of disability your sibling has or had. (i.e. autism, intellectual disability, Down syndrome with intellectual disability etc)</strong></td>
<td></td>
</tr>
<tr>
<td>Intellectual disability</td>
<td>38</td>
</tr>
<tr>
<td>Autism</td>
<td>12</td>
</tr>
<tr>
<td>Down Syndrome</td>
<td>13</td>
</tr>
<tr>
<td>other intellectual or developmental disability</td>
<td>14</td>
</tr>
<tr>
<td><strong>Q9 Does/did your sibling have the ability to make reasoned/informed decisions for themselves?</strong></td>
<td></td>
</tr>
<tr>
<td>Definitely not</td>
<td>17</td>
</tr>
<tr>
<td>Definitely yes</td>
<td>12</td>
</tr>
<tr>
<td>Might or might not</td>
<td>21</td>
</tr>
</tbody>
</table>
Q10 My sibling with disability lives/lived most of the time:

<table>
<thead>
<tr>
<th>Description</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>My sibling lives at home with parents</td>
<td>33</td>
</tr>
<tr>
<td>My sibling lives in supported group home accommodation</td>
<td>22</td>
</tr>
<tr>
<td>My sibling lives in supported accommodation by themselves</td>
<td>11</td>
</tr>
<tr>
<td>My sibling lives independently without paid support with one or more other people</td>
<td>1</td>
</tr>
<tr>
<td>My sibling lives with me</td>
<td>1</td>
</tr>
<tr>
<td>My sibling lives with another family member</td>
<td>2</td>
</tr>
<tr>
<td>Other</td>
<td>7</td>
</tr>
</tbody>
</table>

Q11 Your relationship status

<table>
<thead>
<tr>
<th>Description</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am in a relationship and my partner lives with me</td>
<td>49</td>
</tr>
<tr>
<td>I am in a relationship but I do not live with my partner</td>
<td>3</td>
</tr>
<tr>
<td>I am not in a relationship</td>
<td>15</td>
</tr>
<tr>
<td>I am divorced or separated from my partner</td>
<td>9</td>
</tr>
<tr>
<td>I would rather not say</td>
<td>1</td>
</tr>
</tbody>
</table>

Q12 Your children, dependants or other people you provide care for (You can choose more than one).

<table>
<thead>
<tr>
<th>Description</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>I do not have any children or dependants who live with me</td>
<td>38</td>
</tr>
<tr>
<td>I have children or dependants who live with me</td>
<td>31</td>
</tr>
<tr>
<td>I provide care for others</td>
<td>9</td>
</tr>
<tr>
<td>I have an adult child/children but they are not dependants</td>
<td>8</td>
</tr>
<tr>
<td>I have an adult child/children who do not live with me but require some form of support</td>
<td>6</td>
</tr>
<tr>
<td>I have grandchildren but do not provide permanent or long term care for them</td>
<td>2</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
</tr>
</tbody>
</table>

Q13 Your work status -

<table>
<thead>
<tr>
<th>Description</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am not in the paid workforce (unemployed)</td>
<td>5</td>
</tr>
<tr>
<td>I work part time or casual</td>
<td>29</td>
</tr>
<tr>
<td>I work full time</td>
<td>24</td>
</tr>
<tr>
<td>I am retired</td>
<td>7</td>
</tr>
<tr>
<td>I am studying</td>
<td>3</td>
</tr>
<tr>
<td>I volunteer</td>
<td>2</td>
</tr>
<tr>
<td>Carer for family member</td>
<td>1</td>
</tr>
<tr>
<td>Stay at home mum</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
</tr>
</tbody>
</table>

Q14 Briefly describe your job title/role, or if you no longer work, what was your most worked job title/role?

Results presented in Chapter 4 – Results of phase one data analysis

Q15 Please describe your experiences as a child growing up with a sibling with disability.

<table>
<thead>
<tr>
<th>Initial coding topics</th>
<th>Frequency</th>
<th>Main themes</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Normal childhood</td>
<td></td>
<td>Positive childhood</td>
<td>30</td>
</tr>
<tr>
<td>Growing up with a SWD was a positive experience.</td>
<td>14</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>16</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Developed independence/grew up fast</td>
<td>14</td>
<td>Independence &amp;</td>
<td>23</td>
</tr>
<tr>
<td>More understanding/compassionate</td>
<td>9</td>
<td>maturity</td>
<td></td>
</tr>
<tr>
<td>SWD had parent’s attention/SWD focus of attention</td>
<td>20</td>
<td>SWD main focus in</td>
<td>29</td>
</tr>
<tr>
<td>Needs/behaviours of SWD limited family outings/activities</td>
<td>8</td>
<td>family</td>
<td></td>
</tr>
<tr>
<td>Jealousy</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Childhood was challenging</td>
<td>7</td>
<td>Negative childhood</td>
<td>20</td>
</tr>
<tr>
<td>Childhood was hard</td>
<td>7</td>
<td>experiences</td>
<td></td>
</tr>
<tr>
<td>Childhood was difficult</td>
<td>6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Initial coding topics</td>
<td>Frequency</td>
<td>Main themes</td>
<td>Frequency</td>
</tr>
<tr>
<td>-------------------------------------------------</td>
<td>-----------</td>
<td>-------------------------------------------------</td>
<td>-----------</td>
</tr>
<tr>
<td>Yes/fully understood</td>
<td>22</td>
<td>Provided with information and understood disability</td>
<td>37</td>
</tr>
<tr>
<td>Parents explained everything</td>
<td>13</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Enough information</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes, knew no different</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Not until older/adulthood</td>
<td>3</td>
<td>Some understanding</td>
<td>21</td>
</tr>
<tr>
<td>Knew they were ‘special’/’different’</td>
<td>9</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Limited information</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Believe so – no memories of wanting to know more</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mostly</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some information but it wasn’t discussed</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>10</td>
<td>No information or understanding</td>
<td>16</td>
</tr>
<tr>
<td>Not really – linked to diagnosis</td>
<td>6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Received counselling</td>
<td>1</td>
<td>Received support</td>
<td>1</td>
</tr>
<tr>
<td>Worse when SWD was older</td>
<td>1</td>
<td>Decline in abilities of SWD</td>
<td>1</td>
</tr>
<tr>
<td>No response</td>
<td>1</td>
<td></td>
<td>1</td>
</tr>
</tbody>
</table>

Q19 Have you ever accessed support services for yourself in regards to your sibling with disability, such as counselling or peer support? If so, please indicate which services.

Results presented in Chapter 4 – Results of phase one data analysis

Q20 How often do you/did you contact your sibling? This may be by phone, email or in person.

<table>
<thead>
<tr>
<th>How often do you contact your sibling?</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>about once per week</td>
<td>20</td>
</tr>
<tr>
<td>more than once per week</td>
<td>20</td>
</tr>
<tr>
<td>once or twice per month</td>
<td>14</td>
</tr>
<tr>
<td>once per month or less</td>
<td>16</td>
</tr>
<tr>
<td>my sibling lives with me</td>
<td>7</td>
</tr>
</tbody>
</table>

Q21 Briefly describe your relationship with your sibling at the moment.
<table>
<thead>
<tr>
<th>Q22 What sort of support do you/did you provide to your sibling? Select as many that apply to you.</th>
</tr>
</thead>
<tbody>
<tr>
<td>physical support with daily living, including personal care</td>
</tr>
<tr>
<td>physical support with transport, outings</td>
</tr>
<tr>
<td>practical home support (for example - housework, shopping)</td>
</tr>
<tr>
<td>support with financial planning, booking of appointments, legal support</td>
</tr>
<tr>
<td>mental/emotional support</td>
</tr>
<tr>
<td>any additional support</td>
</tr>
<tr>
<td>my sibling doesn’t require any physical or practical support</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Q23 Does your sibling with disability access paid support from service providers?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>Maybe</td>
</tr>
<tr>
<td>Not sure (skip next question)</td>
</tr>
<tr>
<td>No (skip next question)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Q24 Select the type of support your sibling currently receives from paid service providers. Select as many that apply.</th>
</tr>
</thead>
<tbody>
<tr>
<td>physical support with daily living, including personal care</td>
</tr>
<tr>
<td>physical support with transport, outings</td>
</tr>
<tr>
<td>practical home support (for example - housework, shopping)</td>
</tr>
<tr>
<td>support with financial planning, booking of appointments, legal support</td>
</tr>
<tr>
<td>Support in the workplace or supported work (sheltered workshop)</td>
</tr>
<tr>
<td>Unsure</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Q25 Do you expect that you will need to provide physical, emotional or practical support to your sibling with disability in the future?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>Probably yes</td>
</tr>
<tr>
<td>unsure</td>
</tr>
<tr>
<td>probably not (skip next question)</td>
</tr>
<tr>
<td>no (skip next question)</td>
</tr>
</tbody>
</table>
Q26 Please explain why you think you will need to provide future care. For example, your sibling currently lives with your ageing parents, or your siblings care needs are increasing.

<table>
<thead>
<tr>
<th>Initial coding topics</th>
<th>Frequency</th>
<th>Main themes</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>SWD is ageing/needs are increasing</td>
<td>10 33 4</td>
<td>Ageing</td>
<td>47</td>
</tr>
<tr>
<td>Ageing parents</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Decline in parent’s physical or mental health</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support services are inadequate</td>
<td>11 2</td>
<td>Support services</td>
<td>13</td>
</tr>
<tr>
<td>Can’t trust/unreliable support services/carer</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Love/care what happens to SWD</td>
<td>6 15 2 1 4</td>
<td>Responsibility</td>
<td>28</td>
</tr>
<tr>
<td>Assumed care</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Requested to care</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>The ‘right thing’ to do</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parents/family expectation</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diet needs monitoring</td>
<td>2 6</td>
<td>SWD needs</td>
<td>6</td>
</tr>
<tr>
<td>SWD complex needs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other siblings cannot or will not provide care or support</td>
<td>1 3 9</td>
<td>Lack of other support</td>
<td>13</td>
</tr>
<tr>
<td>No other siblings</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No other family support</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unsure/did not provide an answer</td>
<td></td>
<td>Unsure</td>
<td>3</td>
</tr>
</tbody>
</table>

Q27 Do you/Did you or another of your siblings act as Power of Attorney or Legal Guardian for your sibling with disability?

<table>
<thead>
<tr>
<th></th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>24</td>
</tr>
<tr>
<td>No</td>
<td>46</td>
</tr>
<tr>
<td>Unsure</td>
<td>5</td>
</tr>
<tr>
<td>The Office of the Public Advocate acts as the legal guardian for my sibling</td>
<td>2</td>
</tr>
</tbody>
</table>

End of survey