

Siblings' relational experiences of disability during young adulthood

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Siblings' relational experiences of disability during young adulthood

Ariella Meltzer

A thesis in fulfilment of the requirements for the degree of
Doctor of Philosophy



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Arts and Social Sciences

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Sibling relationships are formative influences in many people's everyday lives. Yet where one sibling has a disability, studies have typically focused on the psycho-emotional outcomes of and caregiving done by siblings of people with disabilities, rather than looking at how disability figures in the everyday relations that siblings both with and without disabilities share. Thus, even though it may be influential, little is known about siblings' everyday relational experience of disability. This is especially the case during young adulthood, a time when siblings may undergo significant changes and transitions.

Using a sociological, relational and phenomenological approach, this qualitative study begins to address this research gap. The study draws on the accounts of 25 young adult siblings with disabilities and 21 without disabilities (aged 15-29), using accessible and relationally informed methods. Siblings took part by interview or documented contribution, either jointly, separately or alone.

Two streams of findings highlight siblings' everyday relational experience of disability. Firstly, the study found that disability is formative within siblings' everyday relations; for example, how they talk or act together. However, disability is nevertheless enacted within a scope of relations that are normative to siblings irrespective of disability. Disability's formative influence is also subject to siblings' life-stage in young adulthood, to the contemporary conditions of society and to each sibling's position and perception as either a sibling with or without a disability. Thus, disability is relationally *influenced* even as it *influences* sibling relationships.

Secondly, the findings explore some overall felt experiences that arise from disability's presence in the sibling relationship. Using the concept of 'relationality' to conceptualise these experiences, the findings articulate how disability may – under different conditions – feel like an unremarkable or intense experience; like an aspect that is hard to see, understand or place within the relationship; like a challenge to siblings' normative horizontal power relations; or like it has more or less of an inherent connection to the sibling relationship.

The thesis finishes by detailing the implications of the findings for further developing evidence, policy and practice in ways that foreground the experience of the sibling relationship.

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Abstract

Sibling relationships are formative influences in many people's everyday lives. Yet where one sibling has a disability, studies have typically focused on the psycho-emotional outcomes of and caregiving done by siblings of people with disabilities, rather than looking at how disability figures in the everyday relations that siblings both with and without disabilities share. Thus, even though it may be influential, little is known about siblings' everyday relational experience of disability. This is especially the case during young adulthood, a time when siblings may undergo significant changes and transitions.

Using a sociological, relational and phenomenological approach, this qualitative study begins to address this research gap. The study draws on the accounts of 25 young adult siblings with disabilities and 21 without disabilities (aged 15-29), using accessible and relationally informed methods. Siblings took part by interview or documented contribution, either jointly, separately or alone.

Two streams of findings highlight siblings' everyday relational experience of disability. Firstly, the study found that disability is formative within siblings' everyday relations; for example, how they talk or act together. However, disability is nevertheless enacted within a scope of relations that are normative to siblings irrespective of disability. Disability's formative influence is also subject to siblings' life-stage in young adulthood, to the contemporary conditions of society and to each sibling's position and perception as either a sibling with or without a disability. Thus, disability is relationally *influenced* even as it *influences* sibling relationships.

Secondly, the findings explore some overall felt experiences that arise from disability's presence in the sibling relationship. Using the concept of 'relationality' to conceptualise these experiences, the findings articulate how disability may – under different conditions – feel like an unremarkable or intense experience; like an aspect that is hard to see, understand or place within the relationship; like a challenge to

siblings' normative horizontal power relations; or like it has more or less of an inherent connection to the sibling relationship.

The thesis finishes by detailing the implications of the findings for further developing evidence, policy and practice in ways that foreground the experience of the sibling relationship.

Plain English summary¹

Why was this study done?

Sibling relationships are important for many people. Where one sibling has a disability, most research has been about the sibling without the disability only. Most research has been about the impact of disability on siblings without disabilities, not about the role disability plays in the sibling relationship. There is a need to know more about what both siblings think about the role of disability in their relationship.

What happened in this study?

This study included 25 siblings with disabilities and 21 siblings without disabilities. It asked about the role of disability in sibling relationships during young adulthood. Some people took part by interview and some sent in a response. Accessibility supports were available.

What did the study find?

The study found that disability has a role in how siblings talk, act and feel about each other.

- Sometimes disability has a big role and sometimes it has a smaller role.
- Other things also have a role, for example, what siblings usually do together, how old siblings are, what services they have available or other characteristics about them.
- Siblings with and without disabilities see the role of disability differently to each other. Siblings without disabilities focus on disability more than siblings with disabilities.

¹ Included as an accessible abstract.

The study also found that disability influenced what the sibling relationship feels like.

- Sometimes siblings feel that disability is just the way things are between them, but sometimes it makes them feel more intense emotions.
- Sometimes siblings feel unsure about how disability fits in to their relationship.
- Sometimes siblings feel that care makes it hard for them to feel like siblings.
- Sometimes siblings feel like their relationship is very much connected to disability and sometimes they feel like it is not really connected to disability.

What is important about the findings?

It is important that policy and practice helps siblings to feel like siblings. It is also important to continue to include siblings both with and without disabilities together in research.

Presentations

Meltzer, A. (2014) *Care, disability and everyday life: Navigating the power relations of care between young adult siblings with and without disabilities*. August 18, 2014. Invited presentation for the Department of Developmental Disability Neuropsychiatry, UNSW Australia.

Meltzer, A. (2013) *Living disability relationally*. Society for Disability Studies Conference, June 26-29, 2013, Orlando, Florida, USA.

Meltzer, A. (2013) *Researching disability studies and siblings together: Offerings and possibilities*. June 18, 2013. Research Colloquium at the University of Illinois at Chicago, Department of Disability and Human Development, Chicago, USA.

Meltzer, A. (2013) *Disability studies and siblings: What do they offer each other?* Nordic Network on Disability Research, 12th Research Conference, May 30-31, 2013, Naantali, Turku, Finland.

Meltzer, A. (2012) *Common differences: Exploring relationality for young people with disabilities and their siblings without disabilities*. Dis/connections: Faculty of Arts and Social Sciences Postgraduate Conference, November 15-16, 2012, University of New South Wales, Sydney, Australia.

Meltzer, A., Dowse, L. and Muir, K. (2012) *Side by side: Hearing the voices of people with and without disabilities together in inclusive research*, Inclusive Research Workshop, March 26, 2012, School of Education, University of New South Wales, Sydney, Australia.

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Chapter 1. Introduction

This thesis is about the everyday lives and relationships shared between young adult siblings where one has a disability. It is a qualitative study that explores how disability figures in the relationships between siblings with and without disabilities, particularly how disability figures in their everyday enacted relations with each other and in the overall felt experience of their sibling relationship during young adulthood. This perspective is important because, despite a wealth of research about siblings where one has a disability, little is known about the experience of disability within the sibling relationship. Yet such experiential knowledge is important for understanding the relational role that disability may play in siblings' everyday lives and relationships as they move towards adulthood. This work seeks to develop relational knowledge about disability in siblings' lives and to deepen understanding of the complexity of siblings with and without disabilities' relational experiences together.

1.1. Background

The sibling relationship is an important element of family for many people; a relationship of many everyday and formative experiences (Edwards et al., 2006) and potentially one of the longest-lasting relationships of a lifetime (Cicirelli, 1995). Particularly in childhood, adolescence and early young adulthood when they commonly live together, siblings are very often there for the small, day-to-day moments of each other's lives, sometimes experiencing intensity of emotion and often conflict, but also often providing support to each other and sharing information that other family members of an older or less similar age might not be able to provide (Edwards et al., 2006, Gillies and Lucey, 2006). In this sense, sibling relationships are important everyday relationships for many people.

However, where one sibling has a disability, research has rarely examined siblings' everyday experiences together. Rather than attending to everyday life and the small

moments that siblings with and without disabilities may share, studies of siblings and disability have most commonly focused on the impact of disability causing non-normative experiences for siblings of people with disabilities. For example, as documented in Chapter 2, much work investigates whether and how disability causes damage to the psycho-emotional wellbeing of siblings of people with disabilities, causes them to have a range of positive or negative experiences, leads to their involvement in caregiving or lessens their perceptions of warmth, intimacy or conflict within their sibling relationship compared to siblings where neither has a disability. By concentrating on these impacts of disability, the everyday lives and relations shared between siblings both with and without disabilities move out of focus. Further, by focusing on the impact of disability specifically upon the sibling without the disability only, the shared relational experience that involves siblings *both* with and without disabilities is missed. It is then difficult to see or understand the shared relational experience of disability for both siblings, even though this may be a key or formative aspect of their lives.

This thesis focuses on the everyday relational experience of disability as it occurs between siblings both with and without disabilities during young adulthood. Rather than looking at the impact of disability, attention is given to the role and character that disability has in the everyday relations of young adult siblings' lives together. It also maps what disability means for the overall experience of the sibling relationship. Rather than coming from an approach of measurement – measuring psycho-emotional wellbeing or level of care-giving – a sociological, relational and phenomenological approach is used, which explores the details of lived experience.

Through interviews with 25 siblings with disabilities and 21 siblings without disabilities, this thesis examines what both say about the role and character of disability in their sibling relationships, particularly when these relationships are set in the context of the changes and transitions happening in their lives as young adults. It looks at what disability means for and how it figures in the behaviour, interactions, perceptions and emotions that make up the everyday relations of sibling relationships during young adulthood and looks at how disability also features in the overall experience of the relationship. This is an original contribution to studies of

siblings where one has a disability, taking a very different approach to most research on the subject. In addition to the previous focuses on psycho-emotional wellbeing, caregiving or positive or negative experiences, the work here aims to inform knowledge about the role of disability in young adult siblings' everyday lives and relationships together.

1.2. Theoretical approach and scope

In shifting towards a view of how disability figures in the relationships that young adult siblings with and without disabilities share, this thesis takes a sociological, relational and phenomenological approach. It is informed by previous sociological research about siblings (Edwards et al., 2005, 2006, Edwards and Weller, 2014, Mauthner, 2002, Gillies and Lucey, 2006, McIntosh and Punch, 2009), by relational theory focused on the shared experiences and interactions that are fundamental to social life and lived experience (Mauthner and Doucet, 1998, 2003, Ward, 2014, McCarthy and Prokhovnik, 2014) and by a phenomenological approach to studying everyday life (Merleau-Ponty, 1958 [1945]), particularly the embodiment and enactment of disability in everyday relations (Titchkosky, 2007). Further, a phenomenological approach to analysis is used, based on looking at participants' reflections on, as well as their descriptions of, their lives (Smith et al., 2009).

More abstractly, this work is also informed by some of the complexity of theoretical approaches that make up disability studies. Disability studies is an inter-disciplinary field focused on conceptualising disability as more than only incapacity and that resists views of disability as a problem or tragedy (Linton, 1998, Goodley, 2011a). Methodologically, it is also focused on redressing the history of research that has seen the exclusion, objectification and exploitation of people with disabilities (Dowse, 2009, Kidney and McDonald, 2014). Instead, disability studies works with a critically engaged conceptualisation of disability, where disability expresses a range of experiences that are each more than only incapacity or tragedy and where people with disabilities are inherently foregrounded in and recognised by research. Focusing on the experience of *both* siblings, including those with disabilities, and exploring the everyday relational experience of the role and character of disability

thus fits disability studies' focus of ensuring a complex and engaged view of disability that recognises people with disabilities. This approach informs the theory and analysis in the following chapters; while not always foregrounded in the writing, the intention to represent a complex and detailed view of disability in siblings' experiences is always there.

Theoretical context from youth studies also informs the work here. Focused on young people from their early-to-mid-teens to their mid-twenties, one of the theoretical approaches of youth studies is in mapping the changes and transitions that occur in young people's lives as they move from adolescence to adulthood. This may include transitioning out of school, into work, into independent living and into partnership and parenthood (Settersson and Ray, 2010), but also includes personal development and an emerging a sense of adult identity (Erikson, 1968, Arnett, 2000). Youth studies argues that these changes and transitions are non-linear, complex and inconsistent between young people (Wyn and Woodman, 2006, Worth, 2009, Slater, 2013). These changes and transitions are conceptualised in this thesis as providing a normative temporal background to the relational experience of disability that siblings may share in their everyday lives – that is, that siblings' life-stage matters to what happens in the relationships between them.

Based on this background and these theoretical approaches, the thesis has a very particular scope. It is about the relational and phenomenological experience of disability, not about assessing the impact of disability upon siblings. It is about a complex, critically engaged and relational view of disability, not about disability as incapacity or as a problem or tragedy. It is about young adult siblings; while sometimes reflecting on the implications of young adult experiences for the further scope of experiences across the life course, detailed examinations of childhood or later adult life are not included. Further, the work sits between and connects various disciplines and theoretical approaches. Rather than being centred in one scholarly location, it draws together research about siblings, disability and young adulthood and connects sociological, relational and phenomenological approaches, as well as the stated precedents from disability and youth studies. Based on these theoretical foundations, the scope of this work ultimately has a specifically relational character.

1.3. Aims, research questions and methods

Following from this background and from these theoretical approaches, the study on which the thesis is based had a clear set of aims. The aims were to:

1. Connect scholarship from disability studies and youth studies with scholarship about siblings and disability;
2. Develop, explore and apply a relational perspective on disability for young adult siblings with and without disabilities;
3. Expand the foci and theoretical approaches used in research about siblings and disability;
4. Contribute to methodological development in *how* to do research that includes siblings both with and without disabilities.

Drawing on these aims, the study had one core and three supplementary research questions, each aimed at furthering understanding of the core question:

- What is the everyday relational experience of disability for young adult siblings with and without disabilities? How does this experience reflect the inter-relationship between experiences as siblings, of disability and of young adulthood?
 - How is disability experienced in the relationship between young adult siblings with and without disabilities?
 - How is the experience of disability in the sibling relationship set within the context of young adulthood and/or how does it influence siblings' young adult experiences?
 - What are the implications of recognising an everyday relational experience of disability for young adult siblings with and without disabilities?

To achieve these aims and explore these research questions, the study involved accessible and relationally informed research methods. As further explained in Chapter 4, this meant commitment to redressing the history of people with disabilities' exclusion from research, while also accommodating the sibling

relationship and the perspectives and experiences of both siblings in the research process. This approach was operationalised by providing qualitative ways to accessibly and relationally include participants, such as choices about whether a pair of siblings took part together, separately or just one sibling alone; opportunity to participate in semi-structured interviews or by documented contribution; and provision of a range of accessibility supports designed to accommodate some participants with disabilities' communication support needs and to be engaging for young people. Further, the study adopted a hybrid form of thematic and phenomenological analysis, aimed at capturing the inter-relationship between participants' experiences as siblings, of disability and of young adulthood in a way centred on reflective examples. These accessible and relationally informed methods and the hybrid analysis mean that the theoretical approaches based in relational theory, phenomenology and disability studies were carried over into the study's methodology and, ultimately, informed a study that included both siblings as participants and that came to situated relational findings. In this way, the approach is relational both in methodology and content.

1.4. Notes on language

In the following chapters, some terminology is used in ways that either have specific meanings or that otherwise require accounting for. These terms are detailed below. Further detail about the core conceptualisations of the research is included in Chapter 3.

Siblings with and without disabilities. The terms 'siblings with disabilities' and 'siblings without disabilities' are used to refer to people with disabilities and their brothers and sisters without disabilities respectively. This choice of terminology reflects two considerations.

Firstly, this phrasing adopts person-first language, commonly accepted in Australia, the United States and used internationally, such as in the United Nations Convention on the Rights of Persons with Disabilities. This terminology places the person first and only afterwards refers to disability, aiming to foreground personhood. In the United Kingdom, the terms 'disabled people' and 'non-disabled people' are however

used, as these locate an individual as disabled by society. Both sets of terminology are contested, but also commonly used. Given the Australian context of this thesis, person-first language is applied here.

Secondly, while most research refers to ‘siblings of people with disabilities’ and then to ‘children/adults/people with disabilities’, this work departs from that convention by referring to both siblings as ‘siblings’. This phrasing is used is to, at every stage, reaffirm that the sibling relationship inherently is a two-way relationship that involves both parties. Referring to both siblings as ‘siblings’ is a linguistic marker of this. A shorthand reference to ‘both siblings’ is also often used as a linguistic device referring to siblings both with and without disabilities.

Siblings where neither has a disability. The term ‘siblings without disabilities’ above should not be confused with references to relationships where neither sibling has a disability. Siblings in such relationships are referred to as ‘siblings where neither has a disability’ in order to clearly mark the differentiation.

Siblings irrespective of disability. Sometimes there are references to ‘siblings irrespective of disability’. This term is used when making a statement that could apply to all siblings, including those in relationships where one has a disability and those where neither have a disability.

Disability. Debates about the usage of the term ‘disability’ are prevalent in disability studies, where the word ‘disability’ is often used to refer to exclusionary or oppressive social structures or barriers, rather than to physical or cognitive impairments of body or mind (UPIAS, 1976, Oliver, 1990, Thomas, 1999). While use of this terminology has been one of the cornerstones of the advancement of disability studies, many scholars also now critique the distinction and argue for a range of more complex and situated understandings that do not create binaries between society, body and mind (Priestley, 2003, Bhaskar and Danermark, 2006, Shakespeare, 2006, Kafer, 2013). This thesis follows these latter critiques in that, as explained further in Chapter 3, it adopts a critical realist conceptualisation of disability, where disability is seen as a multi-faceted phenomenon that has a range of physical, biological and psychological elements as well as social, economic and

cultural elements that all interact with each other to produce an overall and complex experience of disability (Bhaskar and Danermark, 2006). Following this critical realist conceptualisation, the references to 'disability' in the following chapters may denote any of a range of physical, cognitive, emotional, social or temporal elements of disability. That is, the term 'disability' is used with diversity and variety. Markers are placed throughout the text to show which element of disability is being discussed.

Young adulthood. As further outlined in Chapter 3, the term young adulthood is used to denote a stage of the life course between early-to-mid-adolescence and mid-twenties when many practical changes and transitions (Setterson and Ray, 2010), identity developments (Erikson, 1968, Arnett, 2000) and new experiences, thoughts or perceptions (Worth, 2009) occur in young people's lives as they move from a child to an adult role. In practice, in recognition that many of these changes and transitions are occurring later for young people in contemporary society (Setterson and Ray, 2010), participants into their late 20s are included in the study, with an age range of 15-29 for participants.

Young people and young adults. The terms 'young people' and 'young adults' are both used to refer to those within the life-stage of young adulthood. 'Young people' is the preferred term, as this has currency within youth studies and policy and practice in Australia. However, it is difficult to attach this term to the sibling status without creating confusion with siblings in childhood: that is, 'young siblings' could also be easily understood to refer to siblings who are young children. For this reason, 'young people' is used as the preferred general reference, but the term 'young adult siblings' is used specifically in application to siblings.

1.5. Chapter outline

The forthcoming chapters are structured to answer the research questions and build an argument about the everyday relational experience of disability between young adult siblings with and without disabilities.

Chapter 2 begins by reviewing the relevant literature. Through a detailed, holistic review of sibling-disability research – the study of siblings where at least one has a disability – the first part of chapter shows how this field has been dominated by studies of the impact of disability upon the non-normative experiences of siblings without disabilities and establishes the need to further explore the everyday relationships that siblings both with and without disabilities share. The review also identifies that the sociological, relational and phenomenological frameworks needed to take up this everyday relational focus have not so far featured in sibling-disability research. The second part of the chapter thus provides a selective account of the precedents from other sibling research (where neither sibling has a disability), disability studies research and youth studies research that can develop this everyday relational focus.

Chapter 3 details the theoretical framework used to explore siblings' everyday relational experiences of disability. It combines diverse aspects of theory, including about relationships, a critical realist perspective of disability, embodiment and enactment, views of young adulthood as transitional and generational and elements of constellational, ecological and intersectional theories. Importantly, in theorising relationships, this chapter establishes foundational work for the following analysis of the everyday relations that siblings share and of their overall experience of the sibling relationship. Through theorising inter-personal relationships, the chapter delineates what siblings' 'everyday relations' entail in a practical sense. The chapter also draws together a range of disparate references in the literature to describe a concept to account for the overall experience of a relationship: *relationality*. A working definition of relationality as the overall felt experience of a relationship is proposed in this chapter, which is then applied throughout the analysis and used to come to some of the core findings and overall contribution to scholarship.

Chapter 4 gives an account of the methods by which 25 siblings with disabilities and 21 siblings without disabilities participated in the study. The chapter outlines the study's methodology, including its accessible and relationally informed research approaches, research design and planning, data collection and data analysis. It describes the methods used, including providing the choice to participate jointly,

separately or alone in semi-structured interviews or documented contributions, with accessibility supports available where needed. The chapter also discusses the ethical issues and power relations involved in siblings' participation.

Chapter 5 introduces the participants, detailing their family structure, demographic characteristics, social and economic engagement and sibling relationships. The chapter also outlines how participants' accounts are quoted or otherwise used in the thesis.

Chapters 6-9 detail the research findings, developing an argument about the roles that disability can play in the sibling relationship. The chapters show how in different circumstances disability may variously constitute, create or contribute to siblings' everyday relations, relationality and some of their individual experiences.

Chapters 6 and 7 establish the foundations of these findings. Chapter 6 begins by looking at disability's physical, cognitive and emotional presence and role in the sibling relationship and Chapter 8 continues by exploring disability's relational role in social and temporal context. These two chapters together give a sense of how many multi-faceted elements of disability are naturally drawn into the everyday enactment of sibling relationships. It is through these chapters that the basic argument that disability may constitute, create or contribute to siblings' relations and relationality is established. The chapters also begin detailing a set of relationalities – overall felt experiences of the relationship – that are experienced by siblings.

Chapters 8 and 9 further nuance the argument. Chapter 8 considers the way in which siblings do not always accept or draw disability into the relationship, detailing how some siblings resist the presence of disability-related care between them. Chapter 9 concludes the findings by looking at the roles of positioning and perception in how siblings understand and interpret the relational role of disability. It explores how siblings with and without disabilities have different views to each other about the relational role of disability in their individual experiences during young adulthood. These two chapters also further expand the set of relationalities

begun in the earlier chapters, allowing articulation of a set of overall felt experiences that may happen where disability has a presence in the sibling relationship.

Chapter 10 draws the findings into a broader discussion, articulating how they answer to the aims and research questions of the study and discussing their implications for evidence, policy and practice about siblings with and without disabilities. The chapter discusses the key insights and contributions offered by the findings; that is, articulating the conditions in which disability is formative within the sibling relationship, the importance of relationality, the centrality of siblings' temporal context to their relational experiences and the methodological implications of conceptualising the sibling relationship as a two-way relationship. The chapter also outlines the implications of the findings, showing how, based on a relational perspective, there is capacity to use policy and practice to protect siblings with and without disabilities' felt experience as siblings. The limitations and scope of the thesis are also discussed and areas outlined for future research. Chapter 11 then offers some concluding remarks on the importance of the relational findings and perspective.

In between the early chapters of the thesis, some short 'positionality pieces' appear. These are partially academic and partially self-reflective, and address the need for researchers to account for their own position, intellectual biography and reflexive experiences when conducting research (Thomas, 1999, Stanley, 1990, 1996, Mauthner and Doucet, 2003). The pieces depart in style from the thesis chapters in that they are written in the first person and address issues of the motivation for research, the interface of personal experience and conceptual thought and reflections on what positionality and reflexivity are. They aim to give a personal background to the scholarly work of the thesis.

Positionality 1. Researcher statement

Accounting for positionality and reflexivity is important within the qualitative frame. On the one hand, the positioning of a researcher with a personal connection to their research topic presents risks and challenges for objectivity and boundaries (Sarantakos, 2005). Yet at the same time, there are increasing calls for researchers to account for *and use* their position and own intellectual biography in how they have come to the frameworks and concepts of their research, especially within feminist and experiential scholarship (Thomas, 1999, Stanley, 1990, 1996, Mauthner and Doucet, 2003). Further, disability researchers in particular are now more commonly accounting for their various relationships to disability (O'Toole, 2013, Smith, 2013, Ostrove and Rinaldi, 2013), experiences of selfhood (Broun and Heshusius, 2004) and personally political intellectual journeys through their disability research and scholarship (Kittay, 2009, Rinaldi, 2013, Garland-Thomson, 2014). Each are set against a backdrop of the benefits and dilemmas of accounting for subjectivity and relational knowing in a way that uses the personally political experience of a researcher while also being cautious of bias and barriers to objectivity (Peshkin, 1988, Doucet, 2008).

Against this intellectual and scholarly setting, I state my positions. I come to this research as the twin sister of a woman with a physical and intellectual disability and as a young scholar studying young adulthood. I come after being involved in sibling support, advocacy and communities for many years. I come from a background first as a support worker in disability services and then as a researcher in the social policy and research sphere that informs those services. Each of these influences inherently position my scholarship.

Yet stating only each of these positions does little to articulate the relational journeys that have led to this research and that have happened in parallel to and in combination with the process of coming to the words on the following pages. Simply stating each of my positions does little to explain how my thinking has changed, how my relationship with my sister has grown and matured or how my identity has been informed by my scholarship. It does little to articulate the tumult of how the years in which I have come

to disability scholarship have also been some of the strangest, scariest years of my sister's health – and how, when combined, these two experiences have challenged my mind, my heart and eventually brought me to deeper relational understandings. Yet, in being reflexive, these are each experiences that must be evident in order to understand my motivation, intellectual biography and conceptualisation of what positionality and reflexivity are in this research.

When doctoral researchers write of these kinds of reflexive experiences in a PhD thesis, it is usually in a researcher statement in an introductory or methodology chapter – however, this is a format that I feel could not express what I have to say. So I seek other forms of writing. Others have woven together beautiful (Chawla, 2003, 2007) and fiercely passionate (Kittay, 1999, 2009, Broderick, 2013) works about their positioning and reflexivity – about how the relations of their own lives interweave with their scholarship and theoretical understandings to form the situated, experiential words on their pages. Each of these works are in other types of scholarship, not a thesis: in journal articles (Chawla, 2003, 2007, Kittay, 2009), books (Kittay, 1999, Broderick, 2013) and, more informally, in the blogosphere (Lewis, 2014a, 2014b, 2015a, 2015b).

In seeking to adapt something of these works to a thesis, I am, as far as I know, trying a format that is new. Woven between some of the forthcoming chapters are three further pieces that speak to my positioning and reflexivity in this research. Each articulate a moment or part of my journey in coming to the words in these pages, drawing out a personal implication linked to the literature, theory and methodology of my study. Each piece is composed after a journey through the research process where I have strived to grow – and where I have listened to and learnt from those who have guided me in how to be a rigorous, passionate researcher who knows her own heart, but who also knows, respects and foregrounds the needs of methodologically robust research as well. The pieces are, overall, here to show who I am and what I have thought as I have formed and written this thesis, showing how I personally position my research, but always hold the standards of being an objective scholar within myself as well.

Chapter 2. Literature review

This thesis has been informed by a review of several areas of literature. Primarily, it is set within sibling-disability research – the study of siblings where at least one has a disability. However, other literatures that represent the components of the research topic are also relevant. Sibling research (where neither sibling has a disability) is important for accounting for how sibling relationships are more generally understood. Disability studies research – the critical, sociological and political study of disability – is important for giving a broad and complex understanding of how disability features in lived experience. Youth studies research is important for understanding siblings' experiences during young adulthood.

This literature review first documents sibling-disability research in detail, giving a holistic and comprehensive view of the field. Tracking the history of sibling-disability research from the mid-20th century, the review highlights its well-established psychological foci, the developments that have followed the diversification of disciplines in the field and documents how sibling relationships have been studied. Through this review, the need to further explore the everyday relationships that siblings with and without disabilities share is established, with explanation that to do so requires sociological, relational and phenomenological frameworks that have not so far featured in sibling-disability research.

The second part of the literature review seeks out the needed sociological, relational and phenomenological frameworks through a selective account of sibling research, disability studies research and youth studies research. This selective account identifies the research approaches that each of these fields offer for opening up sibling-disability research. The conclusion of the chapter details how these new frameworks will be applied in this work.

2.1. Sibling-disability research

Sibling-disability research is predominantly seen as the study of siblings without disabilities – that is, siblings of people with disabilities. However, a key argument of this thesis is that it is more appropriately seen as the study of siblings where at least one has a disability, as this gives the possibility of including siblings both with and without disabilities. Historically, the field has focused on identifying the impact of disability on siblings without disabilities' psychology and experiences of caregiving, however more recently some social, cultural and political analyses have also emerged. The following sections begin by documenting the well-established psychological and caregiving work and then discuss the emerging approaches that are opening up new areas of inquiry in the field, finally detailing the scope of work on sibling relationships. Throughout, the review identifies the approach taken in this thesis and how this approach compares to the literature.

2.1.1. Well-established work

Since the mid-20th century, a substantial amount of sibling-disability research has been undertaken, mostly in the Global North. Reflecting historical concern about hardship for families of children with disabilities (Lalvani and Polvere, 2013) and about experiences of psychological trauma, stress and isolation for siblings (Jones, 2004, Castles, 2004, Brockley, 2004), there has been extensive examination, particularly within the discipline of psychology, of the impact of disability on siblings without disabilities. This has led to the majority of sibling-disability research being characterised by three main bodies of work, each focused on documenting the non-normative experiences of siblings without disabilities. These three areas are the psycho-emotional impact of disability on siblings without disabilities, their positive and negative experiences and their involvement in caregiving.

Psycho-emotional impact

A large proportion of sibling-disability research deals with the psycho-emotional impact of disability on siblings without disabilities. This psycho-emotional approach began in early research by exploring siblings without disabilities' frustration, tension,

anxiety and deviant behaviours (Farber, 1959, 1960, Farber and Jenne, 1963, Gath, 1973, 1974). Over time, the concepts of adjustment and functioning gained currency, with a focus on measuring the capacity of siblings without disabilities to adapt to disability and their family circumstances (Breslau et al., 1981, Breslau, 1982, Lobato et al., 1987, McHale and Gamble, 1987, Cadman et al., 1988, McHale and Gamble, 1989, Bischoff and Tingstrom, 1991, Damiani, 1993, Seltzer et al., 1997, Doppelt et al., 2004, Lobato et al., 2005, Cuskelly and Gunn, 2006, Macks and Reeve, 2007, Petalas et al., 2009, Barnett and Hunter, 2012, Walton and Ingersoll, 2015). Contemporary work examines risk and protective factors for adjustment, including, for example, the mediating impact of parenting style, family resources and socio-economic status (Giallo and Gavidia Payne, 2006, Neely-Barnes and Graff, 2011). Psycho-emotional explorations have also been stratified by birth order (Breslau, 1982), age gaps (Breslau, 1982), disability type (Hastings, 2007, Petalas et al., 2009) and disability severity (Kowalski, 1980, Smith et al., 2015).

This body of work has identified a wide scope of possible psycho-emotional experiences among siblings without disabilities. It includes common identification of negative psycho-emotional outcomes (Senel and Akkök, 1995, Barnett and Hunter, 2012), but also positive (Pilowsky et al., 2004, Cuskelly and Gunn, 2006) and mixed outcomes (Macks and Reeve, 2007, Neely-Barnes and Graff, 2011). Overall, meta-analysis has identified a statistically small likelihood of psycho-emotional problems – a likelihood that is much smaller than originally assumed (Rossiter and Sharpe, 2001, Sharpe and Rossiter, 2002). There have also been very detailed accounts of the differences in psycho-emotional wellbeing of siblings with different characteristics or experiences. For example, there has been exploration of how psycho-emotional problems are compounded by poor family resourcing and low socio-economic status (Giallo and Gavidia Payne, 2006, Neely-Barnes and Graff, 2011) or linked to disabilities that include violent or challenging behaviour (Petalas et al., 2009, Fishbein, 2010, Barker, 2011). These detailed accounts are useful for understanding which siblings may or may not be particularly at risk and importantly acknowledge the particular difficulty of some siblings' experiences.

However, the level of detail and, at times, inconsistency in identifying different

characteristics among siblings and the often negligible differences in their wellbeing means that, overall, this literature appears inconclusive. Going beyond the individualising approach of measuring differences in the impact of disability upon siblings without disabilities is therefore important. This requires a shift towards a less quantified and more experiential exploration of siblings' experience of disability in their everyday lives and relationships. This gives possibilities for extending the understanding of the role and character of disability in the sibling relationship beyond incremental measurement of psycho-emotional impact. It is this more experiential focus that is applied in this thesis.

Positives and negatives

Another significant focus within sibling-disability research is detailing how, alongside difficult experiences, disability also leads to 'positives' (Guse and Harvey, 2010), 'opportunities' (Dyke et al., 2009), 'possibilities' (Abrams, 2009) or 'advantages' (Mulroy et al., 2008) for siblings without disabilities. For example, common benefits such as increased tolerance, compassion, patience, acceptance and gratitude for their own abilities are identified (Mulroy et al., 2008, Guse and Harvey, 2010, Abrams, 2009). These benefits are almost always cited alongside more difficult experiences, for example, isolation, over-responsibility, premature independence, anger, guilt, stress and difficulties with family life and in achieving attention from parents (Mulroy et al., 2008, Guse and Harvey, 2010, Abrams, 2009). The dualistic framing of these 'positives' and 'negatives' is often presented as precisely the essence of the sibling-disability experience itself: that is, that it is an ambivalent experience.

However, while the family lives of many people commonly have both positive and negative aspects, the dualistic framing of these 'positives' and 'negatives' risks falling into the troubled 'tragic'/'overcoming' dichotomy that has been used in application to people with disabilities (Morris, 1991) and their families (Fisher and Goodley, 2007). This dualistic framing implies that the difficulty of the sibling-disability experience can only be overcome through developing 'more-than-normal' tolerance, compassion, patience or acceptance. This is instead of, for example, conceptualising disability as contributing to teaching the patience or acceptance that

is a normative part of emotional development. The dualistic framing then means that even the 'positives' are an expression of the non-normative impact of disability upon siblings without disabilities.

Rather than applying this dualistic approach, there is importance to shifting towards a less binary exploration of siblings' experience of disability in their everyday lives and relationships. This thesis thus applies a more experiential approach, offering an account of what happens between siblings rather than the nature of the impact of disability upon them. Further, disability is not evaluated as either 'positive' or 'negative' in siblings' lives. Instead of impact or evaluation, the *experience* of the interactions between siblings is the focus.

Care

A third major focus in sibling-disability research is the involvement of siblings without disabilities in providing care to their brother or sister with a disability. Reflecting the focus on adjustment, studies of psycho-emotional outcomes and caregiving (Stoneman et al., 1988, McHale and Gamble, 1989, Rae-Seebach, 2009) have shown an association between increased caregiving and poorer adjustment (McHale and Gamble, 1989). Other investigations have used a gendered analysis, showing that older, female siblings are most likely to be involved in care in childhood (Stoneman et al., 1988) and to take on more extensive caregiving in adulthood (Seltzer et al., 2005). Relatedly, siblings without disabilities have been shown to provide care across the life course (Stoneman et al., 1988, Harland and Cuskelly, 2000, Dew et al., 2004).

Much of the work on care compares siblings' involvement with that of parents. Compared to parents, siblings without disabilities have been found to be more likely to give emotional rather than instrumental care (Seltzer et al., 2005); to step in for a shorter primary role (Bigby, 1998) or provide a respite function (Harland and Cuskelly, 2000); and to have a more egalitarian and reciprocal care style than parents (Kramer, 2009, Dew, 2010). Siblings without disabilities' attitudes towards care have been found to be influenced by worries about future caregiving (Davys et al., 2010), balancing care with other commitments (Harland and Cuskelly, 2000) and

the risk of prematurely taking on more responsibility than they can handle (Rawson, 2010).

While this work is significant for establishing the importance of siblings without disabilities to caregiving, the experiential side of care has remained relatively unexplored. Much consideration is given to instrumental descriptions of siblings without disabilities' involvement in care or of the individual impact of their involvement – again reflecting a focus on non-normative experiences. There is however little differentiation between normative care among all siblings (Eriksen and Gerstel, 2002, Edwards et al., 2006) and care that is or feels non-normative because of its link to disability. Further, with the exception of the contributions by Kramer (2009) and Dew (2010) who identify and discuss siblings' egalitarianism and reciprocity, there is little exploration of what this non/normative nexus means to or feels like for siblings. In seeking to extend knowledge in this area, this thesis thus investigates the experiential and relational character of care for siblings with and without disabilities.

This work on psycho-emotional impact, positive and negative experiences and care represent the well-established areas of sibling-disability research, suggesting a relatively narrow scope to the main areas of the field. However, as sibling-disability research has recently begun to move out of predominantly psychological research and to diversify in disciplinary perspectives, some new approaches have also developed. This recent work offers greater insight into the multiple perspectives and contexts relevant to siblings.

2.1.2. Recent and emerging approaches

Over the last decade, the disciplines represented in sibling-disability research have begun to diversify and this has seen new developments in the field. These more recent developments have better included the perspectives of siblings *with* disabilities in the research and have also started to address the social, cultural and political context of disability for siblings, as well as differentiate siblings' experiences across the life course.

Insights from siblings with disabilities

Historically, sibling-disability research did not include the perspectives of siblings with disabilities. Prior to the mid-2000s, only one study directly focused on the views of people with disabilities about their brothers and sisters (Zetlin, 1986). A small number of other studies included both siblings together with their parents in research into disability and family life, but not directly about sibling relationships (Magill Evans et al., 2001, Hussain, 2003), or included some very brief views of people with disabilities about their siblings in research with a more detailed focus on other aspects of their life experience (Connors and Stalker, 2003).

More recently this lack of representation of siblings with disabilities has been critiqued (Sanders, 2004, Dew et al., 2008b, Heller et al., 2008). The result has been that a small number of studies have emerged seeking the perspectives of both siblings with and without disabilities together (Davis and Salkin, 2005, Kramer, 2009, Dew, 2010, Tozer et al., 2014, Burbidge and Minnes, 2014) or of siblings with disabilities alone (Serdity and Burgman, 2012, Petalas et al., 2015) directly about their sibling relationships. This has had two significant implications for the scope of knowledge about siblings and disability.

Firstly, the inclusion of both siblings has markedly changed the focus of some sibling-disability research. In contrast to the individual-level studies of psycho-emotional impact and positive and negative experiences, there has been new identification of situated forms of reciprocity between siblings (Dew, 2010, Kramer, 2009, Kramer et al., 2013). Some work conceptualises reciprocity through siblings with disabilities participating in shared aspects of family life, such as shared activities or roles as aunts or uncles (Kramer et al., 2013). Other work has described how siblings with disabilities give symbolic or emotional support in return for instrumental assistance (Dew, 2010). These insights about reciprocity are important for giving a relational, two-way sense of the emotions and everyday interactions of the sibling relationship itself.

Secondly, the perspectives of siblings with disabilities also sometimes run counter to those of siblings without disabilities. For example, while siblings without disabilities

have indicated that their sibling relationships are unequal and not very competitive during childhood (Dallas et al., 1993a, 1993b, Eisenberg et al., 1998), siblings with disabilities themselves say they often feel equal with or dominant over their siblings without disabilities in childhood and that there is commonly conflict in their sibling relationships (Serdity and Burgman, 2012, Petalas et al., 2015). The diversity of siblings' perceptions demonstrates the importance of including the perspectives of *both* siblings for investigating the experiential aspects of their relationship.

Significantly, while this body of work has focused on siblings in childhood (Serdity and Burgman, 2012, Petalas et al., 2015) and middle and late adulthood (Kramer et al., 2013, Dew et al., 2013, Davis and Salkin, 2005, Burbidge and Minnes, 2014, Tozer et al., 2014), both siblings have not yet been included together as young adults in research directly about their sibling relationships. This thesis thus includes both siblings as young adults to help extend examination of their diversity of perspectives to other stages of the life course.

[Social, cultural and political insights](#)

A second new development in sibling-disability research is the emergence of some more sustained analysis of the social, cultural and political context of disability for siblings. This analysis has developed insight in three main areas – locating siblings intersectionally, in service frameworks and in systemic policy and advocacy.

Firstly, there has been greater consideration of how siblings' experiences of disability intersect with other factors, such as culture and gender. Studies have explored the experience of siblings of specific cultural backgrounds (Lobato et al., 2005, 2011, Sage and Jegatheesan, 2010) and the role of religion in interpreting the experience of having a sibling with a disability (Gross, 2005, Pollak, 2008, Jegatheesan, 2013). In particular, there is emerging attention to siblings from Asian cultures (Kuo, 2008, 2014, Hwang and Charnley, 2010a, 2010b, Rohde-Brown and Frain, 2014). For example, Hwang and Charnley (2010a) consider how Korean siblings' meanings of care reflect Confucian values – familial obligation and a positive valuing of sacrifice – in contrast to the concept of 'burden' common to Western cultures. Similar intersectional consideration has been given to gender. For

example, McGraw and Walker (2007) discuss how sisters without disabilities participate in a gendered culture of family care, Dew et al (2008a) identify that brothers focus more on the practical and financial arrangements of care compared to sisters' common emotional considerations and Kuo (2014) identifies the 'chaos' of Taiwanese brothers without disabilities transitioning to an unfamiliar, feminine care role. These intersectional works give more socio-cultural analysis than has previously featured in the field.

Secondly, consideration of siblings' location and role in service frameworks is also beginning to emerge. Sibling-disability research has always included studies of sibling support (Evans et al., 2001, Naylor and Prescott, 2004, D'Arcy et al., 2005, Giallo and Gavidia-Payne, 2008, Welch et al., 2012, Gettings et al., 2015, Roberts et al., 2015). However, recent research has also focused on the placement of siblings in relation to disability services more broadly, including the roles of siblings in evaluating initiatives for future planning (Heller and Caldwell, 2006), assisting with personalisation policy (Atkin and Tozer, 2014) and complementing formal residential services through providing social inclusion based on family connections (Bigby et al., 2012, 2014). Further, other research has also acknowledged that under-servicing of people with disabilities also has implications for siblings without disabilities (Taylor and Hodapp, 2012). Each of these new studies provide a greater focus on policy and service contexts for siblings.

Finally, there has also been recent consideration of how siblings are positioned in systemic policy and advocacy. Some work has considered human rights issues for siblings where one has challenging behaviour that is a danger to themselves or others and there is a need to protect the rights and safety of both (Benderix and Sivberg, 2007, Muir and Goldblatt, 2011). Arnold et al (2012) have also described sibling support in terms of the need for system improvement, education, funding, systemic coordination and improved public disability awareness and employment conditions for support workers. This work prompts a socio-political framing of siblings through highlighting systems and structures that affect their experiences.

Overall, this body of work reflects a recent focus on the social, cultural and political context of disability for siblings, which contrasts with the well-established work on

psycho-emotional impact, positive and negative experiences and care. These new insights are important contextualising features for studying the conditions that influence sibling relationships and, in this thesis, are taken as contextualising factors for the exploration of siblings' everyday lives and relationships together.

Life course and young adulthood

There has also been greater recent consideration of life course frameworks in sibling-disability research. While previously focused on children, recent agenda setting in the field has recommended that greater work also be undertaken on the experiences siblings have during adulthood and later life, with attention to key life course transitions (Seltzer et al., 2005, Hodapp et al., 2005, Heller et al., 2008). This has resulted in a small but growing body of work on the transition of siblings without disabilities into more sustained roles in care in adulthood and later life (Dew, 2010, Kramer, 2009, Bigby et al., 2012, 2014, Coyle et al., 2014, Holl and Morano, 2014, Burke et al., 2015, Davys et al., 2015) and work into how experiences in childhood affect siblings' relations in later life (Dew, 2010, Dew et al., 2011, 2013).

Reflecting the growth of life course frameworks for siblings, there has also been more focus on young adulthood. Some studies include samples of young adult siblings without disabilities, yet remain focused on psycho-emotional outcomes (Altman, 1993, Bellin et al., 2009, Opperman and Alant, 2003) or positive and negative experiences (Graff et al., 2012). However, others articulate experiences specific to young adulthood. Difficulties balancing study, work and family or care responsibilities (Harland and Cuskelly, 2000) and developing concern about future care (Rawson, 2010) have been found to be characteristic young adult concerns for many siblings without disabilities. Some reflection on siblings without disabilities leaving for college has also emerged in North America, examining how having a sibling with a disability may influence college choices, social lives and academic experiences (Weisman, 2007).

However, overall, existing studies of young adult siblings lack an underpinning in theoretical perspectives on young adulthood. The studies cited above are located within a theoretical framework of family and disability, rather than considering the

transitions (Setterson and Ray, 2010), identity developments (Erikson, 1968, Arnett, 2000) and new experiences, thoughts or perceptions (Worth, 2009) that characterise young adulthood as a distinct time of life. The main exception is Dew's (2010) work that applies Arnett's (2000) theory of emerging adulthood. Dew (2010) describes both siblings with and without disabilities' experiences of reaching the personal qualities and transition markers of adulthood, taking a retrospective view by asking siblings to look back in later life on their young adult years. Hussain (2003) has also explored siblings' transitions into adulthood, yet her work is focused more strongly on a theoretical framework of ethnicity and gender. There is, as such, much scope to further develop a theoretically informed approach to young adulthood for siblings, especially for those who are *currently* experiencing young adulthood.

Reflecting the need for this theoretically informed approach for current young adult siblings, the theoretical framework developed in Chapter 3 includes consideration of how siblings' young adult experiences of change and transition and their contemporary generational conditions affect their experiences of disability and as siblings. This framework is intended to contribute to further developing the theoretical underpinning of work on siblings, disability and young adulthood.

2.1.3. Sibling relationships

In shifting the focus away from the impact of disability on siblings without disabilities' non-normative experiences to examine the everyday lives and relationships shared by siblings both with and without disabilities, it is important to account for how the sibling relationship has so far been studied. Study of the sibling relationship runs through the history of sibling-disability research, reflecting several approaches.

One common approach is to quantitatively compare the relationship between siblings with and without disabilities to the relationships of a control group of siblings where neither has a disability. Findings from such research suggest that relationships between siblings with and without disabilities are less warm (Eisenberg et al., 1998, Doody et al., 2010), intimate (Kaminsky and Dewey, 2001), egalitarian (Dallas et al., 1993a), reciprocal (Dallas et al., 1993b, Love et al., 2012) and

conflictual (Eisenberg et al., 1998, Love et al., 2012) than those between siblings where neither has a disability, but potentially more rivalrous, due to parents' extra time spent caring for the sibling with a disability (Love et al., 2012). This comparative quantitative approach however has limitations. Firstly, similarly to measuring the impact of disability on the psycho-emotional outcomes of a sibling without a disability, this approach measures the impact of disability on the sibling relationship itself; it is thus an extension of the focus on non-normative experiences. Further, this approach also describes sibling relationships in terms of what they are *not*, rather than unpacking the situated relations that *are* experienced between siblings with and without disabilities. Shifting towards this latter approach, this thesis examines the experience of the relations that *do* happen between siblings where one has a disability.

Other studies have identified factors that affect sibling relationships. For example, some work has suggested that poor understanding of the disability (Sage and Jegatheesan, 2010), communication impairments (Smith, 2010), invisible disabilities (Aksoy and Yildirim, 2008) and high levels of disability-related violence (Stalker and Connors, 2004) or anxiety (Pollard et al., 2012) may damage relationships between siblings with and without disabilities. Conversely, good support, family resources (Sage and Jegatheesan, 2010) and maternal warmth (Kersh, 2007) are found to promote happier sibling relationships. These studies are important for giving a sense of the influences on the sibling relationship, yet often remain focused on the impact of specific disability types, rather than explaining how disability is experienced in the everyday inter-personal relations between siblings.

Very few studies examine how disability is experienced in everyday inter-personal relations. Harland and Cuskelly (2000) identify blurring between the recreational activities that siblings choose to do together and the respite function that this time can provide to parents. Heller et al (1999) and Pit-ten Cate and Loots (2000) discuss the difficulty of adapting activities to a sibling's support needs and the frustration and regret that may be felt if siblings with disabilities cannot participate or if their communication presents difficulties for doing activities together. These studies identify how disability becomes an experiential feature of siblings' lives together,

rather than simply stating the impact of disability on the relationship. These kinds of situated insights are further explored in this thesis, which details everyday ways disability is experienced within sibling relationships.

In unpacking these everyday experiences of disability, the insights of studies that include siblings with disabilities are useful. Several of these studies focus on shared activities between siblings, such as shared leisure (Kramer et al., 2013), exercise, going shopping, to restaurants, the movies or visiting friends and relatives together (Burbidge and Minnes, 2014). These studies show that siblings are aware that disability affects their relationships, for example, that siblings recognise that disability influences their conflicts and their differing interests (Petalas et al., 2015), that support needs limit the telecommunications they can use together (Burbidge and Minnes, 2014) and that disability sometimes means that they have different ways of offering support to each other (Kramer et al., 2013). These insights are useful for giving more of a sense of the unique roles that disability may play in siblings' everyday lives together.

These insights are also useful because despite recognising the unique relational roles of disability, at an experiential level some siblings say their relationships nevertheless feel typical overall. This gives an important further sense of how disability is experienced. Siblings with disabilities say they feel they experience normative conflict and competition with their brothers and sisters (Serdity and Burgman, 2012) and that their sibling relationships include various aspects of affection, admiration, knowledge, support, fun, activities, conflict and aggression, just as they perceive of the relationships between siblings where neither has a disability (Petalas et al., 2015). Other research has found that siblings without disabilities experience similar but more ambivalent thoughts: they report that their sibling relationships feel both familiar and strange (Hwang and Charnley, 2010b), normal and different (Stalker and Connors, 2004) and the same and different compared to their perceptions the relationships of siblings where neither has a disability (Weisman, 2007).

These experiential insights suggest that there is a need to know more about how disability affects the experience of the everyday relations between siblings and also

to know more about the overall experience of disability in the sibling relationship. What is disability like for siblings in everyday life? What does it mean for their relationships? How does it figure in their relationships? Why is it that their relationships feel both 'typical' and 'strange'? How else do their relationships feel? What kinds of everyday relations is disability experienced in, and how and why? Is this different for siblings with and without disabilities? And what does all of this mean for the overall experience and character of the sibling relationship itself? These are questions that this thesis begins to tackle.

With its history of psychological and impact-based focuses, sibling-disability research however remains largely without the conceptual frameworks necessary to thoroughly explore the sibling relationship in this everyday, experiential way. These experiential questions about everyday relations and the overall experience of the relationship have a relational, sociological, phenomenological character that has not historically featured in sibling-disability research. As such, this literature review now looks beyond sibling-disability research to each of its component literatures: sibling research, disability studies research and, for the purposes of this specific thesis on young adult siblings, youth studies research. A selective account is given of the relational, sociological and phenomenological insights from each that can build an experiential approach for exploring the everyday relational experiences of siblings with and without disabilities.

2.2. Sibling research

Like sibling-disability research, research about siblings where neither has a disability also has psychological origins. However, recently a sociological focus has developed within the field that provides useful insights and precedents for conceptualising siblings' everyday relations and the overall role of disability in their relationships.

Early sibling research, until the 1970s, reflected a range of psychoanalytic and family systems focuses. For example, Sanders (2004) describes how early sibling research accounted for the displacement (Freud, 1917), family reorientation (Adler, 1958) and sibling rivalry (Levy, 1943) caused by the birth of a younger sibling; the impact of birth order, age spacing, gender pairings and family size on siblings' roles in the

family and development (Toman, 1994 [1961]); and the ways that sibling relationships reflect the family system, including being influenced by spousal relationships between parents and each parent-child relationship (Minuchin, 1974). Later psychological research in the 1980s and 1990s focused on how siblings observe, imitate and learn from each other and provide a comparison for developing one's own abilities, personality, self-esteem and confidence (Dunn and Plomin, 1990). Other studies focused on measuring sibling relationship quality, via warmth/closeness, relative status/power, conflict and rivalry (Furman and Buhrmester, 1985). Social and structural stratifications were also layered in, accounting for cultural context (Cicirelli, 1995), life course (Cicirelli, 1995) and disadvantage (Sanders, 2004). Together, this research created a thorough picture of how siblings interact, develop and influence each other across the life course in different social, cultural and structural circumstances.

However, like in sibling-disability research, up until the 1990s the field rarely examined what happens between siblings in everyday life. However, in the 1990s and early 2000s, developments in family sociology led sibling research to this everyday focus. The key development was the conceptualisation of 'family practices' (Morgan, 1996, 1999, 2011) to express "'doing' rather than simply having or being" a family (2011:5) and express "a sense of family life as a set of activities" (2011:6). The concept of family practices gave a sense of the everyday relations between family members and the day-to-day actions, talk and emotions between them, as opposed to describing, for example, the psychology of the family.

Following the idea of 'doing' family relationships, a body of sociological work on siblings developed which detailed the experiences and activities siblings share together in everyday life. This work included attention to the lateral or horizontal orientation of sibling relationships, where siblings are relatively more equal in power than, for example, parent-child relationships, even while still experiencing power inequalities, often based on birth order and gender (Mauthner, 2005, McIntosh and Punch, 2009). It also detailed the practices siblings enact together and the implications of these practices for their experiences of connection, care, power and gender, particularly during late childhood, adolescence and early young adulthood

(Edwards et al., 2005, 2006). These and other key contributions are detailed below, showing how each give useful insights and precedents for conceptualising the everyday relational experiences of siblings with and without disabilities.

2.2.1. Sibling practices

One key contribution of this body of sociological research about siblings is in conceptualising 'sibling practices'. Drawing on the precedent of 'family practices' (Morgan, 1996, 1999, 2011), 'sibling practices' give a sense of the enactment of sibling relationships and of how identities as a brother or sister have "corresponding everyday experiences through which this identity position is constructed and maintained" (Edwards et al., 2006:60).

Edwards et al (2005, 2006) coined the concept of 'sibling practices' and described practices of talk, activity, care and power, each with a particularly gendered focus. In the sibling practices of talk and activity, closeness and connection are largely signified and maintained in sister relationships through talking (for example, about "life", their home or boys), whereas for brothers and brother-sister pairs it is more often through sharing activities (for example, going fishing, to the cinema or watching DVDs) (Edwards et al., 2005). Siblings may become distant where their established patterns of talk or activity are disrupted, including during young adulthood when siblings move out of home and into new social and economic endeavours (Edwards et al., 2005). In the sibling practices of care and power, sisters generally give guidance and emotional support while brothers protect against bullying and other threats in the community (Edwards et al., 2006). Care commonly gives the caring – usually older – sibling increased power in the relationship, however sometimes conventional power hierarchies are disrupted and younger siblings care for older ones in circumstances where an older sibling is ill or where siblings position themselves as equals despite age differences (Edwards et al., 2006). Together these sibling practices of talk, activity, care and power provide a sense of the enactment of sibling relationships in everyday life.

While not specifically framed as sibling practices, other work also fits within the concept. For example, McIntosh and Punch (2009) highlight what can be considered

practices of barter, deals, bribes and threats. They highlight how, given siblings' lateral relationship where there is less of a power differential between them than in their vertical relationships with parents, siblings bargain and negotiate with each other. It is through 'strategic interactions' of bartering and bribing with objects, money or favours that siblings enact and negotiate power. Similarly, Gillies and Lucey (2006) describe what can be considered a practice of siblings sharing knowledge, experience and information. They highlight that siblings' relatively similar age means that they are well positioned to inform each other's experiences and that sharing of experience becomes particularly important as siblings move into young adulthood and broach new experiences that other older adults in their families might not have recent experience of. Again, these sibling practices of bartering, bribing and sharing information give a sense of the enactment of sibling relationships in everyday life.

Importantly, sociological work on siblings also highlights how their everyday practices affect the overall experience of the relationship. For example, Mauthner's (2002) study of 'sistering' highlights how it is at least partially through sisters' talking together that they each develop in their own subjectivity and then fall into patterns where their relationship feels like sometimes a best friendship or sometimes a close or more distant or troubled companionship. This means that the enacted practices of sibling relationships are important for the overall emotional and relational experience of the relationship as well.

Further, the sociological work on sibling practices provides a way of conceptualising how the enactment of the relationship may also be linked to each sibling's experience of other social categories and identities. For example, Edwards and Weller write of "gender as embedded in and constructed through the dynamics of mundane and situated interactions between brothers and sisters" (2014:197). They discuss how, as siblings grow towards adulthood, their gendered identities are constructed as siblings share mundane but gendered activities (brothers playing computer games together), have gendered expectations of each other (a brother "should" give a lift in his car to a sister, while his sister can tell him how he "should" style his hair) or compare gendered displays (sisters comparing clothing or

boyfriends). They argue that it is in such interactions that siblings learn and practice what gender identity means for them as young adults. For examining siblings' experiences of disability, this is an important insight: while assuming direct equivalence between siblings' experiences of gender and disability is problematic, this sociological work nevertheless provides a precedent for beginning to think about how disability may be similarly experienced through the everyday happenings between siblings.

For developing relational, sociological and phenomenological frameworks in sibling-disability research that can explore siblings with and without disabilities' everyday relations and overall experience of their relationship, this sociological work on siblings then provides two important precedents and insights. Firstly, it shows that there is a link between the enacted practices and interactions that occur at an everyday level between siblings and their overall experience of the relationship. Secondly, it gives a way of beginning to conceptualise how disability might also be experienced in these enacted practices between siblings. In this thesis, these insights are applied by focusing on both the everyday relations that directly occur between siblings with and without disabilities and on the overall experience that these relations generate for their sibling relationship, as well as by looking at siblings' experiences of disability in the everyday enactments of their relationship. The body of sociological work on siblings thus provides key avenues for deepening an experiential focus within sibling-disability research. However, this focus also requires a thorough understanding of disability itself and here the contributions of disability studies research are useful.

2.3. Disability studies research

Disability studies is an inter-disciplinary field of theory, research and practice focused on problematising disability so that it is seen as more than only incapacity, a problem or a tragedy (Linton, 1998, Goodley, 2011a). The field has developed through, for example, politics (UPIAS, 1976, Oliver, 1990), philosophy (Kittay, 2002b, 2005, 2006), bioethics (Shakespeare, 2006, Parens and Asch, 2003), phenomenology (Michalko, 2002, Titchkosky, 2003, 2007), the humanities (Snyder and Mitchell, 2001,

Linton, 1998, Koppers, 2009) and postmodern (Goodley, 2007, Reeve, 2012), feminist (Thomas, 1999, Shildrick, 2009), intersectional (Erevelles and Minear, 2010, Kafer, 2013), critical (Meekosha and Shuttleworth, 2009) and critical psychological (Goodley, 2011b, Goodley and Runswick-Cole, 2015) theories. These disciplines each apply a critically engaged conceptualisation of disability.

This variety of disciplinary perspectives means that disability studies reflects diversity of thought. Disability is variously explained via – but not limited to – structural (UPIAS, 1976, Oliver, 1990), personal (Thomas, 1999), global (Erevelles, 2011, Meekosha, 2011) and critical realist (Danermark, 2002, Shakespeare, 2006) lenses. Many concepts are used to explain disability, including – but again, not limited to – embodiment (incorporating disability into selfhood) (Turner, 2001), disability/impairment (impairment as bodily limitation, disability as restrictions of activity and oppression) (UPIAS, 1976, Oliver, 1990, Thomas, 1999) and ableism/disablism (ableism as a preference for able-bodied norms, disablism as discrimination against people with disabilities) (Kumari-Campbell, 2012, Goodley, 2014). Within this diversity, the common feature is that disability is treated as a complex phenomenon of interest.

Given this diversity, an exhaustive review of all disability studies perspectives is beyond the scope of this thesis. Instead the following sections give a selective account of the strands of disability studies that can contribute to an experiential understanding of disability for siblings. The strands that are most relevant include disability studies' contributions to theorising family, care and relationships.

2.3.1. Family

Disability studies has reflected on families in many ways. Some work has identified that families have interconnected experiences with their members with disabilities, experiencing stress and anxiety about social barriers, prejudices and service bureaucracy just as people with disabilities do (Dowling and Dolan, 2001, Chadwick et al., 2013) or having their lives seen as tragic by others in much the same way as happens for people with disabilities (Lalvani and Polvere, 2013). Other research has critiqued the role of families in over-protecting people with disabilities, fostering

dependency and isolation (Hussain, 2003, Soulis and Andreou, 2007), and has highlighted that families can contribute to abuse, neglect and questionable care practices towards people with disabilities (Calderbank, 2000, Kafer, 2013). Disability studies thus gives space for accounting for a diversity of experiences of family and disability. Within this diversity, two strands of work are particularly important for a relational focus on siblings.

Firstly, some disability studies research details how disability becomes part of family life. This work identifies how disability mediates families' communication practices by blending family voices where one family member provides assistance to another with communication (Green et al., 2012); becomes a part of families' shared humour by creating familial humour based on shared understandings of disability (Rieger, 2005); and becomes part of the culture of a family, through blurring challenging behaviour with simply being an outrageous family (Albee, 2013). Each of these contributions are about how the experience of disability becomes embedded within family relations. This work provides an important precedent for this thesis to conceptualise a so far unexplored focus on how disability might similarly become embedded within sibling relations.

Secondly, important work has also been undertaken where critical disability studies engages with issues of family, childhood and parenting. This body of work has taken a critical perspective on children with disabilities' and parents' experiences, including exploring how both children and parents sometimes contest professional and/or public codings of disability (Goodley and Tregaskis, 2006, Goodley, 2007, Fisher and Goodley, 2007, Goodley and Runswick-Cole, 2011, Curran and Runswick-Cole, 2013). This work has explored the resistance that both children with disabilities and parents employ to deal with the codings of disability imposed by others and to reassert their own meanings of disability and family. For example, there has been studies describing how children engage in resistant acts to contest others' responses to disability (Goodley and Runswick-Cole, 2012) and how mothers undertake emotional labour to manage such responses with strangers, friends and family (Runswick-Cole, 2013). This work provides a precedent for this thesis to explore the ways that siblings with and without disabilities may also resist professional or public

codings of disability in their everyday lives. Further, this body of work also sometimes applies concepts usually used to understand the experiences of people with disabilities – for example, the ‘tragic’-‘heroic overcoming’ dichotomy (Fisher and Goodley, 2007) and concept of the ‘rhizome’ (Goodley, 2007) – to explain the experiences of parents. This establishes a precedent for using theories usually applied to people with disabilities to unpack experiences of disability also for other family members. This thesis takes this precedent to, as detailed in Chapter 3, apply theory about the embodiment of disability to both siblings. This precedent is thus important for facilitating new experientially-based theory in sibling-disability research.

2.3.2. Care

Disability studies’ work on care can also contribute to understanding how disability may be experienced by siblings. Care has a complex place within disability studies, sometimes used for theorising people with disabilities’ personhood (Kittay, 2002b, 2005), but the power relations of care are also often critiqued for depicting people with disabilities as passive (Keith, 1992) and disempowered (Morris, 1997). As the feminist movement has highlighted, care is also associated with stress and marginalisation for caregivers (Forbat, 2002). Thus care is an area where, on both sides, conflictual politics and problematic power relations are sometimes at play (Hughes et al., 2005, Bondi, 2008, Kroger, 2009). Yet despite this conflictual setting, there is recognition that care and inter/dependency are also innate parts of familial obligation, human life and society (Kittay, 2002a, 2002b).

It is this latter disability studies work on the familial place of care that is important for siblings. A focus on siblings can pick up on work that questions how easily disability-related care can be separated from “the weave of any social relationship” (Beckett, 2007:365). Writing of spouses, Beckett states, “I may make tea for a partner because I care about them” – she then asks, “If that partner is or becomes disabled so that I have to make tea, do I then become a carer for them?” (2007:365). This question echoes for siblings. In a context where siblings commonly provide some care to each other even where neither has a disability (Cicirelli, 1995, Eriksen and Gerstel, 2002) – and where care has indeed been described a ‘sibling practice’

(Edwards et al., 2006) – to what extent does that care change when one sibling has a disability? These questions provide an opportunity for this thesis to extend disability studies work by opening up discussion of the questionable ab/normativity of siblings' roles in care and what their roles mean for experiencing sibling relationships.

Further, disability studies scholarship that recognises the importance of specific relationships to care is also important for siblings. Kelly (2013) writes of the relationship of a “frien-tendant”: a friend without a disability who sometimes acts as an attendant for someone with a disability. She writes of the awkwardness of doing tasks “not normally associated with friendship” (2013:785) and quotes Watson et al in saying that in friendship “disabled people and their assistants do not experience personal assistance in purely contractual, unemotional and instrumental terms” (2004:338). Within the concept of the “frien-tendant” is acknowledgement that the relationship in question matters to the conduct and felt experience of care. This insight provides space to ask what care is like in other relationships. Accordingly, this thesis explores what disability means for the care that is at least sometimes characteristic of sibling relationships.

2.3.3. Relationships

Finally, disability studies has also theorised relationships directly. Disability itself has been seen as relational and there have been relational examinations of positioning, inclusion and everyday relations. These approaches give important background to how disability might be considered relationally.

Firstly, disability itself has been conceptualised as relational. Thomas' social relational model defines disability as “a social relationship between people” (1999:40), a relationship based on oppression of people who experience bodily limitation by those who do not. Alternatively, disability is also seen as a relationship between people and context. This contextual relationship finds disability in its intersections with other categories such as gender, race, class and sexuality (Kafer, 2013, Rakes, 2013) or, for example, the Nordic relational model sees disability as a mismatch between a person and his or her environment (Tøssebro, 2004). These models give relational understandings of the nature of disability itself, although have

connotations not directly relevant to conceptualising the everyday relations that siblings share.

Secondly, other work aims to foster the social and political inclusion of people with disabilities by strengthening their relationships. Given the prevalence of social exclusion among people with disabilities, this work highlights that “people need social relationships that are supportive and positive to create a sense of belonging” (Nunkoosing and Haydon-Laurelut, 2013:11). Relational studies have thus examined people with disabilities’ friendships (Cavet, 1998, Anderson et al., 2011), community networks (Hillman et al., 2013) and intimate relationships (Knox and Hickson, 2001, Lafferty et al., 2013). These studies give a sense of the scope of relationships that sibling relationships may be part of.

Thirdly, some work discusses how one’s positioning in relationship to disability affects his or her understanding of disability issues. For example, in discussing civil rights histories, Carey (2010) identifies how the parents’ movement and self-advocates have different views of disability rights by virtue of their different relationships to disability: parents, reflecting their normative roles in nurturing and caretaking, envision rights to state care, whereas the perspectives of self-advocates who have a disability themselves are angled towards rights to their own voice and self-determination. This work can be drawn on to understand how siblings with and without disabilities might have different understandings or experiences of disability to each other.

However, given the focus here on the everyday relations and inter-personal relationships between siblings, a body of disability studies work that examines disability within inter-personal relations is most relevant. This inter-personal work points out that disability becomes meaningful through the everyday encounters and interactions that people share. This insight stems from a phenomenological focus on embodiment, where disability becomes embedded in one’s corporeal presence and/or identity. Titchkosky describes how “the meaning of disability lies ‘between’ people and not merely in people” (2007:18) because embodied disability is enacted through the “everyday talk and conduct surrounding disability” (2007:13). Thus, it is in the implications of disability for everyday relations, talk and conduct with others

that disability takes on meaning. This shared enactment of disability reflects “concerns with encounter, with relationship and becoming-in-the-world-with-others” (Price and Shildrick, 2002:62). For siblings, these references to “talk”, “conduct” and “encounter” may be considered to reflect everyday ‘sibling practices’ like talk or activity (Edwards et al., 2005), merging insights from disability studies and sibling research. This inter-personal work thus forms a major theoretical foundation for conceptualising how disability is experienced in the everyday relations between siblings. It will be further detailed as a key component of the theoretical framework in Chapter 3.

This body of inter-personal work also acknowledges the specificity of the experience of disability in particular relationships. Reflecting on his work as “a blind professor”, Michalko (2002:173) writes phenomenologically of going to class with a guide dog and of asking his students to find a way other than raising their hands to ask a question. He says, “I do things like everyone else no matter how differently I do them” (2002:149) and that he does this because “I am a blind professor” (2002:173): that is, he needs to do the activities that are part of his relationship to his students even if disability inscribes *how* he does them. Extrapolating from himself to others, he then writes of experiencing:

... a compelling and seductive need to be a professor, to be a lawyer, to be a mother, to be... It is the compulsion to be these things, disabled (2002:173).

Michalko’s (2002) work gives a sense of how disability inscribes and is experienced within the specificity of the particular relationships that one has in life: as a professor, mother or lawyer. This insight can be extended to explore how disability may be experienced within the specificity of the sibling relationship as well.

Others expand on how disability inscribes the practices that are specific to certain relationships. Kittay (1999) writes that while she enacts the same practice of socialising her daughter for acceptance as all mothers, she feels the influence of disability in her own practice as her daughter has a disability. For example, she says that socialising her daughter for acceptance means ensuring attractive clothes and cleanliness in a way that would be less necessary if not trying to get past the

“repugnance... of so many people toward disability” (1999:19). This work about the specificity of experiencing disability in the particular practices of motherhood gives an important precedent for exploring how disability may also be experienced within the specificity and practices of the sibling relationship as well.

Together this work from sibling research and disability studies research provides a foundation for a new experiential approach to exploring the everyday relational experiences of siblings with and without disabilities – one that goes beyond the existing frameworks of sibling-disability research. Yet for a focus specifically on young adult siblings, there is also a need to look to youth studies research in order to conceptualise how the experience of disability in sibling relationships is also set within the young adult life-stage.

2.4. Youth studies research

Focused on young people from their early-to-mid-teens to their mid-twenties, youth studies, like disability studies, is characterised by diversity. Youth studies includes focuses on young people’s identity formation (Erikson, 1968), their social, economic and inter-personal transitions towards adulthood (Settersson and Ray, 2010), their sense of futurity towards imagined futures (Worth, 2009), their deepening independence, responsibility and explorations in love, work and worldviews (Arnett, 2000) and their subcultures for expressing agency and resistance (Blackman, 2005, France, 2007). Disciplinarily, youth studies includes exploration of young people’s experiences from the perspectives of youth development and psychology (Erikson, 1968, Arnett, 2000), sociology (Bynner, 2005), geography (Worth, 2009) and cultural studies (Blackman, 2005). It also includes generational framings of young people’s contemporary social, cultural and historical conditions (Wyn and Woodman, 2006), structural framings of how institutions shape young people’s social and economic experiences (Bynner, 2005) and critical framings that question the assumptions of normative independence that underlie many images of young people transitioning to independent futures (Slater, 2013).

Like disability studies, the diversity of youth studies means that an exhaustive account of the field is beyond the scope of this thesis. The following sections

therefore selectively discuss the strands of youth studies that can contribute to exploring how young adult siblings experience disability within their relationship together. The relevant strands are those that link the experiences of young people with disabilities and ‘young carers’, that question normative definitions of independence and that contextualise young people’s changing relationships during young adulthood.

2.4.1. Young people with disabilities and ‘young carers’

One body of research within youth studies examines particular identities and characteristics that may influence young people’s trajectories into adulthood, either exploring the experiences of young people who have these characteristics or ways to promote their positive wellbeing, transitions, aspirations and outcomes. This work includes young people who are, for example, a migrant or refugee (Nunn et al., 2014), Indigenous (Senior and Chenhall, 2012), gay, lesbian or sexually-diverse (Talburt, 2004), who are outside of education, employment or training (Roberts, 2011, Muir et al., 2015) or who are in mental health, formal care or juvenile justice systems (Foster et al., 2010, Mendes and Moslehuddin, 2006). Significantly, both young people with disabilities (Hudson, 2006, Stewart et al., 2010) and ‘young carers’ – including children of parents with disabilities and sometimes siblings without disabilities (Smyth et al., 2011, Hamilton and Adamson, 2013) – also form part of this body of research. This research provides two useful contributions for a focus on siblings and disability.

Firstly, the inclusion of both young people with disabilities and their siblings, as ‘young carers’, is useful for recognising potential commonality between siblings with and without disabilities. Aside from the small body of work in sibling-disability research that includes both siblings, this strand of youth studies is one of the few places where there is recognition that both siblings with and without disabilities may similarly be living lives that are different compared to peers who do not have disability in their lives. While their actual experiences may differ from each other – with the literature reflecting on, for example, the lack of opportunities for young people with disabilities (Abbott and Carpenter, 2014) and on ‘young carers’ bounded agency in education, work and social relationships (Hamilton and Adamson,

2013) – the presence of both siblings in this section of youth studies nevertheless establishes that disability may be influential in both of their young adult trajectories. This insight provides a foundation for this thesis to explore the experience and implications of both siblings living young adult lives influenced by disability alongside each other.

Secondly, siblings without disabilities are recognised in this work as ‘young carers’ (Smyth et al., 2011, Hamilton and Adamson, 2013). Given that ‘young carer’ is a framing of siblings that has also been problematised for prioritising care relationships over sibling relationships (RANZCP, 2011), it is important to understand what and how siblings themselves think of this framing. What do they think of the carer identity and of how it relates to their experience as siblings? What does it mean for their relationships with each other? This thesis builds on work that explores the nexus of when, where and why siblings do and do not consider themselves ‘young carers’ (Smyth et al., 2011, O’Dell et al., 2010) and raises new questions about the experiential implications of a ‘young carer’ framing for the sibling relationship itself, considering its implications for the everyday relations and overall experience of the relationship between siblings.

2.4.2. Trajectories towards independence

Other areas of youth studies relevant to young adult siblings are those proposing and critiquing the idea that young adulthood involves young people moving towards increased independence and responsibility. This movement includes transitioning out of school, into work, into independent living and into partnership and parenthood (Settersson and Ray, 2010), but also includes young people’s personal development and sense of adult identity (Erikson, 1968, Arnett, 2000). This area of youth studies gives a context for understanding the expectations on young people and the changes that may be occurring in their lives during young adulthood.

However, the idea of moving towards a defined independent state has also been critiqued for assuming a linear progression through expected, normative transitions that may not apply to everyone (Wyn and Woodman, 2006, Worth, 2009, Slater, 2013). It is now generally accepted in youth studies that movement into

independence is non-linear for many young people (Wyn and Woodman, 2006, Worth, 2009). The challenge of youth studies is then to strike the balance between using the framework of normative transitions to independence to understand the changes that *may* be happening in young people's lives, but not to assume that these normative transitions are necessarily happening in the same ways for all young people, at the same time or in a consistent linear order. As further discussed in Chapter 3, the theoretical framework for this thesis accordingly recognises that there are changes normatively expected of young people and that regardless of whether they actually achieve these themselves, the changes remain a normative background against which young adult siblings' experiences occur. This normative background may then shape siblings' perceptions of what actually happens for each of them.

These debates about young people's movement towards independence are particularly pertinent for siblings with and without disabilities. Research highlights that some young people with disabilities do not meet normative young adult transitions (Stewart et al., 2010, Hudson, 2006) and that some siblings without disabilities may have bounded agency for doing so (Hamilton and Adamson, 2013). Further, scholars at the intersection of disability and youth studies have highlighted that common visions of young people's independence are linked to concepts of individualism and autonomy that do not recognise the interdependencies of disability (Priestley, 2003), the interconnected lives that many young people with disabilities lead (Slater, 2013) or the 'early transitions' of some young people who provide care (Hendry and Kloep, 2007). This background from youth studies then highlights that disability may influence both siblings with and without disabilities' movement into independence, yet potentially in different ways to each other. There is then opportunity to examine whether and how siblings with and without disabilities have young adult experiences that are different to each other and, if so, what the relational implications of this are. What do siblings think of each other moving into young adulthood? What might this mean for their relationship? These experiential questions are explored in this thesis.

2.4.3. Changing relationships

Finally, insights from youth studies about young people's changing relationships also have important implications for siblings. Young adulthood is a time when young people normatively develop some autonomy from family, particularly from parents, but also retain a level of dependence on family as they are still developing into adult roles (Aquilino, 2006). Simultaneously, friends, peers and partners become increasingly significant to young people (Collins and van Dulmen, 2006, Conger and Little, 2010). Further, it is a time when many young people deepen in relational maturity (Kaplan et al., 1991) and learn to accept responsibility for themselves (Arnett, 2000). In this respect, young adulthood is a time of significant relational change for many young people, where they normatively move from child to adult relationships. Yet, like the insights above about independence, young people's changing relationships also remain a normative background: young people may change in their relationships to different extents and in different ways.

For thinking about the everyday relations that siblings share and the overall experience of their relationships, young people's relational changes are significant. The changes give a context to explore how the sibling relationship itself may change during and/or be specific to young adulthood. Do siblings with and without disabilities have relational experiences together that are specific to young adulthood, and if so, what are they, how do they happen and why? What does young adulthood mean for sibling relationships, especially in the context of disability? These questions and the context of young adult siblings' changing relationships set the frame for this thesis to explore siblings' experiences together within temporal context.

2.5. Conclusion

This literature review identified the need for more research about the everyday relationships that siblings with and without disabilities share. However, the sociological, relational and phenomenological frameworks necessary for this everyday, relational focus have not so far featured in sibling-disability research. Accordingly, the literature review provided a selective account of what sibling

research, disability studies research and youth studies research offer for developing a relational view of siblings.

Three key areas have been identified that require further work in order to understand how disability figures in siblings' everyday relationships. Firstly, there is a need to know more about how disability figures in the enactment of siblings' everyday relations, including those that are characteristic specifically of the sibling relationship, as well as how it figures in the overall experience of the sibling relationship. Secondly, there is a need to clarify and explore the implications of disability-related care for the relationships between siblings with and without disabilities. Where some care is normative among siblings irrespective of disability, it is important to understand more about whether and how disability influences the experience of care between siblings with and without disabilities. Finally, there is a need for greater exploration of how the young adult experiences of both siblings interact with their sibling relationships. This includes developing an understanding of how siblings think about their possibly different trajectories into adulthood when disability is present in each of their lives and about how their relational experiences may be specific to their life-stage. Focusing on how disability figures in the relationship, on the experience of care and on siblings' young adult experiences forms the basis this thesis. However, the analysis and findings are also based on a theoretical framework that defines the approach to each of the core concepts of the research. This framework is detailed in Chapter 3.

Positionality 2. The myth and the monolith

That thing.

That thing where the literature measures sibling relationships in terms of what they are not.

I have lived that.

I have lived it *hard*.

I suspect that it is uncommon for people not to know when a child or a teenager has a twin. Yet to the external eye, I function in this world as just one unconnected person – and so throughout my life I have had the same strange conversations time and time again where people find out for the first time that I am a twin. Typically, the conversations go in one of two directions: either the other person does not believe me at all and I am left in the ridiculous situation of trying to convince them of a fundamental reality of my existence or I get hit with *those* questions, those ridiculous questions that have become imprinted upon my identity in the strangest of ways:

Wow! That's so cool – do you look the same?

Think the same?

Act the same?

Have the same friends?

The same interests?

It's a stereotype – I know that. With some part of my objective brain, I have always known that this is a stereotype, something that is not real; a societal wish, an imagining, a myth; and that no one, no twin, really completely has this. But despite knowing that, I still always felt the suffocating weight of expectation: *Measure up*, the questions said, *measure up now; do it now or you're not 'real' twins*.

But we didn't measure up. As a child and teenager, I found myself always answering 'no' to those questions – and in that 'no', disability was always the monolith. Look the same? No – sure, our hair and eyes are the same, but her wheelchair and physical disability dominate too much to really be able to honestly answer 'yes' to that question without qualification. Think and act the same? No – for so long I believed her intellectual disability meant our thinking was so different to each other. Have the same friends? No – we went to separate schools so she could attend a support unit and school has so much to do with friends when you are a young person. Have the same interests? No – her obsession with respite carers dominated everything and how could I ever share in that? The answer was always 'no' and disability always dominated the 'no'.

However, it followed that in constantly answering 'no' to the myth – and in disability dominating my 'no' – I came to always see our relationship in the negative, for what we were *not*, not for the situated *real* relations that we actually share; the relations where care merges with humour, where assistance is a way of spending time together, where the patterns of our thinking are similar even if our actual thoughts are pitched differently, where she is the place I come home to, where I rely on her simplicity and predictability as a source of stability in my life.

But set against the monolith, the myth, all of these situated *real* relations eluded me and, for so long, all I ever saw was the myth that we were so clearly not fulfilling. The myth became a dream and an aspiration that I fell for and wished for, desperately. It took me so long to see past that monolithic myth and to value us *for what we actually are* in all its disability-inflected uniqueness. I got there in the end, but it took me so long to get there.

Now a scholar, I can see this story of defining sibling relationships in terms of what they are *not* imprinted across the literature. Deeply, I feel the personal consequences of those studies that say that the relationships between siblings with and without

disabilities are less warm, intimate, egalitarian and conflictual than those of other siblings where neither has a disability (Dallas et al., 1993a, 1993b, Eisenberg et al., 1998, Kaminsky and Dewey, 2001, Doody et al., 2010, Love et al., 2012). Those studies take away the opportunity to value what we actually are. And so as a scholar – and as a sister – something at the core of me keeps coming back to the importance of studying, affirming and understanding siblings with and without disabilities for who and what they *are* together, rather than what they are *not*. I know that not all siblings will be like my sister and I, but I believe that, in all their diversity and variety, many siblings will nevertheless have deeply situated ways that disability appears in their relationships and that, whatever these ways are – whether they are enjoyable, difficult or somewhere in between – I want them to be recognised. Unabashedly, I want my work to show the situated *real* relations between siblings with and without disabilities, unpacking the unexpected, unseen ways that disability figures in their relationships. I want to create a space for whatever it is – in all its diversity and variety – that siblings are to be okay, to be expected, to be accepted. I want siblings with and without disabilities to find in these pages words for the elusive realities of their relationships lived in the presence of disability that maybe they have never had words for before. If this work can recognise *more* about siblings' relationships, creating space for who and what they really *are* together, then I see this as new and ultimately useful knowledge.

Chapter 3. Theoretical framework

The literature review established that a key task for this thesis is addressing the gap in knowledge about how disability figures in the everyday relations and overall experience of the relationships between siblings with and without disabilities. This chapter explains the theoretical framework used to explore how disability figures in these sibling relationships. The framework draws together sociological, relational and phenomenological approaches. It combines relational, critical realist and phenomenological theories to explain inter-personal relationships and disability. In explaining the conditions that influence sibling relationships, it also draws on theories about young adulthood and constellational, ecological and intersectional influences.

The theoretical framework was developed iteratively. Some conceptual background was developed during the initial conceptualisation of the study, however the process of data analysis itself also informed which theories best accounted for participants' contributions. The result is that the framework combines an initial focus on relational theory and contextual influences with the phenomenological concepts of embodiment and enactment that emerged as pertinent based on participants' accounts of their experiences.

3.1. Relationships

The theoretical framework begins from relational ontology. Relational ontology describes how people live in an interconnected web of existence (Mauthner and Doucet, 1998), where shared experiences, interactions and decisions are fundamental to social life and lived experience (Mauthner and Doucet, 1998, 2003, Ward, 2014). As highlighted in Table 1, as an alternative to the widespread Western emphasis on individualistic notions of independence, rationalism and self-determination (Mauthner and Doucet, 1998, 2003), relational ontology emphasises that the lives and trajectories of individuals cannot be separated from those of the

people around them. This interconnected existence imbues all social life and lived experience.

Table 1: Relational ontology vs. Western individualism

Western individualism	Relational ontology
Individualistic beings	Relational beings
Individual selves	Selves-in-relation
Personal choice and control	Shared, relational decisions
Autonomy, independence	Inter-dependence
Separate	Connected
Self-sufficiency	Interaction
Rational	Emotional
Reason	Perception
Clear	Murky, messy
(Surrey, 1991, Mauthner and Doucet, 1998, 2003, Mackenzie and Stoljar, 2000, Furlong, 2013, Ward, 2014)	

Relational ontology has been widely described and applied in feminist scholarship, often as an orientation to theorising care (Bondi, 2008, Weller, 2012), ethics (Kittay et al., 2005, Kittay, 2013) or approaches to analysing research data (Mauthner and Doucet, 1998, 2003). Here, relational ontology sets a basis for seeing that siblings with and without disabilities live interconnected, relational lives and that this interconnection is fundamental to describing what happens to and for them. Beyond ontology, there is however also a need to understand siblings' interconnection through a more concrete conceptualisation of their inter-personal relationships and everyday relations.

Defining inter-personal relationships is complex and firm definitions are elusive. Indeed, Jamieson and Milne (2012:266) comment that, "It is telling that, in his reflections on 'What is a Relationship', the anthropologist Miller (2007) does not actually offer a definition". In the absence of a firm definition, Hinde (1981:6) offers the following description:

Relationships have both behavioural and affective/cognitive aspects; they depend on interactions yet involve more than interactions; their

parts must be studied, but so must the whole; they must be related to the personalities of the participants and to the social context in which they exist.

Hinde's description of the different parts of relationships is useful for conceptualising what the 'everyday relations' between siblings entail. Hinde acknowledges the behavioural aspects and interactions that occur within relationships – for siblings, this could be, for example, the sibling practices of talk and activity (Edwards et al., 2005). However, in acknowledging the affective and cognitive aspects of relationships and the relevance of personality, Hinde's description also allows an understanding of siblings' emotions towards and perceptions of each other and of their relationships. Further, Hinde also allows an understanding that social context situates relationships. This combination of behaviour, interactions, emotions, perceptions and social context synthesises a picture of the many parts of inter-personal relationships and of what the content of siblings' 'everyday relations' entail.

Yet Hinde also highlights that relationships “depend on interactions yet involve more than interactions” (1981:6) and that a relationship's “parts must be studied, but so must the whole” (1981:6). This suggests that an overall experience needs to be accounted for in relationships: an emergent relational experience that is more than the sum of the relationship's parts and that expresses what the sum of these parts means or how the sum is experienced by the people in the relationship. The need to theorise this overall or emergent aspect of relationships is particularly important due to the study's focus including the overall experience of the sibling relationship. Moreover, the literature review in Chapter 2 identified the particular need to fill the gap in knowledge about the overall experience of the sibling relationship for siblings with and without disabilities. However, theorising this overall experience is a complex task because of its intangible nature.

'Relationality' is one useful concept for beginning to theorise this overall relational experience. Thayer-Bacon describes relationality as a concept that encompasses and/or is expressed through “mystical, mysterious, poetic kinds of qualities” (2010:149). In reflecting on her use of the concept of relationality, she says:

I want to emphasize how things overlap, associate, integrate, refer, compare, connect, relate to each other, and in that relating, how things affect each other, and change each other (2010:149).

Perhaps as a result of expressing these “mystical, mysterious, poetic kinds of qualities” (Thayer-Bacon, 2010:149), relationality is a concept that is “complex, elusive and difficult to grasp” (McCarthy, 2012:185). For this reason, there is importance to coming to a working definition of the concept. McCarthy and Prokhovnik provide the clearest definition, using a phenomenological approach to articulate “relationality as lived out in embodied practices and felt experiences” (2014:37); they describe relationality as concerned with meta-level relational experiences such as “forms of being, experience, connection, inter-subjectivity and communication” (2014:36) and as influenced by an abstract “sense of being ‘bound up’ with others” (2014:31). In this sense, McCarthy and Prokhovnik’s work provides the basis for conceptualising relationality as an overall meta-level felt experience of being in a relationship with another person.

However, there are also many other disparate references to relationality in a wider range of works that can be used to broaden this definition. Mapping where these references occur and which other concepts relationality coincides with reveals other ideas and experiences that relationality either relates to or, at least in part, resembles. While these references are often not explained or used in a consistent way, they remain useful for building a fuller understanding of how the meta-level felt experience of a relationship is contextualised. Based on this mapping, Table 2 summarises four categories of concepts that relationality coincides with. Some concepts provide more detail about what the overall felt experience of a relationship may entail, while others show how that felt experience is contextualised through the care, positioning and the context/conditions of the relationship.

Table 2: Meso-level mapping of relationality

Relationality coincides with references to ...	<i>Concepts that detail the overall felt experience of a relationship</i>
	Affect (Ward, 2014, Carrillo in Rakes, 2013)
	Inter-subjectivity (Bondi, 2008)
	Memory, biography, embeddedness, messiness (Smart in Wilson et al., 2012)
	Embodiment (McCarthy, 2012, Rainey, 2011)
	Felt experience and phenomenology (McCarthy, 2012)
	<i>Concepts that contextualise the overall felt experience of a relationship</i>
	The exchange of care and reciprocity in a relationship
	Care (Rainey, 2011, Ward, 2014, Bondi, 2008, Weller, 2012, Philip et al., 2012)
	Inter-dependency and reciprocity (Weller, 2012)
	Wellbeing (Ward, 2014)
	Nurturing (Macmurray in McArdle, 2010)
	The positioning that happens within a relationship
	Orientation towards others (Carrillo in Rakes, 2013)
	Multiplicities, contingencies and shifts (Carrillo in Rakes, 2013)
	The experience of the conditions and context of a relationship
	Places and spaces (Ward, 2014, Edwards and Weller, 2014, Weller, 2012, Goodley and Roets, 2008)
	Time (Edwards and Weller, 2014, Goodley and Roets, 2008)
	Resources – relationality “draws in objects, ‘things’ and ‘stuff’” (McCarthy and Prokhovnik, 2014:37)

Seeing this scope of concepts that relationality coincides with helps to clarify that where relationality is understood as the overall felt experience of a relationship (including the overall felt experience of its everyday relations – behaviour, interactions, emotions, perceptions and social context), it is also contextualised through the care, positioning and conditions/context of that relationship. In this

sense, the meso-level mapping supports a working definition of relationality as expressing an overall, meta-level felt experience of a relationship; a felt experience that is more than the sum of a relationship's parts and that exists at an emergent and deeply contextualised level. The range of concepts reflected in Table 2 also highlights that relationality may sometimes be shared by both siblings or may be one sibling's own personal felt experience of the relationship.

Accounting for relationality in theorising sibling relationships is just as important as theorising siblings' everyday relations. For this reason, alongside accounting for these direct relations or parts of the sibling relationship, the analysis in the following chapters aims to account for siblings' relationality by applying the working definition above, with a focus specifically on understanding the implications of disability for relationality. The thesis will examine what the presence of disability within young adult siblings' everyday relations means for their overall experience of their relationality as siblings. However in order to do this, the theoretical framework also draws on conceptual consideration of disability itself.

3.2. Disability

In adopting a relational ontology, theorisation of disability also has to be broadly relational. In politics, activism, sociology and critical theory, there is much debate about how to theorise disability. These debates have shifted the theorisation of disability from only a clinical, medical experience of an impaired body or mind towards, for example, definitions that see disability as exclusionary societal structures or barriers (UPIAS, 1976, Oliver, 1990, Thomas, 1999), an economic-materialist phenomenon (Finkelstein, 1996) or an embodied experience of identity (Michalko, 2002, Titchkosky, 2007).

In a relational framing, these various theorisations of disability all hold potential to either influence or figure in the different parts of relationships. For example, physical, intellectual or cognitive impairment might influence siblings' behaviour towards each other; siblings' embodied experience of disability identity might reflect much about their emotions towards and perceptions of each other; and social or political experiences of disability may influence the social context of relationships. In

this sense, a relational orientation to disability requires a theoretical perspective that can account for the many ways that disability and relationships may interact or become part of each other. That is, in a relational perspective, disability must be a multi-faceted phenomenon.

To theorise disability as a multi-faceted phenomenon, a critical realist perspective is useful. Critical realism argues that disability operates with a range of levels of explanation (Bhaskar and Danermark, 2006). For example, Bhaskar and Danermark (2006) give the examples that physical, biological and psychological elements as well as social, economic and cultural elements all simultaneously interact with each other to form disability. Other cognitive, emotional, temporal or political elements of disability might also be reasonably added to their examples. The existence of these different elements is an independent reality (Danermark, 2002); that is, the range of elements exists whether people acknowledge them or not. For different people in different circumstances and at different times, these different elements of disability interact and manifest differently in their lives (Bhaskar and Danermark, 2006). This means that although disability is always a complex interaction of multiple factors (Shakespeare, 2006), sometimes primarily bodily or cognitive, primarily social or primarily economic experiences of disability may come to the forefront for individuals. This provides an understanding that multiple facets of disability may be relevant to relationships, but sometimes some may seem or be more significant than others.

Critical realism acknowledges that the external, independent reality of disability is too complex to be perceived in full by those experiencing disability. It explains that people have transitive understandings of disability, which are “a social product much like any other” (Bhaskar, 1978:21 in Danermark, 2002:8). That is, people have different ways of understanding disability which are partial and ultimately a product of their social conditions (Danermark, 2002). Relationships can be considered one part of the social conditions that influence these transitive understandings of disability. This means that not only may disability influence relationships, but also that relationships may influence or become part of people’s understanding and experience of disability itself. A critical realist conceptualisation of disability thus

allows an understanding of how disability can be a fundamentally relational experience for siblings.

A critical realist view of disability is applied in this thesis. Given the attention to relationships and young adulthood, the elements of disability considered to most reflect these two areas will be the focus: that is, the physical, cognitive, emotional, social and temporal elements of disability. Yet in order to thoroughly apply this approach, it is also necessary to elaborate a framework for *how* disability becomes part of relationships and *how* relationships become part of the transitive understandings of disability. Here concepts of embodiment and enactment are central.

3.3. Interaction between disability and relationships

Drawing a the tradition that utilises Merleau-Ponty's (1958 [1945]) work on the phenomenology of everyday life, the concepts of embodiment and enactment – already suggested as pertinent in the literature review – can further clarify *how* disability and relationships become part of each other. Embodiment and enactment are also particularly appropriate concepts here as they link to the meso-level mapping of relationality, which included embodiment, felt experience and phenomenology (see Table 2) (McCarthy, 2012, McCarthy and Prokhovnik, 2014).

In embodiment, the body (Turner, 2001), an assistive object (Iwakuma, 2002) and/or the social experiences that attend to that body or object become part of a person's conception or feeling of their own self or being. This could be part of that person's corporeal practices, such as talking, walking, sitting, dancing or eating (Turner, 2001) or part of that person's subjective experience of their own identity (Iwakuma, 2002) or self (Turner, 2001). Either way, the body and the objects and social experiences attendant to it come to mark a person's "sensuous and practical presence in the life world" (Turner, 2001:260).

For siblings with and without disabilities, embodiment can express how either a bodily, cognitive or socially-conditioned experience of disability may become part of an individual sibling's feelings of self. This might be part of that sibling's corporeal

bodily/cognitive practices or his or her identity. The broad scope of functional, supportive, assistive and social elements that may become embodied also shows how embodiment can incorporate the multi-faceted view of disability that is appropriate to relationships. While the concept of embodiment has mostly been used to describe the experiences of people with disabilities, siblings without disabilities may also be understood to embody some of the social, economic, cultural or psychological elements of disability within their conception of their identity (Iwakuma, 2002) or self (Turner, 2001). Thus, embodiment can express how both siblings with and without disabilities may experience disability within their own selves.

However, while embodiment happens within individuals, the “life world” in which embodiment is experienced “is already social” (Turner, 2001:260) and so “embodiment is not an isolated or individual project; it is located within a social and historical world of interconnected social actors” (Turner, 2001:260). This means that embodiment has important implications for how relationships between those interconnected people are enacted. As established in Chapter 2, Titchkosky (2007) particularly unpacks the connection between the embodiment of disability and enactment in a way that relates to inter-personal relationships.

Titchkosky writes that once a person embodies disability, their “lived-embodiment” (2007:17) is enacted through the everyday relations they share with other people. She describes how embodiment is made meaningful through the shared enactment of the “everyday talk and conduct surrounding disability” (2007:13). She suggests that, “people make relations with what has made them” (2007:18): that is, people form their relationships through the experiences, including the experiences of disability, that have formed them as individuals. For example, a person’s embodied corporeal practices, such as how they talk, walk or move with disability (Turner, 2001) might influence their “talk” or “conduct” with others. Equally, their perceptions of their identity (Iwakuma, 2002) or self (Turner, 2001) might influence what they say to others or how they act with them. At the same time as a person’s embodiment influences how they act with other people, those other people’s embodiments also influence their relations with that person. This means that the

embodiment of disability inherently plays out through the enactment of shared everyday relations. Through these shared relations people come to experience and understand what disability means for them in their relationships: “How we come to imagine disability has everything to do with how we forge relations between ourselves and others” (Titchkosky, 2007:18). This relational imagining of disability speaks to critical realist transitive understandings of disability (Danermark, 2002). It gives a process to appreciate how these transitive understandings may indeed be relationally formed and influenced.

The concepts of embodiment and enactment thus give a framework for understanding how multi-faceted disability influences relationships as well as for understanding how relationships become part of the transitive understandings and experience of disability. Importantly, embodiment and enactment also link to what is already known about how siblings enact their relationships. For siblings, the “talk” and “conduct” (Titchkosky, 2007:13) through which embodied disability is enacted could include the relations specific to sibling relationships: ‘sibling practices’ of talk, activity, care, negotiating power relations and sharing experiences (Edwards et al., 2005, 2006, McIntosh and Punch, 2009, Gillies and Lucey, 2006). Embodiment and enactment thus offer a flexible framework that can build on existing knowledge about siblings and can offer a way to explore the relational experience of disability within the specificity of the sibling relationship.

3.4. Young adulthood

As this thesis focuses specifically on young adult siblings, it is also important to theorise how young adulthood sets a context both around siblings and around experiences of disability. The life course is a major concept in sibling research, because sibling relationships are one of the few relationships with the capacity to span the whole life course: childhood, adolescence, young adulthood, adulthood and old age (Cicirelli, 1995). A life course perspective highlights that at these different life-stages different issues come to the fore and different events, decisions, roles, transitions and turning points are associated with different times of life (Priestley, 2003, Elder et al., 2004). Given its focus on young adult siblings, this thesis

focuses specifically on the life-stage of young adulthood, but with recognition that this period exists as part of a broader scope of life-stages.

Three streams of theory can account for siblings' trajectories through the events, decisions, roles, transitions and turning points of young adulthood. As established in Chapter 2, these changes and transitions may not however apply to all young people or may be experienced in a variety of situated ways. The changes and transitions are therefore treated here as a *normative background* to siblings' experiences rather than assumed to apply to all. However, these changes and transitions are nevertheless used to articulate what *may* be happening around young adult siblings as they embody and enact disability in their sibling relationships.

Firstly, young adulthood normatively includes young people's transition through 'core timing shifts'. These shifts include transitioning out of school, into work, into independent living, into partnership and parenthood (Setterson and Ray, 2010). For some young people – especially those in a socio-economically advantaged, Western context, as is the case for most of the participants in this study – other milestones are also common, including learning to drive, travelling, tertiary education, civic engagement, cohabiting (Lowe et al., 2013) and becoming financially independent (Arnett, 2000).

Secondly, young people also experience subjective changes in identity, relationships and self-sufficiency. Young adulthood is a time of learning to accept responsibility for oneself, to make independent decisions (Arnett, 2000), to develop in relational maturity (Kaplan et al., 1991) and to move away from family (Aquilino, 2006) and instead focus on relationships with friends, peers and partners (Collins and van Dulmen, 2006).

Thirdly, young adulthood also normatively includes young people's explorations in relationships, work and worldviews (Arnett, 2000) and an accompanying sense of becoming or futurity (Worth, 2009). Young adulthood is a time when young people commonly extend their identifications, widen their social and personal interests, set their motivations and expand their self-image or perceived place in society (Worth, 2009).

These changes and transitions represent a general picture of what *might* be happening in some young adult siblings' lives. Siblings with and without disabilities may or may not change in these ways or may do so along a continuum where these changes are done more or less substantively or in situated ways. Regardless, the normative expectation that young people *should* experience change and transition still frames their experiences either way. As siblings navigate these young adult changes and transitions in the context of disability, the concepts of embodiment and enactment suggest that any struggles they experience may become embodied in their identity and then enacted within their everyday relations together. Where disability makes some changes and transitions difficult, complicated or not possible for some young people with disabilities (Stewart et al., 2010, Hudson, 2006) or siblings without disabilities (Hamilton and Adamson, 2013), these complications may then be understood as examples of the embodiment of disability within their young adult selves. The normative background and expectations of young adulthood may thus become part of young adult siblings' relationships with each other in interaction with disability.

However, beyond change and transition, young adult siblings also embody and enact disability within a specific generational context. The concept of generation captures a sense of "people who belong to a common period of history or whose lives are forged through the same conditions" (Wyn and Woodman, 2006:496, Mannheim, 1998 [1952]). By virtue of being born – often – within a few years of each other, many siblings share a generation, where their lives are forged through similar social, cultural and historical conditions, particularly compared to other older members of their families, such as parents. In this sense, this thesis uses the concept of generation to express a general reference to the contemporary conditions that siblings together grow up in and share, especially compared to older family members, rather than as a specific reference to an established generational system, such as Generation Y and Z (in which the siblings in this study are located).

This kind of general generational lens gives a view to the contemporary conditions within which young adult siblings experience disability and their relationships. This includes the conditions of contemporary young adulthood. Wyn and Woodman

(2006) describe how current young people's lives are forged through economic, social, cultural and political conditions that emphasise young people as consumers, choice-makers and flexible workers and that bring concerns with responsibility, choice, balance in life and valuing relationships to the fore. This gives a sense of the contemporary expectations and values within which both siblings and their experiences of disability are set. Similarly, a generational lens gives a view to what the contemporary views and circumstances of disability may mean for young adult siblings' relationships – for example, a view to what the rise of more accessible technologies (Hynan et al., 2014, Schreuer et al., 2014) or what changing disability service philosophies (Atkin and Tozer, 2014, Purcal et al., 2014) may mean for sibling relationships. Further, siblings who are young people *now* are also one of the first generations to live completely without institutionalisation within their lifetimes and thus that can have everyday interactions together. A generational lens thus importantly acknowledges the influence of social, cultural and historical conditions upon young adult siblings.

3.5. Social context

Relationships are also influenced by social context (Hinde, 1981). This thesis primarily focuses on young adulthood as the main contextual factor of influence for siblings. However, some other social factors feature less prominently in the analysis, but are incorporated here in the theoretical framework to understand the broader social context that influences sibling relationships. These factors are detailed below and are applied mainly in Chapter 7.

Firstly, constellational factors – such as birth order, age gaps, gender pairings and family size – are key influences upon many sibling relationships. Siblings' constellations influence their interactions and activities (Edwards et al., 2006), power relations (Mauthner, 2002), roles and responsibilities and often personalities (Toman, 1994 [1961]). For example, older female siblings in large families often have more care responsibilities and power over younger siblings (Cicirelli, 1995). In this way, siblings' constellational factors give a context to the enactment of their sibling relationships.

Secondly, ecological factors also influence sibling relationships. An ecological approach recognises that siblings are set within micro-systems (families, schools, peers), meso-systems (connections between micro groups), exo-systems (wider communities) and macro-systems (structures, services, policies, laws) (Bronfenbrenner, 1979). Each of these systems forms a context for individual experiences and inter-personal relationships. An ecological approach can account, for example, for how sibling relationships are enacted in the context of other family relationships, such as the spousal relationship and each parent-child relationship (Minuchin, 1974) and can account for how the family's resources, communication and routines may impact sibling relationships (Giallo and Gavidia Payne, 2006). Equally, an ecological approach can also account for how structural factors, such as welfare benefits, disability services or political discourses, may influence sibling relationships.

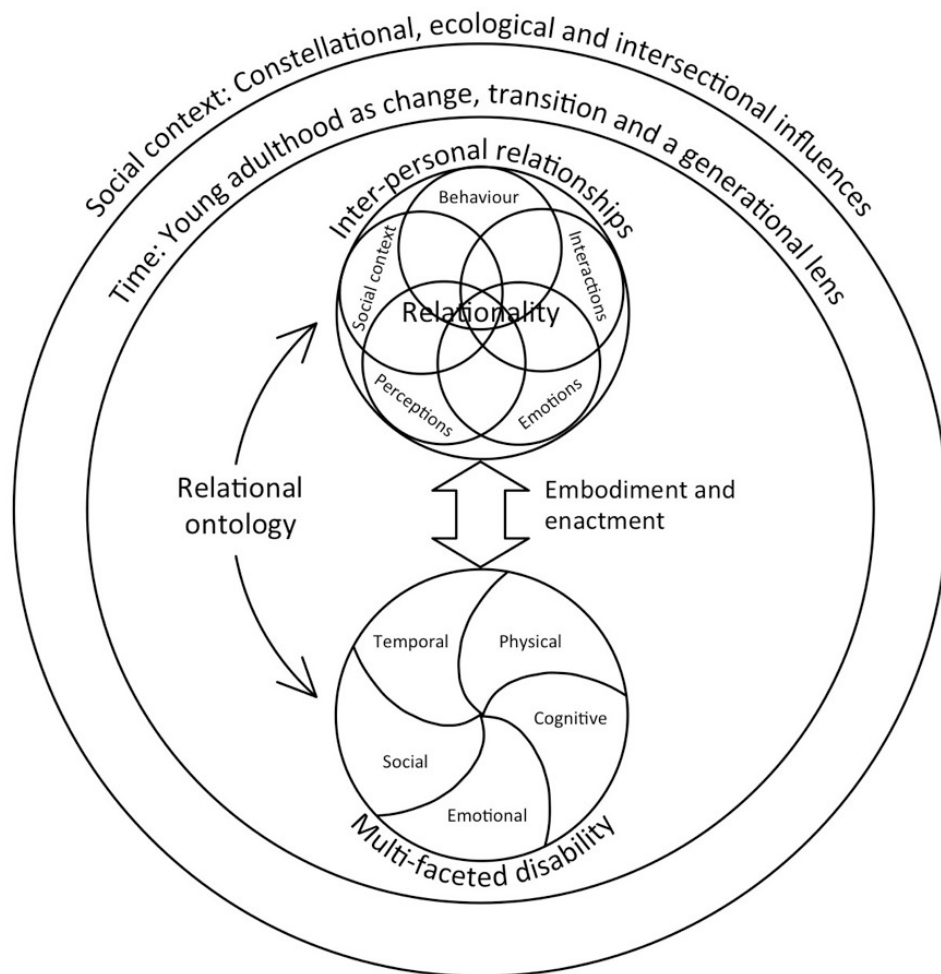
Finally, intersectional factors also influence sibling relationships. Theories of intersectionality highlight that social categories and identities do not exist discretely or separately, but rather overlap to provide situated, contextualised experiences (Crenshaw, 1989, Collins, 2003). Applied to disability, an intersectional approach acknowledges that disability is experienced in intersection with, for example, gender, sexuality, culture and class (Goodley, 2011a). An intersectional approach acknowledges that just as siblings may embody disability, so too may they embody experiences of gender, sexuality, culture and class. In their enactment of their sibling relationships, these multiple overlapping influences may then *together* influence their relations with their brothers and sisters.

3.6. Conclusion – Theoretical framework

Studying how disability figures in the relationships between siblings with and without disabilities – including their everyday relations and overall experience of the relationship – is a complex task that requires a theoretical framework that can incorporate diversity in inter-personal relationships, disability, time and social context. Starting from relational ontology, this chapter has drawn together theory about inter-personal relationships and relationality; a critical realist perspective of

disability; embodiment and enactment; views of young adulthood as transitional and generational; and elements of constellational, ecological and intersectional theories. Together this work offers a theoretical framework that will be applied to understand how siblings with and without disabilities relationally experience disability. This framework is depicted in Figure 1.

Figure 1: Theoretical framework



As Figure 1 illustrates, the theoretical framework ultimately sees both inter-personal relationships (in this case, sibling relationships) and disability as two complex experiences that inter-relate and become part of each other through everyday processes of embodiment and enactment. The inter-relationship between relationships and disability and the processes of embodiment and enactment all occur within a broader context, which, for young adult siblings, includes the changes,

transitions and generational context of young adulthood, as well as constellational, ecological and intersectional influences.

The theoretical framework offers a relational way of understanding everyday and overall experiences of sibling relationships and disability, within time and context, for siblings with and without disabilities, drawing both on theory and on the precedents from the literature in Chapter 2. Chapters 6-9 apply this framework to siblings' experiences and Chapter 10 discusses some of its implications for knowledge, evidence, policy and practice about siblings and disability. However, first Chapter 4 explains the methodology used to implement the focus on siblings, disability and young adulthood.

Positionality 3. Strange juxtapositions

I take my laptop and write sections of this thesis at my sister's hospital bedside.

I write academic words about siblings while machines beep and my sister rambles deliriously and screams.

I both marvel at and try not to think about the strange juxtaposition of it.

It is part of a story inherent to this research.

We are told as scholars to account for our 'intellectual biographies' (Thomas, 1999, Stanley, 1990, 1996), the stories of our own lives that have shaped our thoughts and brought us to the analyses and words on our pages. Although I have been involved in issues around siblings and disability for many years, the latest period of my 'intellectual biography' is one that particularly shapes my intersecting identities as a disability scholar and sibling. It has been a time when my entry as a new scholar in disability studies and academia has merged with some of the strangest years of my sister's health: a half-decade period where, on top of her lifelong disability, she has had repeated episodes of delirium and autonomic dysreflexia, sometimes lasting for up to 10 months. Episodes where she has writhed and screamed in a hospital bed, while the medical establishment under-estimates and under-treats her and devalues the importance of her being able to relationally engage with others... while, all the while, I am studying siblings, relationships and disability theory. It is a strange juxtaposition.

The enormity of trying to account for what this strange juxtaposition has meant for my mind – and for my heart – is steep. On the one hand, disability studies has given me a framework to critique those who under-estimate, under-treat and devalue her. This is, at times, a source of comfort and strength. Yet in the face of only so recently coming to value us for who and what we are together – after a lifetime of battling with the myth and the monolith – to have who and what we are together periodically challenged and

changed by delirium and dysreflexia has been especially hard for me, particularly when studying siblings, disability and relationships at the same time as her illness has forced me to be objective about our relationship and the changes to it in a way that was probably not good for my grief about her being so unwell and so relationally unavailable.

Yet at the end of the day, these struggles have likely been good for my scholarship – even if it seems a betrayal to my sister to say it. These struggles have *forced* me to see not only the version of us and our relationship that I want, but to also acknowledge and work with who we are even in the moments when I would prefer to believe that we are not ourselves. The theory I have read about disability and relationships has *demand*ed that I think more critically about *all* that our relationship entails – even in the hard, delirious moments – than I ever would have done otherwise. This has, at times, been personally and relationally devastating, but it has also improved me as a scholar because it has forced me to expand my thoughts about and theoretical approach to disability and relationships beyond the things that I want to see... and this is exactly what objectivity entails. If I can be objective even at the hard extremity of my own life, then I can do this with data from others too.

The strange juxtapositions of my ‘intellectual biography’ are just that: strange. And they have hurt. But they have also brought my mind to a place that can tackle the multi-faceted nature of disability – and, I hope, have brought my mind and my heart to a place that can look honestly at the multi-faceted nature of my relationship with my sister too.

Chapter 4. Methodology

This chapter outlines the methodology used to undertake this sociological, relational and phenomenological study of how disability figures in the relationships between young adult siblings with and without disabilities. It details the accessible and relationally informed approach taken and the research design and planning, data collection and data analysis. Where the work contributes to furthering the methodologies of sibling-disability research, this is highlighted. The methods in this study were approved by the Human Research Ethics Committee at the UNSW Australia in 2012 (approval number HC12370) and also received subsequent ethical approval from three community disability organisations to enable their assistance with recruitment.

4.1. Accessible and relationally informed research

Underpinning the methodology was an intention to do accessible and relationally informed research. These two approaches were both separate and inter-connected goals in the research process, designed to foster a study appropriate to siblings both with and without disabilities, both individually and in relationship to each other. The approaches operated as a moral under-pinning to the study that was operationalised in the research design, recruitment, data collection and analysis.

In being accessible, the aim was to make the study appropriate, engaging and ‘do-able’ for as many participants as possible. The accessible approach primarily meant following methods to allow people with disabilities – particularly intellectual disabilities and complex communication needs – to participate, although also meant being engaging for young people more generally. The accessible approach was important as it redresses the long history of exclusion, objectification and exploitation of people with disabilities in research (Dowse, 2009, Kidney and McDonald, 2014). As detailed in the rest of this chapter, the study aimed to capture siblings with disabilities’ perspectives in whatever form they were able to provide,

whilst also providing a range of specific accessibility supports to assist. Accessibility had particular importance for this study because, as documented in Chapter 2, sibling-disability research has historically excluded siblings with disabilities and so there is a need to better access and include their perspectives in order to extend knowledge about sibling relationships.

In taking a relationally informed approach, the aim was to ensure that the study always thoughtfully considered the relationships under investigation and put in place methods that reflected knowledge of and respect for the sibling relationship itself and for both siblings in it. In reflecting knowledge and respect for the sibling relationship, the study was ethically committed to methods that would not negatively impact or disrupt the relations between siblings and that could accommodate the context of the relationship. For example, this meant methods that could incorporate the differential experiences of voice, power and influence that normatively happen between many siblings within the data collection and analysis (Mauthner, 2002, Edwards et al., 2006, Kuba, 2011). In reflecting knowledge and respect for both siblings in the relationship, the relationally informed approach also aimed to ensure that siblings both with and without disabilities could contribute to the research and that efforts to accommodate one did not come at the expense of the other. That is, accessibly including siblings with disabilities did not mean that siblings without disabilities' perspectives became any less important, just as sensitivity to siblings without disabilities' perspectives did not preclude including siblings with disabilities. Whereas much other research has focused on one group or the other, the relationally informed approach meant prioritising hearing from *both* siblings.

In combination, the accessible and relationally informed approaches fostered a study that was committed to redressing the history of people with disabilities' exclusion from research, while also focused on the sibling relationship and on the perspectives and experiences of *both* siblings. This is unique, as sibling-disability research has mostly focused on siblings without disabilities' perspectives only, while disability studies has followed inclusive models for hearing people with disabilities' accounts, but that rarely also have the same focus on including the perspectives of

participants without disabilities alongside (Walmsley, 2001, 2004, French and Swain, 1997, Zarb, 1992, Barnes and Mercer, 1997). The argument here is that having a methodology under-pinned by accessibility *and* by the intention to hear from *both* siblings is key for extending knowledge about siblings' experience of disability and relationships. Without this combination of approaches, the relational findings and contributions outlined in the following chapters would not have been arrived at.

4.2. Research design and planning

4.2.1. Study design

The study used qualitative research methods. Given the need to reflect the complexities of everyday relationships, the qualitative approach was appropriate as it "lends itself... to the messiness and particularities of family relationships and everyday intimate life" (Gabb, 2008:29). Within the qualitative approach, two further features also characterised the study, reflecting the accessible and relationally informed approaches outlined above.

Firstly, either one or both siblings in a specific pair could take part and they could do so jointly, separately or alone. Following the relationally informed approach and precedents from other research with siblings and multiple family members, this choice allowed siblings to pick a participation option that best suited their relationship. It acknowledged that some siblings might prefer to give a joint account, for example, by speaking to the researcher together (Harden et al., 2010). Further, joint accounts also importantly enabled observation of their relationship in action (Arskey, 1996, Mauthner, 2000). Yet the available options also allowed siblings to speak to the researcher separately or for just one sibling to participate in the study alone if joint participation would curtail their freedom to talk openly (Mauthner, 2000), would be difficult for their relationship (Punch, 2007), if there was a risk of one sibling forcing the other to participate (Forbat and Henderson, 2003) or if siblings simply did not want to or could not participate together (Wittenborn et al., 2013), for example, due to conflict between them or one having a very high level of disability. Allowing siblings choice between participating jointly, separately or alone was thus a key element of the research as it allowed them to take part in a way

informed by their relationship and allowed the study to include participants in a variety of circumstances.

Secondly, two data collection options were available. One option was for participants to take part in a semi-structured interview. Interviews were chosen for their capacity to reflect issues that are complex (Sarantakos, 2005), personal, situational or contextual (Ezzy, 2002) – such as relationships. The semi-structured component allowed perspectives on consistent themes, yet enabled siblings to also direct the interview to examples important to them (Denzin and Lincoln, 2005). Further, the semi-structured framework also allowed the adaptability needed to meet diverse communication support needs (Cambridge and Forrester-Jones, 2003), important for an accessible approach. However, in considering accessibility, it was also recognised that interviews might not be possible for all participants and that there was a need for another method of participation that allowed contribution of just one or a few key points in whatever form participants were able to provide. Accordingly, siblings could also take part by documented contribution. This meant sending in a documented response of a length and format of their choice, for example, a written, pictorial or technological response. Flexibility and adaptability in length and format are suitable for participants with intellectual disabilities or complex communication needs who might find it difficult to take part in a prolonged interview (Booth and Booth, 2003, Boxall and Ralph, 2009, Nind and Seale, 2009). Having the two data collection options was thus key to the accessible approach of the study and to hearing from the widest range of participants with disabilities possible.

4.2.2. Eligibility

To be eligible for the study, participants had to fulfil three criteria. Firstly, the participant had to have a brother or sister, an inherent criterion for a study of siblings. Secondly, either the participant or his or her brother or sister had to have a lifelong disability. Lifelong disability was chosen as it offers a view to how experiences of disability and of relationships develop together across the life course. It was defined as any physical, intellectual or sensory disability from birth or early childhood. Later-onset conditions, such as mental illness or neurological conditions,

were excluded. Thirdly, the sibling with a disability and at least one sibling without a disability (the participant, if it was a sibling without a disability participating, or one non-participating sibling without a disability) had to be aged 15-29, although other siblings in the family might be younger or older. Initially the study sought siblings aged 16-25, but this was expanded for the purposes of flexible recruitment, also acknowledging the later transitions of many contemporary young people (Setterson and Ray, 2010). Screening for eligibility involved a short phone conversation or email exchange to check that potential participants met each criterion.

4.2.3. Sampling frame

To ensure a diversity of participants, the study included a multi-stratified sampling frame (see Appendix 1). It divided equally between siblings with and without disabilities to ensure inclusion of both. It also divided equally between males and females, important given the gendered nature of sibling relationships (Edwards et al., 2005, 2006, Edwards and Weller, 2014). Further, the sample divided equally between participants aged 15-18 and 19-29. This breakdown was based on the age that young people commonly leave school, acknowledging that as young people get older they are more likely to move through the changes and transitions of young adulthood. Finally, while including any lifelong disability, participants with intellectual disabilities and complex communication needs (unclear speech, little or no speech or users of alternative or augmentative communication) were purposively sampled. This was to assist in furthering the small but growing body of research redressing their particular history of exclusion from research (e.g. Knox and Hickson, 2001, Garcia-Iriarte et al., 2009, Hemsley et al., 2008, Trembath et al., 2010, Anderson et al., 2011, Dew et al., 2011, Green et al., 2012, Hynan et al., 2014), even compared to other people with disabilities (Gilbert, 2004). Siblings with intellectual disabilities and/or complex communication needs needed to together make up half of participants with disabilities, with siblings with any other disability forming the other half. While not specifically stratifying for low socio-economic and culturally or linguistically diverse backgrounds, attention was paid to these characteristics during recruitment.

The sampling frame allowed a variable sample size. To gain sufficient data, there needed to be a minimum of 30 interview participants, yet the sample could include up to 160 people, with the proportions of the sample stratifications maintained across these different sizes. The reason for this variability was that achieving the saturation point of new data not eliciting any further understanding of the issue under investigation depended on the nature of the documented contributions; if there were many brief contributions, it would take a much larger number of participants to develop a thorough understanding of siblings' experiences than if there were many in-depth contributions or if most participants chose to do a more comprehensive interview. In applying the sampling frame, the diversity of sample was also continually assessed. When the minimum sample of 30 interview participants was met, there were still only a small number of participants from low socio-economic and culturally and linguistically diverse backgrounds. The minimum sample was therefore increased to 40 interview participants and subsequent recruitment purposively sampled for socio-economic and cultural diversity.

A total of 46 participants were included in the final sample. This included 40 interview participants and six documented contribution participants; 25 siblings with disabilities and 21 siblings without disabilities; and 13 participants with either an intellectual disability or complex communication needs. The participants are introduced and the characteristics of the sample further detailed in Chapter 5.

4.2.4. Recruiting participants

The study included two recruitment strategies. Primarily, participants were recruited by advertisement and third party approaches through service provider and advocacy organisations. This strategy offered a way of ethically connecting with potential participants without the researcher involved in the initial interaction. Further, through selection of many different third party organisations, it also offered a route to contacting both siblings with disabilities and siblings without disabilities, who might have connections with different organisations. Over 100 disability, youth, sibling and carer organisations were contacted and asked to distribute information about the study to their clients and/or to approach anyone who they thought may wish to participate. The organisations were provided with a recruitment flyer and

‘newsletter blurb’ to assist in approaching clients (see Appendix 2). Interested participants had the choice to contact the researcher directly or to give permission for their contact details to be provided to the researcher who would then make direct contact with them. For younger participants, contact was often initially with parents who in turn passed on the information to their sons or daughters.

Snowball sampling was used as a secondary recruitment strategy. Where one sibling agreed to take part, an invitation to participate was then extended to his or her sibling/s, where the initial sibling agreed to pass on the information. Following ethical approaches in other family research (Harden et al., 2010, Wittenborn et al., 2013), the researcher always emphasised that the second sibling’s participation was a personal choice and had no bearing on the initial sibling’s participation. Further, the snowballed sibling’s voluntary consent was always checked by the researcher outside the presence of the initial sibling to confirm their voluntary participation and guard against coercion between siblings.

Both strategies of recruitment were supported by a website (www.siblingsanddisability.com; no longer active, see Appendix 3), made using a free blog-making platform (Google Blogger). The website contained information about the study’s focus, ways to participate and downloads of all study documentation. The website also featured blog posts giving updates on fieldwork dates, changes to the study and the progress of data collection. The recruitment flyer and ‘newsletter blurb’ directed potential participants to this website to access further information about the research.

The website was used for two reasons. Firstly, given the number and complexity of ways to participate, it provided potential participants with the information necessary to make an informed decision about how to take part. Secondly, the website catered to accessibility. Fenner et al (2012) have identified modern communication technologies, such as the internet, as accessible and engaging for recruiting young people. Further, electronic information is accessible for people with vision or print disabilities (Round Table on Information Access for People with Print Disabilities, 2009). The website also had several specific accessibility features, including:

- A domain name that could be easily recognised and shared via social media;
- A simple design and interface (see Appendix 3);
- Large, well-spaced text recommended for visual accessibility (Vision Australia, 2011);
- RTF downloads of website content and documents compatible with screen-readers;
- Capacity to provide multiple formats of information, including standard, RTF and Easy Read information with pictures recommended for participants with intellectual disabilities (Owens, 2006, Scope, 2007, 2008).

In this way, the website was a key component of the accessible approach of the study, extending this to the recruitment processes used.

4.3. Data collection

As outlined earlier, the study included two data collection methods: semi-structured interviews and documented contributions. Participants could choose between these methods. As shown in Table 3, interviews were more popular, chosen by 40 of the 46 participants. However, while Table 3 shows that only 6 participants chose documented contributions, significantly, all but one of these were people with intellectual disabilities or complex communication needs, suggesting that the documented contributions were a particularly accessible participation option for these groups.

Table 3: Participants' chosen methods of data collection

Interviews	Joint
40 people	10 sibling pairs (20 people, 10 interviews).
30 interviews	Separate
	4 sibling pairs (8 people, 8 interviews).
	1 additional sister did an interview while her brother submitted a documented contribution.
	Alone
	11 individual siblings.
Documented contributions	Separate
6 people	1 brother submitted a documented contribution while his sister did an interview.
6 contributions	Alone
	5 individual siblings.

4.3.1. Informed consent

The study included standard, Easy Read, guardian and supporter consent forms (see Appendix 4). All interviews and documented contributions required informed consent and participants were free to withdraw at any time. For interviews, consent was provided by signing a consent form prior to one's interview. Although the consent forms were available for download from the study's website, the forms were also provided in hard copy on the day of the interview and the information discussed with all participants. The opportunity for this discussion reflects Duncombe and Jessop's (2002) insight that given the complexity of anticipating what research participation will involve, the chance to discuss and reflect on consent is valuable. For documented contributions, this discussion was not possible as the researcher did not meet these participants, but signed consent forms were required in order to accept their contribution to the study. Where applicable due to age or disability, guardian consent was also organised prior to the interview or to the acceptance of a documented contribution.

Particular attention was paid to obtaining consent from participants with intellectual disabilities, as the complexity of gaining their informed consent has been well documented (Stalker, 1998, Gilbert, 2004, Nind, 2009, McDonald et al., 2009). The study followed strategies evidenced in the literature for maximising their consent capacity. For example, Nind (2009) has highlighted that the capacity of people with intellectual disabilities to give consent may be maximised by simplifying the decision-making process. In this study, an Easy Read consent form was provided, with simplified language and framing of the research and with pictures to support comprehension (see Appendix 4). Such forms have been used in other accessible studies (e.g. Kidney and McDonald, 2014). The Easy Read form was discussed with participants with intellectual disabilities and, where appropriate or where there was further concern about their capacity to consent from the researcher, the participant or their family, a third party was present, consent was confirmed in the presence of a third party beforehand and/or guardian consent was additionally sought.

Assent was a useful adjunct to consent for some participants with intellectual disabilities: that is, observing a participant's behaviour to see if he or she seemed happy and comfortable about participating (Beresford et al., 2004). For example, in one case although the participant with an intellectual disability had initially agreed to participate and signed a consent form, on the planned day of his interview observation of his behaviour highlighted that he simply was not in the mood to sit and talk. As a result, the interview was cancelled and he decided to later send in a documented contribution instead. This example highlights how assent, alongside simplified consent procedures, allowed participants with intellectual disabilities different ways to confirm – or not – their willingness to participate.

4.3.2. Recompensing participation

Siblings were recompensed for their participation. Each interview participant received a \$30 gift voucher. Each documented contribution participant was entered in a prize draw to win one of two \$150 gift vouchers, drawn a month following the end of data collection. Vouchers that could be used anywhere that accepted EFTPOS (electronic funds transfer with a credit card-style card) were chosen in order to be most useful to participants.

4.3.3. Interviews

The semi-structured interviews were conducted between September 2012 and August 2013. Interviews took place in three Australian state capital cities, chosen for the availability of service provider and other professional networks that enabled access to siblings with and without disabilities. The cities are not named here in order to protect participants' privacy and anonymity. Interviews took approximately one hour and were conducted face-to-face at a time and location of participants' choosing.

Interviews were conducted according to an interview schedule that was consistent between siblings who took part jointly, separately or alone, but could be adapted for accessibility and communication support needs (see Appendix 5). The interview questions were piloted before the start of data collection and finalised based on the experience in the first few interviews. Redressing the history of sibling-disability research that has focused on siblings without disabilities' non-normative experiences (as explained in Chapter 2), the interview questions aimed to capture participants' relational experience of disability, rather than the impact of the disability on them.

The interview questions asked about the inter-relationship of participants' experiences as siblings, of disability and of young adulthood. However, the sequence of questions first asked participants about their sibling relationships and young adult experiences and only then prompted them to layer in their experience of disability. This aimed to allow siblings to talk about the inter-relationship of sibling relationships and young adulthood with disability, but without assuming that everything in their experience would indeed be about disability. Further, the questions were designed to give space for siblings' own framings, not to introduce specific disability-related concepts. For example, rather than asking about 'care', the questions asked about 'actions siblings take for each other' – a framing that could include 'care', but was not limited to it.

Following this focus, the interview questions had three parts. First, participants were asked about their own and their siblings' interests, study/work, living arrangements

and disability type and support needs. Questions also included what siblings do together, what they agree on or argue about and how that had changed since childhood. Aside from descriptive information about disability type and support needs, these questions did not prompt about experiences of disability, unless participants themselves brought this up.

Second, participants were asked to identify ‘important things’ that had happened for both themselves and their sibling/s during young adulthood, including important events and experiences that had made them feel like an adult. A series of follow up questions asked for explanations of whether and how disability had played a role in those experiences and whether and how those experiences had a role in their sibling relationship.

Finally, participants were asked to reflect on their everyday relations with their siblings, such as whether and how they communicate, take actions for each other or are aware of each other’s feelings. Follow up questions prompted participants to explain how disability played a role in these relations. The final question asked siblings to make an analogy to explain what their relationship was like overall; this aimed to identify what stood out about their relationship overall. Together, these questions then aimed to reflect siblings’ everyday relations *and* their relationality or overall felt experience of their relationship, as identified as the research focus in Chapters 2 and 3. As a whole, the complete set of interview questions reflected the experiential, relational approach identified as needed in sibling-disability research in Chapter 2.

4.3.4. Documented contributions

The documented contributions were designed to be an accessible participation option. The structure of the documented contributions was mapped against the interview questions. The questions to address were:

- What are some of the most important things that have happened for *both* you *and* your brother or sister since your mid teens? For example, ‘important things’ could be important events or changes that have made you feel like an adult.

- How has *disability* played a role in these important things for each of you?
- How have these important things affected your *relationship* with each other?
- What do you and your brother or sister *do, say or feel* when you deal with all of this together?

Participants accessed these questions via the study's website. The website also included instructions about what the contributions could entail, where to send them and what other documentation was required. The contributions were conceptualised as 'creative', intended to accommodate some of the creative and visual methods often used with young people and people with disabilities (Boxall and Ralph, 2009, Fargas-Malet et al., 2010). For example, alongside the option to submit a written response, participants could consider pictorial or technological responses. The final dataset included two written contributions, one multimedia contribution (including text, photos and symbols) and three videos, one with additional written information. All contributions were relatively short, for example, the longest written contribution was just over a page and the longest video just over eight minutes.

All but one documented contribution was provided by a participant with an intellectual disability or complex communication needs. The short nature of the contributions and the profile of the authors suggests that this method provided an accessible way for participants who may not have been able to or did not want to contribute a large volume of data through an interview to still take part in the study. The documented contributions can be considered to have allowed participants to focus on the content most important to them, thereby maximising the value of their input. Given that past research including both siblings has highlighted that siblings without disabilities may dominate research by providing more voluminous or complex data (Dew, 2010), the documented contributions are then one way of maximising the value and content of the contributions made by some participants with disabilities.

4.3.5. Demographic information sheets

All participants were required to complete a demographic information sheet (see Appendix 6). Information sheets could be filled in independently, with assistance or by a supporter. The purpose was to obtain consistent demographic information about all participants to profile the sample. The information included the participant's gender, date of birth, number of siblings, state/territory, postcode, educational attainment, living arrangements, weekly activities, disability type and support needs (if applicable) and contact information (optional). The sheet also asked for information about the participant's brother or sister, but this was minimal as an ethical consideration: minimising the release of personal information not disclosed by the subject of that information. Participants were asked to provide only their brother or sister's gender, date of birth and disability type and support needs (if applicable).

4.3.6. Accessibility supports

Accessibility supports were included for both interviews and documented contributions. The supports aimed to be flexible to diverse communication support needs and are detailed below.

Interview accessibility

In considering the involvement of people with intellectual disabilities or complex communication needs in interviews, Cambridge and Forrester-Jones (2003) emphasise the need for individualised communication: that is, the ability to adapt communication to that which is most suitable to each individual's established ways of communicating. Implementing this in this study meant not only considering an individualised approach, but also working with the fact that due to minimal contact with participants before their interview, it was not possible to have a definitive picture of their communication support needs beforehand. While some details were explained during the screening phone call for eligibility or other email contact, in general, the planned accessibility supports needed to allow the researcher to be, as much as possible, 'ready for anything'. This meant having an approach to

accessibility planned that would allow the researcher to be adaptable, flexible and 'quick thinking' in delivering accessible support options at the time of the interview.

Based on these considerations, the study adopted an 'accessibility toolbox' (see Appendix 7), as has recently been used by Kidney and McDonald (2014). The aim of the toolbox was to offer supports to flexibly adapt the interviews to individualised communication support needs, while also maintaining the integrity of the data and the ease of the interview interaction. The toolbox comprised a number of pre-planned accessibility supports that mapped to the standard interview questions and that could be drawn on, adapted and expanded in-situ in the interviews, depending on what was necessary for a given participant. As the supports could be adapted in the field, they were piloted and refined during the first two occasions they were used and then finalised for the remaining interviews. The toolbox included:

- Two versions of Easy Read interview questions mapped to the standard interview questions, reflecting different levels of complexity;
- A skeleton of 'yes/no' and 'either/or' questions that were mapped to the standard interview questions and required minimal expressive communication;
- An alternative and augmentative communication (AAC) board of procedural and ethical comments that a participant might make (e.g. 'Can you rephrase the question?', 'I'd be worried about my brother or sister knowing I said that');
- Visual prompts about emotions, actions people take in relationships and common young adult experiences. Each picture was mapped to literature and theory about relationships and young adulthood.

Designing the toolbox required thorough understanding the communication support needs that might be involved. For example, the researcher's prior awareness of the effort required to type out long AAC sentences prompted the design of the AAC board, so that participants could better control their interview with minimal effort. Further, each support was informed by careful methodical planning, for example, ensuring that questions were not leading and gave participants scope choose from a diversity of responses. Methodical planning was important as, for example, 'yes/no'

questions might otherwise constrain participants' answers if formulated in a rushed manner during the interview. Knowing the supports were well designed facilitated confidence in working flexibly with them in the interviews.

The 'accessibility toolbox' was brought to each interview and drawn on when either there was indication prior to the interview that accessibility supports would be required or when participants had limited speech and/or comprehension *and* appeared to struggle with answering some of the initial questions. At this point, the toolbox was brought into effect. To deliver its supports, approaches were required such as using straightforward (but not condescending) language, being aware of and responsive to body language and non-verbal expression and checking participants' responses through questioning facial expressions, intonation or a direct question to check (Hemsley et al., 2008). In addition to the toolbox, some participants drew communication support from their sibling in joint interviews and one participant brought a third-party supporter with him to his interview.

The 'accessibility toolbox' is an innovation in sibling-disability research. Accessibility supports such as those included in the toolbox have only very rarely been offered in this field (see Dew et al., 2011, Tozer et al., 2014 for key examples), although have been developed more extensively in other disability research, particularly for people with intellectual disabilities and/or complex communication needs (Sigelman et al., 1981, Booth and Booth, 1996, Cambridge and Forrester-Jones, 2003, Owens, 2006, Nind, 2009, Nind and Seale, 2009, Balandin and Goldbart, 2011, Kidney and McDonald, 2014). The accessibility options offered by the toolbox therefore contribute to bringing sibling-disability research into alignment with other disability research. Ultimately, this is important for being able to access and include the perspectives of siblings with disabilities to expand the relational knowledge generated.

Documented contribution accessibility

Accessibility supports for the documented contributions also reflected the individualised approach recommended by Cambridge and Forrester-Jones (2003) of following individuals' established ways of communicating. Supporters to the

participants who submitted documented contributions commonly first made contact with the researcher, often to confirm the intent to contribute and sometimes to request specific supports to enable each participant to take part. Based on these requests, it was possible to offer individualised accessibility supports. For example, for one participant it was most useful to be provided with a copy of the visual prompts from the accessibility toolbox, whereas another two participants were given easy prompting questions; these easy prompts were used by a supporter to further explain the questions to answer in a way that was consistent with the study's focus. These tailored supports again allowed an individualised approach to accessibility.

4.3.7. Power relations of communication

The power relations of communication were significant and varied across the options of participating jointly, separately or alone. As has been highlighted in other dyadic and family research, separate accounts featured similarities, gaps and contradictions when compared to each other (Song, 1998, McCarthy et al., 2003, Harden et al., 2010, Eisikovits and Koren, 2010) and in accounts from one sibling alone, the gaps meant that only part of a fuller relational story was told. In contrast, joint participation involved a shared narrative and revealed the relationship in action (Arskey, 1996, Mauthner, 2000). For example, in joint interviews, siblings often displayed the banter or different perceptions that they described existing between them and instead of giving a direct answer to a question, siblings often revealed more in their banter or discussion in coming to the answer than they did in the point they eventually arrived at.

While there is a likelihood that some siblings may have self-censored some parts of their accounts in joint interviews in order not to discuss some sensitive topics in front of each other, in other cases, the joint interview context prompted participants to speak about these topics. For example, one participant at first refused to talk about any conflicts between himself and his sister, but upon hearing what she herself revealed about them arguing, he chose to also contribute his own perspective on this as well. In this way, the joint interview context could both censor and prompt siblings in revealing details of their relationships.

Power relations were also evident where several participants with intellectual disabilities or complex communication needs drew communication support from their brother or sister without a disability in joint interviews. Similarly to Kramer's (2009) experience, there were instances where siblings without disabilities either mediated (influenced) siblings with disabilities' responses or gave proxy responses (answered for them). Following the relationally informed approach of the study, these moments were on the one hand observed for revealing the differential voice, power and influence that commonly exists between siblings (Mauthner, 2002, Edwards et al., 2006, Kuba, 2011). However, strategies were also used to protect a space for both siblings' voices. Where appropriate, mediated or proxy responses were checked with siblings with disabilities and/or they were encouraged to qualify or expand the response. Siblings were also asked to each answer some interview questions separately before proceeding to a joint discussion. These questions were chosen for separate responses as they were key questions for each sibling in having the opportunity to represent him or herself (for example, introducing oneself or identifying one's own young adult experiences). These questions were marked on the interview schedule and prefaced beforehand, meaning that if a sibling without a disability tried to mediate or give a proxy response, he or she could politely be reminded to stop. These strategies worked towards protecting a space for siblings with disabilities' perspectives alongside those of their brothers and sisters without disabilities.

Given the need to navigate mediation and proxy responses, it is however significant that many siblings with disabilities still preferred to draw communication support from their brother or sister without a disability, rather than, for example, bringing a third-party supporter to the interview. This gives an important insight into how siblings choose to participate in research. One interpretation of it is that some siblings with intellectual disabilities or complex communication needs perhaps find talking together with their brother or sister a natural or convenient way to communicate, even despite possible mediation – although there may be other factors also at play. Either way, beginning to work towards insight into siblings' power relations and communication during research is important for developing

knowledge about *how* to include both siblings in research in ways that recognise their relationship.

4.3.8. Ethics

The approach to a number of ethical issues has already been discussed in other parts of this chapter. This includes the ethical dimensions of the choice to participate together, separately or alone (Section 4.1), procedures for informed consent and its withdrawal, including assent and guardian consent (Section 4.3.1), confirming the voluntary participation of siblings found through snowball recruitment (Section 4.2.4) and minimising details about non-participants in the demographic information sheets (Section 4.3.5). Upcoming in Sections 4.4 and 4.4.4 respectively are discussions of data de-identification and the under-utilisation of some data for ethical reasons.

In addition, close ethical attention was also paid to issues of disclosure, participants' control over their information and confidentiality between siblings. Following precedent from other sibling research, each participating sibling had control over his or her own sensitive information, for example, the right to reveal one's own disability diagnosis (Mauthner, 2000). All interview participants were also given the opportunity to flag any other particularly sensitive information at the conclusion of their interview. Participants were told at the outset of their interview that there would be an opportunity to identify any particularly sensitive information its the end and then at the conclusion of the interview there was a question asking participants to flag if there was anything they were worried they had mentioned. A recognised strategy for protecting confidentiality in qualitative research (Kaiser, 2009), this flagging process aimed to alert the researcher to information that needed particularly careful treatment, but which might not otherwise be recognisably sensitive. Further, following ethical approaches in other dyadic and family research (Eisikovits and Koren, 2010, Harden et al., 2010), information was never shared between siblings – for example, where siblings participated separately, the researcher did not reveal information or context from the first interview in the second interview. Together these approaches to disclosure, information control and

confidentiality aimed to maintain high ethical standards, as also developed through the ethical approaches described in other parts of this chapter.

4.4. Data analysis

In preparation for data analysis, all interviews were transcribed verbatim and documented contributions were converted to text by transcribing audio content or making substantive notes describing visual content. Approximately one third of interview transcription was done by a commercial provider with a confidentiality agreement in place. The remaining two thirds was done by the researcher, especially for interviews featuring unclear speech. Given the small number of documented contributions, the decision was made to include them as text-based data alongside the transcribed interviews in the main analysis. This was to ensure that the documented contributions did not become sidelined to a separate subsidiary analysis. All identifying information was removed from the transcripts, including names of people, locations, schools or service providers, and replaced with square-bracketed descriptors. Later, at the stage of write up of the data, accumulative details that alone were not enough for identification but together might be inadvertently identifiable were also obscured. All participants and non-participating siblings were given pseudonyms.

The analysis itself was influenced by the multiple analytic needs. Firstly, the analysis involved three distinct focuses: participants' experiences as siblings, of disability and of young adulthood. Each of these is a complex experience in its own right and it was important to identify how participants experienced each one. Yet, secondly, the research questions for the study also required understanding the inter-relationship between these three experiences. As explained in Figure 2 and Table 4, a participant might have separate experiences as a sibling, of disability and of young adulthood, but sometimes two of these experiences might combine or all three might combine. The focus of the thesis is on where all three experiences combine. Therefore, identifying this data about all three experiences was a key analytic task. Finally, in examining siblings' everyday relations and overall experience of the sibling relationship, it was also necessary to look at participants' experiences holistically.

This required interrogating their experiences with a phenomenological approach, where concrete details were less central in favour of a focus on their overall or emergent felt experience or reflections on their experiences.

Given these analytic needs as well as the sociological, relational and phenomenological focus of the study, a hybrid analytic approach was adopted. This hybrid approach combined elements of thematic (Fereday and Muir-Cochrane, 2006) and phenomenological analysis (Smith et al., 2009), as well as attention to both manifest and latent meanings in the data (Berg, 1995, Graneheim and Lundman, 2004). The approach detailed siblings' experiences thematically, while also applying a phenomenological lens to understand their deeper or overall felt experiences. The analysis was implemented in a three-step process, outlined below.

Figure 2: Three experiences to analyse

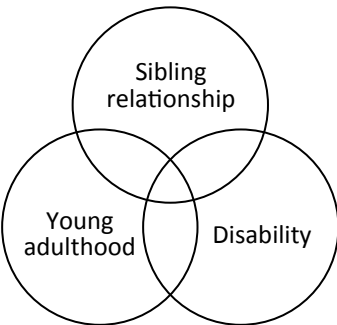


Table 4: Inter-relationships between the three experiences for analysis

One experience	<ul style="list-style-type: none"> • Experiences of the sibling relationship. • Experiences of disability. • Experiences of young adulthood.
Two experiences	<ul style="list-style-type: none"> • Experiences of disability within a sibling relationship. • Young adult experiences with one's siblings. • Young adult experiences of disability.
Three experiences	<ul style="list-style-type: none"> • All three experiences combine: <ul style="list-style-type: none"> ○ Young adult experiences of disability that involve one's siblings. ○ Young adult experiences with one's siblings that involve experiences of disability.

4.4.1. Step 1. Thematic analysis

The first analytic step was to undertake a thematic analysis of participants' separate experiences as siblings, of disability and of young adulthood. This first step involved thematically coding the manifest content in the data, that is, coding the meanings that were directly described and observable in what participants had said (Berg, 1995, Graneheim and Lundman, 2004). Thematic analysis was chosen because, as Fereday and Muir-Cochrane explain, it is a rigorous "hybrid approach" that "incorporate[s] both the data driven inductive approach... and the a priori template of codes" (2006:81). That is, thematic analysis could begin from an approach informed by the review of the literature in Chapter 2 and the attention to the theory about relationships, disability, young adulthood and context in Chapter 3, and also combine this with an inductive emphasis on participants' perceptions expressed through their interviews and documented contributions. In this respect, thematic analysis allowed an approach that could be clearly focused on addressing the gaps in sibling-disability research, but that would also be guided by participants' experiences.

Broadly following Fereday and Muir-Cochrane's (2006) schema for thematic analysis, the first step involved the following process:

Table 5: Thematic analysis process

Fereday and Muir-Cochane's (2006) schema	The study's thematic analysis
<p>1. <i>Develop a code manual</i></p> <p>Develop an initial deductive set of codes, based on theory.</p>	<p>Analysis began with developing an initial deductive coding 'tree' based on literature and theory about relationships, siblings, disability, young adulthood and context and on the structure of the research and interview questions. The initial 'tree' had separate branches to thematically code the sibling relationship, disability and young adult experiences. It also contained branches to separately analyse context and 'relationality', as these were key aspects considered to influence experiences as siblings, of disability and of young adulthood. Given the intention to inductively modify the 'tree', spaces were left for some aspects to be determined entirely inductively as well as for 'other' categories to be disaggregated. The initial analytic framework is summarised in Appendix 8.</p>
<p>2. <i>Test the reliability and applicability of the codes</i></p> <p>Test reliability and applicability of the deductive codes against early data.</p>	<p>Transcripts were coded using NVivo 10. Coding of the early transcripts resulted in inductive changes to the initial 'tree', including adding, moving and refining codes, with changes abating as coding became saturated. Notably for later in the analysis, a lot of data was</p>
<p>3. <i>Apply the codes and undertake additional coding</i></p> <p>Apply the code manual to the whole dataset, adapting inductively to what participants said.</p>	<p>double- or triple-coded at this stage, especially where participants' statements simultaneously related to experiences as siblings, of disability or of young adulthood.</p> <p>Overall, the changes moved the coding framework towards a clearer, more inductive thematic structure of experiences as siblings, of disability and of young adulthood, as well as merged the sibling relationship and 'relationality' together into one relational set of codes.</p>

<p>4. <i>Summarise data, connect codes and identify themes</i></p> <p>Look for patterns in the coded data that represent themes.</p>	<p>During and following coding, connections were made across the codes to determine themes and finalise the thematic structure. This was aided by two processes:</p>
<p>5. <i>Corroborate and legitimate coded themes</i></p> <p>Cluster the themes to arrive at the findings of the study.</p>	<ul style="list-style-type: none"> • Writing notes in a field diary and in memos about data summaries, interesting observations, patterns and insights across the dataset and within individual cases. • Developing a series of schemas for how the data fit together. Each schema tested different ways of clustering the data.

The thematic analysis resulted in a final set of manifest themes and sub-themes, detailed in Appendix 8. These themes delineated participants' experiences as siblings, of disability and of young adulthood and cross-cutting experiences of context, in a way informed by literature and theory but also premised on participants' own understandings. However, this thematic framework sectioned the data into separate streams: experiences as siblings, of disability and of young adulthood. In order to address the study's research questions about what is experienced in the inter-relationship between these three experiences, it was then necessary to undertake a second step in the analysis.

4.4.2. Step 2. Determining relevant data

The second step in the analysis was determining the subset of the manifest data above that reflected the inter-relationship between experiences as siblings, of disability and of young adulthood – that is, that reflected the overlap of the three experiences of interest to the study. This involved carefully reading through the thematically coded data and noting places where participants' statements had been singly, doubly or triply coded to the different streams of the thematic framework, as explained in Table 6. The hypothetical example used in Table 6 illustrates the difference between singly, doubly and triply coded data by showing how depending on the content of a section of data, it could be coded once, twice or three times to different parts of the thematic framework.

Table 6: Explanation of singly, doubly and triply coded data

<p><i>Singly coded data</i></p> <p>Data coded as about only sibling relationships OR only disability OR only young adulthood</p>	<p><i>Example singly coded to sibling relationships:</i></p> <p>Spending time with one's sister.</p>
<p><i>Doubly coded data</i></p> <p>Data coded as about:</p> <ul style="list-style-type: none"> • Sibling relationships AND disability • Sibling relationships AND young adulthood • Disability AND young adulthood 	<p><i>Example doubly coded to sibling relationships AND disability:</i></p> <p>Spending time with one's sister by assisting her to do an activity she needs assistance with because of her disability.</p>
<p><i>Tripily coded data</i></p> <p>Data coded as about sibling relationships AND disability AND young adulthood</p>	<p><i>Example triply coded to sibling relationships AND disability AND young adulthood:</i></p> <p>Spending time with one's sister by assisting her to do an activity that she needs assistance with because of her disability, where the activity is also normative of young people her age; for example, socialising or using social media.</p>

Tripily coded data was automatically of interest for the analysis, but some doubly coded data was also relevant. This was for three reasons. Firstly, in order to build a thorough understanding of how disability figures in sibling relationships, it was illustrative to use some data that only related to experiences as siblings and of disability, but not young adulthood. These doubly coded examples appear at the outset of the findings in the thesis to establish the relational premise of the work. Young adult experiences then layered in progressively throughout the following chapters to further illustrate the complexity of how all three experiences may combine for siblings.

Secondly, at the level of individual participants, some doubly coded data was relevant because some participants spoke predominantly about two experiences, yet their statements could be contextualised by implied information about the third

experience. This occurred because some participants were able to or chose to speak about some of the three experiences more than others. For example, people with intellectual disabilities commonly did not reflect on disability explicitly, yet what they said about sibling relationships and young adulthood implied or indirectly incorporated disability. Similarly, young males tended not to talk explicitly about the sibling relationship, but rather implied this information in their accounts of disability and young adulthood. As such, it was necessary to include some doubly coded data from these participants, but analyse it in relation to the third experience in order to thoroughly cover siblings' experiences.

Thirdly, at the level of analysing data across participants, sometimes two experiences were commonly foregrounded in doubly coded data about a particular issue but the third experience appeared as a contextualising backdrop. For example, as detailed in Chapter 8, the participants commonly described engaging in disability-related care in a way that prioritised their relationship as siblings. This discussion of care foregrounded references to disability and the sibling relationship, however young adulthood was not directly mentioned. Yet, as drawn out in the discussion section of Chapter 8, their status as young people still appeared to contextualise how they viewed care. To give a full account of their views here and in other similar instances, it was then necessary to incorporate some doubly coded data, but again to discuss it in relation to the third experience.

Reflecting these three considerations, the forthcoming findings chapters are structured to illustrate different ways and degrees to which the three experiences might figure together for siblings. The findings first detail the role of disability in the sibling relationship (Chapter 6; using only doubly coded data), progressively building in the contextualising backdrop of young adulthood (Chapters 7 and 8) and then finally focusing on the explicit inter-relationship between all three experiences (Chapter 9).

4.4.3. Step 3. Selection of phenomenological examples

Once the subset of relevant manifest data was delineated, the final step was determining which of this data could be apprehended phenomenologically to

understand participants' overall experiences. This required identifying the subset of the relevant manifest data that also expressed participants' overall perceptions or reflections on their experiences, that is, that reflected latent content or a deeper interpretative meaning (Berg, 1995, Graneheim and Lundman, 2004). It meant seeing the instances where participants not only described the details of *what happened* to them, but also were *reflective* about what happened. This reflects Smith et al's (2009) discussion of what it means to be phenomenological in analysis:

... in our everyday life we are busily engaged in activities in the world and we take for granted our experience of the world. In order to be phenomenological, we need to disengage from the activity and attend to the taken-for-granted experience of it. So for example, take an incident which might happen: a car drives past the window. Seeing the car passing by outside, thinking about who might be driving it, wishing we could have a car like it, later remembering the car going by, even wishing that a car would go by when it had not done so – these are all activities happening in the everyday, natural attitude. Once we stop to self consciously reflect on any of this seeing, thinking, remembering and wishing, we are being phenomenological (2009:13).

In adopting this phenomenological approach, this final step of the analysis involved the selection of a series of examples of participants reflecting on their taken-for-granted everyday relations and overall experiences with their siblings. These reflections formed the phenomenological data eventually presented in the thesis. Further, the selection of these examples also reflected Smith et al's (2009) insight that in phenomenological analysis such examples express the particularity or essence of the phenomenon they were examples of:

... the description of the phenomenological experience of, for example, this particular house, was for Husserl just the first step. What he really wanted to do was get at the experience of 'houseness' more generally (2009:14).

Thus, the selection of data was premised on paying attention to the places where siblings reflected on the particularity of the inter-relationship between their experiences as siblings, of disability and of young adulthood. Data was selected

where their reflections showed the particularity of their everyday relations or experiences of relationality.

The effect of this final analytic step is that the presentation of data in the following chapters mostly comprises a series of discrete examples from siblings, rather than an aggregation of the experiences of the sample overall. Each example is written about in a way that unpacks the detailed experiential nature of each participant's relational experience. The selected data is primarily that in which participants themselves were reflective, although sometimes includes descriptive statements from participants or sections of dialogue from joint interviews which are then more explicitly reflected on by the researcher.

4.4.4. Data utilisation

Within the analysis, some data was under-utilised for ethical reasons. Similarly to other studies of siblings and multiple family members, ethical issues arose in some of the cases where a pair of siblings did separate interviews (Mauthner, 2000, Forbat and Henderson, 2003, Harden et al., 2010). The most appropriate way to address some of these issues was to use their data less than would have otherwise been ideal for the analysis.

In one case, a sibling with and without a disability were embedded in lifelong conflict, mainly centred on one sibling's grief over the other's disability. Although it was evident from their separate interviews that both knew something of each other's perspective, it was unclear the extent to which they knew the details of each other's thoughts. Whilst it would have been illustrative to weave their information together to form a case study of disability causing conflict in a sibling relationship, it was considered that this would go beyond the ethical use of information as it would endanger each sibling's confidentiality and disclosure from the other and might risk the research contributing to their conflict (Forbat and Henderson, 2003). For this reason, it was not obscured that these siblings were a pair and that they were in conflict related to disability, however, the analysis stopped short of combining or contrasting their perspectives.

In another case, in separate interviews the sibling without a disability revealed that the sibling with a disability had a secondary disability beyond the diagnosis that the sibling with a disability had disclosed. As the secondary disability had not been disclosed by the sibling with the disability, it was decided that all information related to it could not be used, as it was a personal detail that the sibling with ownership of the information had chosen not to reveal. This decision followed the ethical approach of the study outlined in Section 4.3.8, as well as precedent in other sibling research where each participating sibling has control over his or her own sensitive information (Mauthner, 2000). However, while not using the secondary disability was ethically important, it also appeared that most of the ways that disability affected this pair's relationship stemmed from the secondary disability rather than the one acknowledged by both siblings. In effect, the ethical decision not to disclose the secondary disability then meant that very little could be discussed about their relationship at all. While this was not ideal, it was the more ethical decision.

Both cases illustrate the limits of a relationally informed analysis. The ethical and methodological quandaries of doing research with multiple family members have been well documented, where disclosure and the depiction of agreements, disagreements and allied or oppositional accounts are all key issues (Song, 1998, Mauthner, 2000, Forbat and Henderson, 2003, McCarthy et al., 2003, Harden et al., 2010). As sibling-disability research has so rarely included both siblings, it has rarely had to deal with complex ethical issues where the politics of disability and of accounting for multiple family perspectives conflict; for example, as in the case above, where the justified choice of some people with disabilities to pass as not having a disability (Brune and Wilson, 2013) has implications for the extent to which relational perspectives of disability can be explored. In fostering a culture of research that equitably deepens engagement with both siblings and that furthers the relationally informed approach of this study, there is a need to continue to work towards balanced solutions that are ethical, relational and respectful of both siblings' perspectives in these difficult issues.

4.5. Methodological limitations

While undertaken as robust accessible and relationally informed research, the study nevertheless has some limitations. Methodological limitations are outlined below and other limitations of the findings and sample are discussed in Chapter 10.

Firstly, the response rate for the documented contributions was low. While the method had demonstrated importance for allowing participants with intellectual disabilities and complex communication needs to accessibly take part, the low take up of it is nevertheless a limitation. The small number of documented contributions perhaps reflects their status as a self-directed response, which may have required additional effort or motivation from participants, such that not as many people responded. Alternatively, the limited take up perhaps stems from the minimum sample requirement of having 30 interview participants, as this meant that most effort was put into recruiting for interviews. Had the study featured only documented contributions, with a recruitment strategy specifically tailored to this method, the recruitment for and take up of this option may have been more successful.

Secondly, while aiming to foster effective and accessible communication, there are likely still limitations in this area. While strategies to guard against mediation and to specifically access siblings with disabilities' perspectives were employed, some mediation still took place. Further, while accessibility supports were used, there were also still likely limitations in some siblings' understandings of the questions asked of them, which may have been better addressed had there been more opportunity to become familiar with siblings' communication needs prior to the day of their interview.

Thirdly, in asking participants to talk about the inter-relationship between their experiences as siblings, of disability and of young adulthood, participants sometimes did not speak much about one of these three areas. For example, as noted earlier, participants with intellectual disabilities rarely spoke about disability, but more clearly articulated experiences as siblings or young adults, while young males tended to give limited information about their sibling relationships, although talked more

readily about disability and young adulthood. To some degree, this is a finding rather than a limitation, as it shows that for some siblings some of the three experiences were more prominent than others and/or that for some siblings the three experiences were more strongly inter-related than they were for others. However, it also caused the analysis to rely more heavily on accounts from participants who spoke more clearly about all three – or at least two – of the experiences, especially the accounts of those who spoke about the inter-relationship of the three experiences. This is a limitation, as there is a shortfall in giving equal attention to all participants. This limitation is addressed, where possible, by accounting for the situations in which siblings might not see an inter-relationship between the three experiences (for example, in Chapter 9).

Finally, in focusing on phenomenological examples of the inter-relationship between experiences as siblings, of disability and of young adulthood, the analysis had less capacity to comprehensively examine participants' sibling relationships as a whole. That is, the analysis is limited in that sibling relationships are not looked at holistically (for example, attempting to chronicle all aspects of the relationship or the relationship's whole history), but rather particular significant interactions and felt experiences are singled out from the scope of the whole relationship. While this approach is well-justified in terms of the research focus, it nevertheless is also a limitation in understanding the whole scope of each of the sibling relationships in question.

4.6. Conclusion

This chapter has detailed the methodology used to undertake the sociological, relational and phenomenological study of siblings, disability and young adulthood outlined in the earlier chapters. It explained the methods used to facilitate an accessible and relationally informed study that could focus on the inter-relationship of participants' experiences as siblings, of disability and of young adulthood, including their everyday relations and their overall experience of the relationship. It is these focuses that are explored in the findings and discussion chapters.

Positionality 4. Time and grace

Methodology.

Positionality.

Reflexivity.

What are positionality and reflexivity, anyway?

I think of a question asked of me half a decade ago, at the beginning of my entry to disability studies and during the first of the episodes of delirium and dysreflexia. In the dusky light of nightfall, I sat with a friend who is older than me, who has known me since I was a child; a friend who has, ever since my childhood, always asked me unabashedly honest questions about my relationship with my sister.

On that night, as a young adult just finished my undergraduate degree, I sat with her on her veranda and we spoke about how in the few days prior I had begun to think for the first time that there were perhaps new ways to think about this whole experience of siblings and disability; that maybe there were frameworks beyond those that I had been exposed to that might offer something new and valuable; that disability studies, politics and activism might have something to say here. I said to her that I wasn't sure yet what that new thinking might be, but that I knew that it was time to think about this issue of siblings and disability in a different way.

And in the falling dusk, she looked at me and asked a question: "Do you have the time and grace to think?"

I have come back to that question many times in the years since that night – and the reason I keep coming back is this: I have come to believe that positionality and reflexivity *are* time and grace. Positionality and reflexivity are taking the time to learn

how to deal with one's personal connection to their research topic with grace; to strip one's assumptions out of their academic work; to get past one's biases in their analysis; to come to terms with the things that theory, analysis and the words of others *demand* that one sees about oneself and one's relationships, even when they do not want to and even when it pushes them to breaking point. These are *processes*. These are not things that scholars just wake up one day and do – especially not young scholars, who are still building their identities and for whom theory and research becomes a part of that identity, as it has done for me.

Positionality and reflexivity *are* time and grace.

PhDs take a culmination of time and grace.

This is a process.

I am further along this process than when I started my research: this thesis and the analysis in the following pages holds as much time and grace as I have ever been capable of. But this is also not the end point. This is but one day on the journey.

Chapter 5. Study participants

This chapter outlines a picture of the siblings in the study and of how the data from them is used. The purpose is to give background and context to the accounts that appear in the following chapters. The chapter starts by giving a brief biographical introduction to the participants. The demographic characteristics of the sample as a whole are then described and the chapter ends with discussion of how participants' contributions are presented in the forthcoming chapters.

5.1. Siblings' biographies

Each of the participants are introduced below, profiled by family and grouped by whether siblings took part jointly, separately or alone. The introductions focus on family structure, demographic characteristics (including disability), social and economic engagement and a description of their sibling relationships. Except where indicated otherwise, siblings live together in an urban, two-parent household. Where there are other brothers or sisters in the family who were not discussed by participants, this is indicated, otherwise those mentioned here are the only siblings in the family.

Following Mauthner (2002), the siblings whose names appear in bold are participants in the study, whereas siblings whose names are in regular text are the non-participating brothers or sisters of participants. All names are pseudonyms. In a small number of cases, some characteristics have been omitted, added or modified to prevent the identification of participants.

5.1.1. Joint participation

Allegra and Lucy

Joint interview – **Allegra**, 28, and **Lucy**, 24, are from a four-sibling family, with their two brothers not included in the study. Lucy has Down Syndrome and works in

supported employment, and Allegra is also employed. They usually enjoy spending time together. However, currently they are in a disagreement because Allegra wants a more independent life for Lucy – for example, for Lucy to live out of home as Allegra does – but Lucy feels unsure about this and would rather remain living with the family. This has caused some tension between them.

Craig and Jess

Joint interview – **Craig**, 27, and **Jess**, 28, are brother and sister. Craig has Cerebral Palsy and either walks with crutches or uses a manual wheelchair. Both are currently employed. They no longer live together, as Jess is married and lives separately with her husband, but they describe a friendly relationship where they will talk on the phone often and sometimes go out together.

Jeremy and Alex

Joint interview – **Jeremy**, 17, and **Alex**, 15, are brothers. Jeremy has Cerebral Palsy and uses either a wheelchair or walker and has unclear speech. Both attend high school, although Jeremy will be finishing in the next year and is currently exploring options for employment. They have different interests, but get on well together and spend time together with their parents and as a family go biking, swimming and camping.

Quan and Tien

Joint interview – **Quan**, 19, who has Down Syndrome, and **Tien**, 17, are brother and sister. They come from a Vietnamese family. They live with their parents, aunt, cousin and their two other younger siblings, who are not included in the study. Tien is in her final year of high school and Quan attends a day program two days a week. They mainly do incidental activities together, such as going to the market or park or negotiating about what television shows to watch.

Samuel and Ben

Joint interview – **Samuel**, 21, and **Ben**, 23, are brothers. Ben has Cerebral Palsy and an intellectual disability. He has minimal physical movement and communicates by

saying a few words and pointing. Samuel has just entered his first job in a professional organisation and Ben attends a day program five days a week. Their relationship includes a combination of doing fun activities together, such as playing Wii games or bowling, and Samuel providing care for Ben. Their mother has a chronic health condition, so Samuel takes on her care role for Ben when she is unwell.

Emily and Jack

Joint interview – **Emily**, 19, and **Jack**, 16, are sister and brother. Emily has Down Syndrome and attends a transition to work program, while Jack is in high school. They describe a relationship mainly based on incidental time together, such as watching the same television shows or walking the dog together.

Violet and Simone

Joint interview – **Violet** and **Simone** are 20-year-old twin sisters. Simone has Cerebral Palsy, with minimal physical movement and uses an electric wheelchair. Both are currently in tertiary education. They have a close relationship based on a lot of talking and sharing, but also some conflict about Violet's role in Simone's care.

Rachel and Harry

Joint interview – **Rachel**, 18, and **Harry**, 16, are sister and brother. They live in a single parent household with their mother in public housing. Harry has a medical condition causing him to have a tracheostomy and scoliosis. He attends a special school, while Rachel is in vocational training. They describe a relationship based on returning small favours for each other, such as picking up something from the shops or covering each other's shifts at their casual jobs.

Vicky and Jono

Joint interview – **Vicky**, 17, and **Jono**, 15, are sister and brother and also have two other siblings not included in the study. They live in a single parent household with their mother in public housing. Vicky has Muscular Dystrophy, which affects her respiratory system, speech and means she uses an electric wheelchair. Both are

attending high school. Their relationship is based on a jovial but sarcastic dynamic where they share similar interests, but not similar opinions, and so enjoy teasing each other about this.

Baha, Raghav and Aakar

Joint interview – **Baha**, 24, Aakar, 19, and **Raghav**, 15, are brothers from an Indian family, and also have one other brother not included in the study. They live in a single parent household with their mother in public housing. Aakar has autism, which means he has little communication and sometimes has aggressive or unpredictable behaviour. Aakar attends a day program, whilst Baha is in vocational training and Raghav attends high school. Both Baha and Raghav describe a relationship with Aakar that is partially about spending time with him and partially about helping their mother look after him.

5.1.2. Separate participation

Adam and Steve

Separate interviews – **Adam** and **Steve** are 15-year-old twin brothers. They attend high school together. Adam has Cerebral Palsy, with hemiplegia mainly affecting one arm. They usually get on well, but sometimes there is tension between them.

Will and Mason

Separate interviews – **Will**, 17, and **Mason**, 21, are brothers. They live in a single parent household with their father. Will has Cerebral Palsy with unclear speech. He has minimal physical movement and uses an electric wheelchair. Will is in his final year of high school, while Mason is working. Will and Mason have a jovial and teasing manner together, which they both enjoy, but on occasion goes too far. They enjoy doing recreational activities together, like going to sports matches or the drive-in cinema, although this does not happen very often.

Ava and Zoe

Separate interviews – **Ava**, 18, and **Zoe**, 17, are sisters, who also have two other siblings not included in the study. Zoe has Cerebral Palsy and uses an electric wheelchair. Zoe attends high school, while Ava is at university. Although it has improved somewhat in recent years, both Ava and Zoe described how their relationship is marked by a history of conflict mainly about Ava's grief over Zoe's disability.

Laura, Isla and Oliver

Separate interviews – **Laura**, 25, **Oliver**, 22, and **Isla**, 19, are siblings. Oliver has autism and an intellectual disability, which affects his communication, behaviour and anxiety. Laura and Isla are at university, while Oliver does a combination of supported employment and a day program. Laura and Isla describe different relationships with Oliver, where Laura often provides emotional support to him while Isla and Oliver squabble more often.

Sarah and Thomas

Sarah, interview; Thomas, documented contribution – **Sarah**, 19, and **Thomas**, 15, are sister and brother. Thomas has autism and an intellectual disability, which limits his communication and impacts his behaviour and anxiety. Thomas attends a special school and Sarah is at university. Both Sarah and Thomas described a relationship based on doing small activities together at home, like singing or reading. Sarah makes effort to engage with Thomas in a way he will enjoy.

5.1.3. Individual participation

Maria and her siblings

Interview – **Maria**, 29, is from a large family from a regional area, where she has several siblings who range in age from 21 to 35. Maria has a mild intellectual disability and limited vision. She is employed and her siblings either work or are raising young families. Maria's description of her relationships with her siblings could not be separated from what she said about her large family: her sibling

relationships were also bound up in relationships with parents, nieces, nephews and her siblings' spouses.

Geoff, Trev and Leah

Interview – **Geoff**, 27, is brother to Trev, 21, and Leah, 29. Geoff is on the Autism Spectrum, which affects his social interaction and understanding of others' communication. Geoff and Trev both live on their parents' property, while Leah lives separately. Geoff is a university student, while Trev is working and Leah is raising a young family. Geoff uses the word "estrangement" to describe their relationship, and feels that the reasons for this include his disability as well as family conflict, interstate relocation and long periods of time when their father was away for work when they were children.

Tara, Erin and Lisa

Interview – **Tara**, 18, has two sisters, Erin, 16, and Lisa, 14. Tara has a hearing impairment, although often passes as not having a disability. She is transitioning from high school to university, while Erin and Lisa are both still at school. The sisters lead busy lives where their relationships together are bound up in school life, sport, friends, popular culture and use of social media.

Nathan, Jesse and Alicia

Interview – **Nathan**, 21, is brother to Jesse, 27, and Alicia, 29. Nathan has Cerebral Palsy – he uses crutches and has some issues with fine motor skills. Nathan is a university student, while Jesse and Alicia both work in professional positions. Nathan's description of his sibling relationships focused on his enjoyment of the activities they do together, such as playing PlayStation with Jesse and Skyping with Alicia, who recently moved overseas.

Danielle and Rebecca

Interview – **Danielle**, 19, and Rebecca, 20, are sisters. Danielle has a hearing impairment. Both are university students. Danielle describes a relationship where they get on well and support each other in their studies, church life and travels.

Fleur, Petra and James

Interview – **Fleur**, 22, is sister to Petra, 26, and James, 24. Fleur has Cerebral Palsy, with minimal physical movement and uses an electric wheelchair. Fleur is a university student, while both Petra and James work in professional roles. Fleur notes doing fun activities with her siblings as well as their emotional and practical support to her.

Macy, Cally and Joshua

Interview – **Macy**, 17, Cally, 15 and Joshua, 19, are siblings. Macy has an intellectual disability and attends a transition to work program. Cally is at high school, while Joshua attends university. Macy comments that she helps Cally and Joshua with tasks around the house and that she went on vacation with them. She values when they are home with her, rather than being home alone, as she says she feels safer when they are there.

Corey and Angie

Documented contribution – **Corey**, 17, and Angie, 21, also have two other siblings not included in the study. Corey has autism, affecting his behaviour and communication – he communicates via facilitated communication. He is near the end of high school, while Angie has finished school. Corey describes feeling close with Angie in the past, although this has been disrupted as they have grown older and Angie found a boyfriend and moved out of their shared bedroom.

Brett, Dean and Beth

Documented contribution – **Brett**, 24, has Cerebral Palsy – he uses an electric wheelchair and has a mild intellectual disability. He attends a day program. His siblings are Beth, 22, and Dean, 17. Brett lives in a regional area with his parents and Dean, while Beth has moved to the city. Although Brett's relationships with Dean and Beth have not always been smooth, he is interested in what they do and describes valuing their presence in his life.

Eric, Jacqui, Zac and Tamara

Documented contribution – **Eric**, 20, has a physical and intellectual disability. He comes from a family of four siblings, where he is brother to Jacqui, 25, Zac, 23, and Tamara, 8. Eric lives in a regional area with his mother, stepfather and Tamara, while Jacqui lives separately and Zac lives with their father. Eric attends a day program, Jacqui and Zac work and Tamara attends school. Eric describes difficult relationships with Zac and Tamara, but has a better relationship with Jacqui. He enjoys being an uncle to her new baby and playing video games with her husband.

Olivia and Scott

Documented contribution – **Olivia**, 19, is sister to Scott, 18. Olivia has Cerebral Palsy, which has a mild physical impact on her walking. She describes Scott treating her as though she does not have a disability and them having both good and bad times together.

Melanie and Jason

Documented contribution – **Melanie**, 18, and Jason, 26, are sister and brother. Melanie has Cerebral Palsy with minimal physical movement and communicates via alternative and augmentative communication. She attends high school, while Jason is at university. Melanie notes that their relationship is improving as Jason shifts out of a rebellious period in his life.

Mark and Claire

Interview – **Mark**, 18, is brother to Claire, 15. Claire has a physical and intellectual disability. She does not speak and while her family are not exactly sure how much she understands, Mark notes that she responds appropriately to the mood in a room or to events happening around her. Mark is a university student and Claire attends a special school. Marks spends time with Claire and their parents at home and particularly feels the impact of her communication impairment on their relationship.

Ruby and Luke

Interview – **Ruby**, 17, and Luke, 24, are brother and sister, and also have another older sister not included in the study. Luke has autism and an intellectual disability, which means he is sometimes aggressive or unpredictable. Ruby is transitioning from high school to either university or work, while Luke works in supported employment. Ruby and Luke's relationship has recently improved. Ruby says the improvement is due to Luke moving out of home to supported accommodation, which has decreased a history of conflict between them.

Mia and Cara

Interview – **Mia**, 23, and Cara, 19, are sisters. Cara has Cerebral Palsy and uses an electric wheelchair. Mia does a combination of university and work, while Cara works in supported employment. Mia notes that Cara is currently experiencing some emotional stress. Mia does not completely understand Cara's current behaviour, but wonders whether it is a mental health issue or perhaps Cara's emotional reaction to really beginning to understand some of the implications of her disability for the first time.

Sophia and Anna

Interview – **Sophia**, 24, and Anna, 15, are sisters. They also have another sister not included in the study. Anna has a physical and intellectual disability, including a history of complex medical problems. Anna uses a wheelchair and Sophia describes her as having minimal physical movement and little understanding of what is happening around her. Sophia has moved away from the family home to study medicine at university. Anna attends a special school. Sophia has felt more positively towards Anna since she has begun her studies in medicine and has moved out of home.

5.2. Composition of the sample

As explained in the sections below, together the siblings profiled above reflect diversity in whether they are a sibling with or without a disability, as well as in

gender, sibling constellations, disability type and affiliations with sibling-disability issues, although are less diverse in cultural and socio-economic background and in that they mainly live in urban areas. In further accounting for these characteristics below, the figures given are either by the number of participants (n=46; 25 with disabilities, 21 without disabilities) or by 'case' (n=31). Here, a 'case' is not used in the sense of a case study, but rather refers to a family. If a pair of related siblings both participated, they form one 'case'. Equally, if one sibling participated alone, he or she also forms one 'case'.

5.2.1. With and without disability

The study sought to include siblings both with and without disabilities. Within this, there was specific effort to include siblings with disabilities but also to allow participants to choose to participate together, separately or alone. In the final sample, 25 cases (80.6%) included a sibling with a disability, indicating that the study was successful in including this group. In 13 cases (41.9%) both siblings took part (either jointly or separately), while in 12 (38.7%) it was just the sibling with a disability and in six (19.4%) it was just the sibling without a disability. The distribution across these options suggests that the study was successful in including siblings with disabilities, but also that participants took up different choices about whether to participate together, separately or alone.

5.2.2. Gender

Given the gendered nature of sibling relationships (Mauthner, 2002, Edwards et al., 2005), the aim was for the sample to split evenly between males and females (see Section 4.2.3). This was achieved, with 22 male participants (47.8%) and 24 female participants (52.2%). This included 13 male and 12 female siblings with disabilities, as well as nine male and 12 female siblings without disabilities. Nineteen cases (61.3%) included a male-female sibling pair, five (16.1%) a male-male pair and seven (22.6%) a female-female pair. Given the higher probability of mixed-sex pairs of siblings, the higher incidence of some disabilities in males (Baron-Cohen et al., 2011, Zwaigenbaum et al., 2012) and the cultural reticence among some males to discuss

relationships (Bergman and Surrey, 2004), the sample provides a reasonably even gender stratification.

5.2.3. Birth order, age and age spacing

As siblings' constellations – such as birth order, age and age spacing – are key features of their relationships (Edwards et al., 2006, Dunn, 1985, Furman and Buhrmester, 1985), it is significant that the participants also reflect diverse constellations. In nine cases (29%) the sibling with a disability was the oldest, in six (19.4%) he or she was a middle sibling and in 14 (45.2%) he or she was the youngest; two cases (6.5%) included twins. Age was evenly spread between the 15-18 and 19-29 age groups accounted for in Section 4.2.3, with 24 participants (52.2%) aged 15-18 and 22 (47.8%) aged 19-29. In assessing age spacing, there were 45 possible sibling pairs², among which 21 (46.7%) had an age spacing of one to three years, 15 (33.3%) four to six years, six (13.3%) seven to nine years, one (2.2%) nine to 12 years and two pairs (4.4%) were twins. The sample thus reflects a diversity of constellations.

5.2.4. Cultural and socio-economic diversity

As cultural and socio-economic background influence sibling relationships (Cicirelli, 1995), it is significant that whilst conducting extra recruitment for siblings from culturally and linguistically diverse and low socio-economic backgrounds (see Section 4.2.3), the sample remained mainly Anglo and socio-economically advantaged. In just three cases (9.7%), siblings self-identified being of a culturally or linguistically diverse background, while in another two cases (6.5%) this could be assumed, but not confirmed, due to participants' surnames. Five cases (16.1%) included siblings of a low socio-economic background. This was determined by living in public housing or by residence in a suburb with an Index of Relative Socio-economic Disadvantage (IRSD)³ decile of one to three. As well as living in this suburb,

² This figure counts families with three or more siblings as multiple dyads, each paired to the sibling with a disability; the figure does not include the sibling pairs from these families where neither had a disability.

³ The Index of Relative Socio-economic Disadvantage is a measure included in the *Socio-Economic Indexes for Areas (SEIFA)*, made up of measures of relative disadvantage and produced by the

each sibling of a low socio-economic background also directly experienced some of the measures of disadvantage that make up the IRSD, such as low levels of education or high levels of unskilled work, unemployment or ill-health in the family; a low family income; being part of a single parent family; or coming from a non-English speaking background. Understanding the cultural and socio-economic limitations of the sample is important for situating the relational experiences in this study.

5.2.5. Disability type

As noted in Section 4.2.3, the study included siblings with a range of disabilities, whilst purposively recruiting for intellectual disability and complex communication needs. Of the 25 siblings with disabilities who participated, 12 (48%) had either a physical or sensory disability, eight (32%) had an intellectual disability and five (20%) had complex communication needs. Participants with intellectual disabilities and complex communication needs together comprised over half of participants with disabilities in the study. This is significant as this was an aim of the sampling (see Section 4.2.3) and as these groups are generally at greater risk of exclusion from research. By diagnosis, siblings (either participants or non-participating siblings of participants) with Cerebral Palsy, Down Syndrome and Autism Spectrum Disorder were most common, although there were also siblings with other physical, intellectual or sensory diagnoses, such as vision impairment, hearing impairment or unspecified physical or intellectual disabilities. Some siblings with disabilities had extensive support needs, while others required very little disability-related support. Where siblings without disabilities took part in the study alone, this was sometimes because his or her brother or sister had a high level of support needs to the extent that he or she could not participate. The variety of disability types and levels of support needs is important for highlighting that this study is not premised on diagnosis, disability type or extent of support needs. Rather, a diversity of functional experiences of disability are included and an overall experiential perspective that is not specific to any one disability is reflected.

Australian Bureau of Statistics. The latest SEIFA scores available from 2011 Census data were used.

5.2.6. Sibling-disability affiliations

It is also significant that the participants were mostly not affiliated with support groups for siblings without disabilities, as has been the case in many other sibling-disability studies (e.g. Weisman, 2007, Kramer, 2009, Heller and Kramer, 2009, Barr and McLeod, 2010, Arnold et al., 2012). While sibling support and young carer groups assisted with recruitment, only two siblings in the final sample actually had sustained, long-term engagement with such groups or were participating at the time of the study. This is significant because it addresses recommendations that more must be done in sibling-disability research to include a wider range of siblings without disabilities beyond those who self-identify as most involved or most interested in sibling-disability issues (Heller et al., 2008). Further, including siblings who either have chosen not to access sibling or young carer support or who have not had the opportunity to do so provides insight into the views of a group not usually included in sibling-disability research. This is important for extending to the perspectives of siblings not previously included in research. Combined with the inclusion of so many siblings with disabilities – who are also not usually included in sibling-disability research – this study then taps the perspectives of a markedly different group of siblings to most studies in the field, positioning it well for bringing to light new perspectives and experiences.

In this way, overall, the sample reflects diversity across having or not having a disability, gender, birth order, age, age spacing, disability type and sibling-disability affiliations, whilst being more limited in cultural and socio-economic diversity and in most participants living in urban areas. This assessment of the degree of diversity in the sample is important for highlighting who the siblings in the study are and for locating their experiences in relation to their broader demographics and characteristics. Section 10.2.3 in Chapter 10 highlights how future research could extend coverage to address the limitations of this sample, include other populations of siblings and generally further the relational approach adopted in this study to other siblings.

5.3. Using siblings' accounts

In reporting on participants' experiences in the following chapters, there were several considerations regarding how to appropriately utilise their accounts. These considerations are discussed below, outlining the implications for how data is used and displayed in the following chapters.

5.3.1. Presentation of information

Self-contained accounts

Overall, siblings' perspectives are generally presented as self-contained. That is, rather than structuring the analysis predominantly to compare or contrast the contributions of a pair of siblings, as many studies that include siblings or multiple family members do (e.g. Song, 1998, McCarthy et al., 2003, Harden et al., 2010), the data is instead presented to illustrate each sibling's own relational experience, including comparisons where these are relevant, but not specifically setting out to compare dyadic perspectives. This self-contained approach was used as it better facilitated an analysis that answered the study's research questions and because, overall, it was not the intention to thoroughly compare and contrast dyadic perspectives. Dyadic perspectives and comparisons do appear occasionally throughout the thesis however and add depth in understanding the role of perspective and perception in siblings' experiences.

Block quotes, quote fragments and vignettes

In laying out siblings' accounts in the following chapters, data is most commonly presented either in block quotes or quote fragments woven into prose. Given the use of discrete phenomenological examples, as explained in Section 4.4.3, these strategies were chosen as straightforward ways to quote participants and for clearly providing information that could then be unpacked through the reflection encompassed in each example.

However, occasionally a vignette is used with the example retold in prose, rather than only using a quote. Vignettes are kept to a minimum (only appearing in Chapter 6)

and are only used where there was a need to summarise long examples, where no single quote sufficiently captured an overall view a participant expressed or to connect information that participants revealed in different parts of their interviews into one example. This happened because siblings' often returned to the same themes or examples multiple times throughout their interviews. Where they are short, vignettes are presented with a box around indented text to clearly differentiate them from block quotes. One longer vignette is presented as indented italicised text at the beginning of Section 6.2.

Attribution

Throughout the main findings chapters (Chapters 6-9), the block quotes, quote fragments and vignettes are almost always attributed to a specific participant. This follows the study's in-depth phenomenological approach and the intention to closely examine each participant's experiences. However, Section 6.1 in Chapter 6 includes unattributed quotes. This is for two reasons. Firstly, this is a prefatory section mapping data against the existing findings of sibling-disability research rather than adopting the phenomenological approach used in the main analysis. Therefore an attribution to particular participants was not necessary. Secondly, this section includes sensitive data, revealing difficult psycho-emotional and relational issues that some siblings experience. Given this sensitivity, it was ethically appropriate to use more extensive protections against the possible identification of participants. Using unattributed quotes was one way of doing so.

The effect of this combination of ways of presenting data is an analysis that foregrounds siblings' experiential and relational perspectives, while accounting for, but not foregrounding, their individual-level psycho-emotional experience. The intention is to acknowledge both, while presenting the data in a way that specifically draws attention to new phenomenological and relational perspectives.

5.3.2. Frequency of accounts

The frequency with which siblings are quoted in the forthcoming chapters is also a key feature affecting the presentation of their accounts. As already noted in Section

4.5, some siblings appear more frequently than others. Some are quoted in multiple chapters, others appear in just one chapter and a few do not appear at all. It is important to understand why some participants are quoted more frequently than others and how those who appear less often have still informed the overall analysis.

Firstly, some siblings' accounts appear less often because of the nature of the data available. Siblings who participated by documented contribution gave briefer information than those who participated by interview. There was usually only enough information in a documented contribution to provide one example for the thesis. This means that while these siblings appear less often, their accounts are still used to the maximum extent possible. In other cases, some siblings gave examples of issues that are discussed in the analysis, yet in the selection of data for the chapters there were more in-depth and illustrative examples of the same phenomena from others. In these cases, the more illustrative examples were chosen in order to maximise the explanatory power of the analysis, yet the views of the participant who was not quoted still informed the thinking on the issue in question.

Secondly, as noted in Section 4.5, some siblings' accounts appear less often because they spoke less about all three of the experiences of interest to the study – experiences as siblings, of disability and of young adulthood – and about the inter-relationship between them. Accordingly, there was less information from these participants to use in the analysis. In particular, those who spoke less about the sibling relationship appear less often, given the work's relational focus. The participants also simply differed in the depth of their responses in general and thus in the amount of information they gave, also influencing how much they could be quoted. However, even the views of participants who appear less often have still informed thinking about the nature of sibling relationships for different demographic groups and about the conditions in which a relational focus can be successfully researched.

Finally, ethical issues also influenced the extent to which some siblings' accounts feature. Sometimes examples were omitted to guard against inadvertent re-identification of participants. Where some participants had particularly unique experiences or circumstances, the intersection of this information with that about

their disability, siblings and family structure was enough to together give the potential for them to be identified. In these instances, there was a need to select examples that did not feature the combination of identifiable information, limiting the amount of data available for use from these participants. In other instances, the use of some specific details presented an unacceptably high risk of disclosure between siblings who participated separately and thus these details could not be used. For example, the disclosure issue discussed in Section 4.4.4 – where one sibling revealed a secondary disability that the other did not – meant that neither siblings' information could be used more frequently. In both issues, ethical obligations meant that some siblings' accounts were not used as thoroughly as would have been ideal.

The combined effect of these data, research focus and ethical issues is that there is a shortfall in giving equal attention to all participants. However, overall, irrespective of the extent to which they appear, all participants had an important role in informing thinking on and analysis of the research topic and, while their accounts may not always be foregrounded, all still inherently contribute to the relational analysis.

5.4. Conclusion

Understanding who the siblings who feature in this study are and how their information is used gives a basis for appreciating the accounts that follow. The siblings are an everyday group who are diverse in terms of having or not having a disability, gender, birth order, age, age spacing, disability type and sibling-disability affiliations, while they are relatively more homogenous in being largely Anglo, socio-economically advantaged and from urban locations. Overall however, the participants form a diverse sample, whose experiences are then discussed and quoted in different ways. Understanding this background to those who feature in the following pages gives important context to the relationships that are illustrated and sets the scene for the conditions in which disability figures in the lives they share together.

Chapter 6. Disability in the sibling relationship

As outlined in the previous chapters, this thesis aims to understand how disability figures in relationships between siblings with and without disabilities. To begin developing this understanding, this chapter starts by exploring the roles of the physical, cognitive and emotional elements of disability in the everyday relations between siblings and looks at what these elements of disability mean for their overall experience of the sibling relationship.

The chapter unpacks how disability is physically, cognitively and/or emotionally embodied in each sibling's own self and then enacted in the everyday relations of talk, conduct and emotion between them, sometimes constituting and sometimes creating key elements of these relations. The overall felt experience of these relations is drawn out to discuss how the presence of disability in the relationship leads to particular relationalities or felt experiences for siblings.

Ultimately, the chapter aims to open up sibling-disability research to a new everyday framework for understanding sibling relationships in which disability is present. Rather than focusing on the individual-level impact of disability on siblings without disabilities, as has been the focus of much previous sibling-disability research, the work here instead looks at the details of the everyday, shared experiences between both siblings and of what is enacted between both siblings when disability is present in their relationship. As discussed in the literature review, this everyday exploration of disability has been a neglected area. Understanding more about the everyday role of disability in sibling relationships is thus important for broadening the focus of sibling-disability research and for extending what is known about the relational experiences of disability shared between both siblings.

6.1. Preface: Siblings without disabilities' individual experiences

As noted above, this chapter and thesis intentionally shifts beyond a focus on the individual-level impact of disability on siblings without disabilities. However, it is nevertheless important to note that many of the individual-level experiences commonly reported in the literature were also evident for many of the siblings without disabilities in this study. Appreciating that many siblings without disabilities demonstrated both the individual-level impacts of disability *and* the relational experiences explored in this thesis is important for understanding that a relational focus and a focus on individual-level impact are not mutually exclusive. While a detailed examination of siblings without disabilities' individual-level experiences is beyond the scope of this thesis, it is thus worth briefly noting some of siblings without disabilities' individual-level experiences in order to contextualise the relational findings.

Some siblings without disabilities highlighted experiences that reflect the focus on the psycho-emotional impact of disability on siblings without disabilities, discussed in the literature review. For example, one sibling without a disability spoke about her feelings of grief about her sister's disability and the effect on her self-perception:

I've got all this grief and feelings about [her disability]... it kind of makes people like me feel really bad about my feelings and my experience with it. You feel like you're this odd one out who has all these awful values and views on the world.

Another spoke about her experience of having an eating disorder and depression. She identified how her doctor had suggested that her conditions might be connected to her sister's disability and that she agrees with this explanation:

In terms of [my] eating disorder and depression, I think, a lot of that – oh, okay: according to the experts... there are a lot of different factors that influence that, but [my doctor] said that perfectionism and that anxiety which is associated with those things is actually found in a lot of research is quite common where there is a disability

in the family... Yeah, I do think that's very accurate to say that [about me] – I'm not blaming my sister, I'm not blaming disability – but...

Other siblings without disabilities reflected the 'positives' and 'negatives' framing of disability, also discussed in the literature review. For example, one sister highlighted 'positives' and 'negatives' together:

If you think about it you can see it, like we don't go through our day going 'Oh, we're so broken', but if you really think about it you can see that it would've been easier if he wasn't the way he was... wouldn't change it for the world though, I wouldn't ever – because he taught us so much: acceptance, patience, tolerance, like he taught us all that, which a lot of people never have the experience of that.

Others accounted for the 'positives' and 'negatives' separately. Some emphasised 'positives' such as that their sibling with a disability "matured" them, "opened [their] eyes in a completely different perspective" or made them "more open-minded" and "less judgemental". Others instead mentioned 'negatives', such as being "frustrated", "angry" or having "responsibilities that I didn't want as a kid".

Many siblings without disabilities also commented on other individual-level experiences that commonly feature in the sibling-disability literature. Some commented on feeling invisible, for example, saying "I don't think views like mine are know or heard about or seen" (Naylor and Prescott, 2004, Abrams, 2009). Others mentioned feeling embarrassment when their sibling came across as "socially awkward" or "weird" (Wilkerson, 2001, Barr, 2011) or feeling socially restricted, for example, not having friends over during high school because of their sibling (Benderix and Sivberg, 2007, Barr and McLeod, 2010). Some felt particularly independent, mature or responsible (Mulroy et al., 2008, Abrams, 2009) and some felt they "sacrificed" their own experiences for the sake of their sibling (Mulroy et al., 2008). Some also commented on being frustrated by other people's reactions, especially when friends or strangers used terms such as "retard" in a derogatory manner (Mulroy et al., 2008, Barr, 2011).

Each of these individual-level experiences are important and highlight that the findings commonly discussed in the sibling-disability literature also apply to the

siblings without disabilities in this study. However, these types of individual-level findings have already been well documented in much existing research and, as outlined in the literature review, there is a need to shift beyond only an individual-level approach. Thus while acknowledging these individual-level experiences, the remainder of this chapter and thesis intentionally shifts beyond them to the relational focus outlined in Chapters 1, 2 and 3.

6.2. The relational roles of disability for siblings

Mark sits down for his interview. After a basic introduction to himself and his sister Claire, who has a physical and non-verbal intellectual disability, the very first thing he mentions is how their relationship is “not really that in depth” because of Claire’s limited communication:

In terms of our relationship, obviously because she doesn’t speak, it’s not really that in depth... You don’t have like that deep emotional connection between the two of you, because you can’t kind of talk about each other’s lives... I don’t have a brother or sister to connect to, but I still have a brother or sister there.

Yet within a minute, Mark then describes how Claire’s limited communication is in fact itself a source of comfort and security to him when he is upset, because it means she can be a “sounding board” to his distress and “she’s not going to tell anyone else”:

I don’t know if it’s ‘comfort’ that’s the right word, but the fact that I can kind of say anything to Claire... she’s not going to say anything else, she’s not going to talk back to me. She’s kind of like a sounding board in a sense, like I can talk to someone, but I can just talk to them, almost talk-at-them-talk-to-them, can open up to her, because I’m secure in the fact that she’s not going to tell anyone else, she’s not going to talk back at me, disagree with me... So that’s comforting sometimes... Often when I’m really upset or distressed about things, I find it helpful, because I feel like I can kind of sink that information in to her.

Mark feels that his relationship with Claire is limited by her lack of speech, yet it is also this exact quality about her that constitutes a relational act that goes deep into Mark's sense of how Claire supports him. He knows she will not talk back; elsewhere in his interview he acknowledges that he does not even know exactly how much she understands what he says – and because of this, he "talks-at-[her]-talks-to-[her]". In moment of the security Claire offers through her silence, Mark finds support and comfort. They enact an everyday relation of support based on the very fact about disability that Mark feels limits their relationship. It is a relational act constituted through disability, yet it does not feel like the relationship that Mark expects they should have.

In the study, siblings were asked about their feelings and perceptions of each other, the activities they do together and the ways they communicate, support each other and argue. Follow up questions prompted siblings to explain the inter-relationship of these aspects of their relationship with disability – that is, they were asked where and how disability had a role in the everyday relations they shared with each other. As highlighted above, this aimed to articulate a so far unexplored focus on relational experience and everyday life.

Through these questions, participants gave numerous examples of the roles that disability played in their relationships and of relational experiences of disability with their brothers and sisters. As shown in the vignette about Mark and Claire above, these relational experiences often had a very different character than where siblings without disabilities accounted for the individual-level impact of disability upon them; instead, these relational examples were about how disability became embedded within elements of siblings' everyday relations with each other. Many of the examples illustrated how the physical, cognitive and/or emotional presence of disability was central to what nevertheless also remained normative sibling relations between participants and their brothers and sisters. Other examples showed how the presence of disability could provide a purposeful or unique character to siblings' relationships or how it could heighten the experience of some of their everyday relations. These different experiences of disability's presence in the relationship are

detailed in the following sections, exploring how each had a role in either constituting or creating siblings' everyday relations with each other.

6.2.1. Central to normative sibling relations

Sometimes physical, cognitive or emotional elements of disability had a central presence in siblings' everyday relations with each other, yet those relations were also still normative to sibling relationships in general. This was the case for Mark in the vignette above. The presence of his sister Claire's lack of speech and comprehension was central in that it constituted the enactment of security, support and comfort between them. Disability was constitutive because Claire's support to Mark was expressed *through* her disability – without it, the substance and form of her support would not exist; her disability thus makes her support what it is and so is central to the relation happening between them. Yet while Claire's act was constituted through disability, the general function of listening and providing personal or emotional support is shared among many siblings irrespective of disability (Mauthner, 2002, Eriksen and Gerstel, 2002, Kuba, 2011, Weller, 2012). Disability is then central to their interaction, but it remains a normative sibling interaction as well. Other siblings similarly identified how disability *constituted* a relation that was also inherently normative.

Tara explained how her hearing impairment figured in a discussion with her sister, Erin, about her boyfriend:

I guess [disability] comes up sometimes when Erin, you know, she might ask me something just offhand, like, 'Oh, have you told [your boyfriend] that you can't hear anything?' and I'd be like 'Yes, of course I have', but then it turns into a conversation about our relationship, not the disability... She's like, 'Well, do you tell him everything?' and I'll be like, 'Yeah, that's the idea' and she's like 'Oh, that's so strange and what about this and have you told him about that?' and it's not anything to do with me not being able to hear. Yeah, she always finds some excuse to talk about him.

Here, Tara and Erin have a discussion about boyfriends that is normative to teenage sisters, many of whom commonly talk about relationships and boys (Edwards et al.,

2005). Yet in this discussion, disability constitutes a shared marker of what it means to trust a boyfriend enough to “tell him everything”. Like for Mark and Claire above, disability is constitutive because the meaning of their conversation is expressed through disability and without it a significant part of their shared understanding and signification would not exist. Yet while disability’s presence constitutes part of the meaning of their conversation, the conversation nevertheless remains one where the general subject matter – relationships with boyfriends – might be discussed between many sisters irrespective of disability. Disability’s presence constitutes and is central to the enactment of a relation that is inherently normative.

Similarly, disability also had a central role in some normative moments of banter between Vicky and Jono. For example:

Vicky: With [exams], I get special considerations, so a reader and a writer and more time and I do it separately in my own room.

Jono: I’m sorry – why?

Vicky: Because with the essays, my hand gets tired.

Jono: Ah, so lazy! [*slightly serious, slightly teasing tone*]

Vicky: No, muscle disease! [*slightly serious, slightly teasing tone*]

Jono: That’s just an excuse, I reckon! [*slightly serious, slightly teasing tone*].

Vicky: Yes, I’m very lazy, that’s why I move around in a chair instead of walking [*sarcastic tone*].

Jono: Danny DeVito does that.

Here disability constitutes the basis on which Jono jibes at Vicky; the jibe hinges on and is expressed through disability. Yet in their interview, Vicky and Jono described how they actually jibe each other about everything: their respective tastes in art,

books and movies, their political opinions and their relationships with other family members. Banter and jibes appear the central dynamic of their relationship. In a context where bickering and banter is common among many siblings (Edwards et al., 2006) and between Vicky and Jono in particular, Vicky's embodied disability is then simply one of a scope of possible subjects of banter enacted between them and, as such, Vicky does not appear to be upset by Jono's jibe, but rather responds to him with the same slightly serious, slightly teasing tone. Disability constitutes this moment of banter between them, but it expresses a broader pattern that exists throughout their relationship.

In other cases, disability was not constitutive – because the relations between siblings were not expressed *through* disability – but rather disability *created* a context for some relations to happen between siblings; that is, those relations happened *because of* disability. For example, Olivia talked about how an unprecedented change in her disability created disconnection between herself and her brother, Scott:

When I was 18, I had major surgery due to my Cerebral Palsy. This was an important thing because I was in a wheelchair for three to six months and got to experience a more severe case of my disability than I have ever known. My brother has always treated me as though I do not have a disability, so experiencing a more severe case of Cerebral Palsy played a major role as it was like a wake up call to the fact that I have a disability and the two of us didn't really know how to feel or react to such a situation.

In this example, Olivia had a new, intense embodied experience of disability – and she and Scott found this change awkward and did not know how to “feel or react” together. In this way, a moment of disruption and difficulty between them was created by or happened because of disability. Yet while disability created the difficulty, such difficulty in talking about personal or meaningful subjects is common in many sibling and other family relationships and difficult subjects are commonly avoided in many families (Guerrero and Afifi, 1995). While disability creates the disconnection that Olivia and Scott experience, it is thus also a type of difficulty that is normative to siblings: a normative reluctance to broach what is new, intimate and

personal together. The presence of disability then creates a difficulty that is reflective of many sibling relationships.

Similarly, Ava spoke about the central role of disability in her feelings of resentment, grief, fear, hurt and anger towards her sister, Zoe:

I just had a lot of resentment towards her because of the disability, and a lot of grief, and I have a lot of fear about the disability and what it does for her, and how it affects her life, and I can't see her not get [sic] to experience the normal things like going to be able to go to school and just have a normal school life, maybe not having friends, having to spend all of your time with your [paid] carers because people your age are kind of like "wheelchair girl, no thank you". That sort of thing I can't really – don't want to see that happen to her, because I don't want to see her get hurt or miss out on these normal experiences. So I just haven't been able to have a friendship with her because to have to see her go through that and to get hurt by that – it just hurts me way too much to have to deal with that... I think that's probably the reason, yeah, that's why I couldn't talk to her. I just had a lot of anger.

Here, Ava emotionally embodies disability, absorbing into her sense of self many of the intense and difficult emotions that have commonly been noted as those that siblings without disabilities may feel towards their brothers or sisters with disabilities (e.g. Opperman and Alant, 2003, Abrams, 2009, Stream, 2009). Ava highlights that it is disability that has created these emotions, saying they are "because of the disability" and "about the disability". Yet, strong emotions are common in many sibling relationships irrespective of disability, particularly among sisters close in age, as Ava, 18, and Zoe, 17, are (Mauthner, 2002, Kuba, 2011). Further, emotional investment in un-actualised images of what one wants for another's life – such as Ava's images of what she wants but does not believe will happen for Zoe – also commonly lead to relational disconnection (Jordan, 2004). This means that even while these intense and difficult emotions have been created by disability, they also remain a normative part of Ava and Zoe's relationship, as disability created their difficulty in ways characteristic of difficulty in many

relationships. Once again, the presence of disability is central to a relational interaction that is also inherently normative.

In each of these examples, disability is centrally present in either constituting or creating the way that many everyday relations between siblings happen. Disability either becomes part of the form of or the reason for many of siblings' everyday relations, including relations of support, talk, banter, shared meaning, disconnection and conflict. Yet these relations also remain normative of what happens between many siblings irrespective of disability. Thus, it is not possible to separate disability in these examples from what relationally happens between siblings anyway. That is, disability becomes part of the experience of the relationship itself.

6.2.2. Purposeful relations

In other cases, disability continued to either constitute or create siblings' relations, but in a much more purposeful way. That is, some siblings actively used disability in their talk and conduct with their brothers and sisters to achieve particular purposes or goals for the relationship. In these instances, disability was mobilised to manage their relations with each other.

For example, Tara identified how her sisters, Erin and Lisa, purposefully use her disability in conflict between them. With a crack in her voice that revealed the intensity of the experience for her, Tara explained how Erin and Lisa use her hearing impairment as "leverage" to win arguments between them:

My sisters, they can use my not being able to hear as leverage in a lot of arguments, like [they pretend], "You didn't hear that right"... They like to use that as a bit of a "We're going to win this argument", which isn't fun for me.

Siblings commonly try to invoke power over each other (Edwards et al., 2006, Mauthner, 2002) and questioning competency, insecurities or anxieties are forms of power enacted between many siblings (Wiehe, 1997). In this example, disability constitutes the way that Erin and Lisa invoke power over Tara: they enact the normative intricacies of conflict and exploitation between siblings through disability itself by capitalising on Tara's embodied disability, her impaired hearing, to

manipulate her and win the argument. While Erin and Lisa could play on other of Tara's characteristics, in this example if disability were not present then their chosen point of manipulation would not exist. Disability thus constitutes what happens between them, but it is also a purposeful interaction that is normative of siblings as well.

Similarly, Geoff used his own experience of disability to attempt to understand his brother, Trev, and sister, Leah, who rarely express their emotions:

Both my brother and my sister do have love – they can't just express it and they probably only express it to certain people in their lives. Kind of like it can be for me – but it's different, because I've got a disability, so it's an added strain with autism of having the concern that you can't hold or have intimate or expressive relationships.

Striving for awareness or understanding of the other is a normative act of relationships (Jordan, 2004) – and here disability constitutes the way that Geoff enacts this normative act. While perhaps less intentional than Tara's example, as he says "kind of like it can be for me – but it's different", Geoff shows how he uses his own embodied experience of disability as a way to understand what emotional expression might be like for Trev and Leah. His understanding is expressed through disability itself. In this sense, disability constitutes a way for Geoff to understand his siblings.

For others, disability created the opportunity to achieve a purpose for the relationship; that is, the purposeful interaction happened *because of* disability, but it was not necessarily enacted *through* disability. For example, Allegra used the presence of disability to support her chosen vision of her sibling relationship. Allegra made the following observation about her sister, Lucy, who has Down Syndrome:

Lucy as much as she loves me has never called me up and said "Lets do lunch" and I think that's something that most sisters would do, but she just doesn't have – it's me who initiates everything... I know she would want to if she had the capacity.

Cultivating idealised images of relationships is common (Jordan, 2004, Murray et al., 1996) – and this is what Allegra does. While her explanation may or may not be

accurate, Allegra says that it is because of Lucy's embodied disability, her impaired "capacity", that her own preferred vision of a reciprocal relationship is not the case. By saying that Lucy does not have "the capacity" to initiate an invitation, Allegra implies that disability has created their one-sided relations and, thus, she uses disability to explain the lack of reciprocity between them in a way that does not challenge her ideal of herself and Lucy having a closer relationship (for example, by questioning whether Lucy wants to return an invitation). While it is more unconscious than Geoff and Tara's examples, Allegra nevertheless uses disability to achieve a purpose for the relationship of understanding herself and Lucy as close and happy together.

These examples show how for some siblings disability constitutes or creates ways to work towards or achieve the ends they want for their relationships. As disability is used in purposeful ways, it forms part of the enactment of normative sibling relations and thus is part of the experience of the sibling relationship itself.

6.2.3. Unique relations

In some sibling relationships – often those where siblings with disabilities had high support needs related to intellectual disability – participants identified difficulty in enacting everyday relations common to many other sibling relationships, such as talking together or sharing activities. However, these siblings often found that disability itself could provide other ways to engage with each other. Here disability offered the possibility of unique relations between some siblings, yet relations that still expressed some level of normative sibling connection.

Examples from Sophia and Anna and from Laura and Oliver show how disability offered unique ways for them to engage with each other:

Sophia and Anna

Sophia described engaging with Anna, her sister who has a high level of both physical and intellectual disability, by tickling her. Although they cannot talk or engage in other purposeful ways together, tickling is something that Sophia feels they both enjoy. While it is not possible to know exactly what Anna thinks of it, tickling constitutes a way for them to engage together through laughter, body and touch, each a successful, embodied way for Sophia to communicate or engage with Anna in the absence of talking, but where, through her disability, Anna responds to more sensory or tactile experiences.

Laura and Oliver

Laura, sister to Oliver who has autism and an intellectual disability, acknowledged that “language is always stressful [for Oliver], so language isn’t so good”. Laura explained how she engages with Oliver via a hand game instead, “something about the repetition [of which] he seems to enjoy more than any other activity [which] would be kind of a chore”. Laura said, “It’s a way to interact with him without him being frustrated” and “It’s a matter of finding something that he won’t just want to get away from”. Yet she also commented that she does not always think of the hand game as part of their relationship. She really has to think, “Well, what do we do?” to see it that way.

In the presence of disabilities related to cognition and communication, both Sophia and Laura substitute verbal communication for day-to-day embodied actions instead: tickling and a hand game. Each action is constituted by disability because it is expressed through the physical and cognitive characteristics of the specific disabilities that Anna and Oliver bring to the sibling relationship: Anna’s combined physical and intellectual disability has meant a bodily character to her relationship with Sophia that demands tactile and sensory contact and Oliver’s autism is perhaps why he appreciates the repetition of the hand game. These are examples of how some relations may not be possible among siblings due to the presence of disability,

but of how disability constitutes an opportunity to enact other unique and embodied relations instead. These are unique ways of engaging that are specific to and expressed through disability itself, however that sometimes really have to be thought about in depth to even be considered part of the sibling relationship at all. In these unique relations, disability is constitutive of how siblings interact. Yet siblings' efforts to find a way to engage together where and how they can also speaks to a foundational normative sibling relation: finding some way to be a part of each other's lives even when they cannot share other normative relations.

In other cases, the presence of disability did not constitute entirely unique relations between siblings, but rather created a unique inflection to their relations; that is, because of disability, their relations were somewhat different to what they might otherwise be. Thomas, who has autism and an intellectual disability, described his relationship with his sister, Sarah:

Sarah took me bowling. Sarah texts me on my sleep study, "Have a good night. I love you". Sarah reads things to me. Sarah plays balloon with me. I see Sarah at Before School Care. Sarah helps me with games. Sarah sings songs with me. Sarah lies with me before I go to bed. We play silly games.

It is normative that siblings share activities, especially brother-sister pairs (Edwards et al., 2005), yet here disability creates a unique inflection to the tone and level of Thomas and Sarah's activities together. Sarah takes Thomas bowling at an age where he might otherwise go independently; they see each other at Before School Care, where Sarah works as a special education assistant; she reads to him instead of him reading to himself; and they do easy activities together, like "play balloon". In each activity, because of the embodied presence of intellectual disability, there is a unique tone or setting to their interaction or its level is simpler and easier than it might otherwise be. While in one respect Thomas and Sarah normatively share activities like any other siblings, disability is present in creating or informing a unique tone and level to the interactions between them.

While Thomas, a sibling with a disability, described these disability-inflected relations with Sarah as just the way things are between them, some siblings without disabilities instead suggested a more liminal feeling to these kinds of relations, where they appeared more aware of the uniqueness and non-normativity of what was happening:

Ruby and Luke

Ruby described how one morning she “kept pretending to be asleep” so that her brother, Luke, who has autism and an intellectual disability, could have the “satisfaction” of waking her up early for work. She explained how she consciously pretended to be asleep and enacted this moment with him because of Luke’s disability: she suspects that he doesn’t always feel like he is her older brother because of his disability, yet she says “he really wants to be my older brother” by doing small favours like that for her – so she gave him the opportunity.

Mark and Claire

Mark described how he “play[ed] along” in conversation with Claire after her weekend away at respite. He described how he said, “Well, what did you do?” She could not say what she did, but responded with a non-verbal vocalisation, so Mark said “Oh really, is that the case?” in order to be “conversational as much as possible”.

In these examples, Ruby and Mark enact what are on one level normative relations of receiving a favour from and chatting with their siblings (Eriksen and Gerstel, 2002, Edwards et al., 2006). Yet, as above, disability also uniquely inflects the tone of their relations: disability created Ruby’s desire to let Luke have a moment of being an older brother and disability constituted a unique form to Mark and Claire’s conversation, where it was expressed through her vocalisations. In this presence of disability, Ruby and Mark also each imply a liminal feeling to their relations. They imply this feeling of liminality in that their comments about “pretending” and “play[ing] along” reveal an extent to which – even though these are relations of

support and talk that resemble the relations between many siblings – these relations also feel somewhat fabricated, set up or inauthentic because of the presence of disability. This feeling of liminality highlights that it can sometimes be hard to see, understand or place disability within the relationship.

Overall, these examples highlight that for some siblings the presence of disability constitutes or creates unique ways of enacting sibling relationships. Embodiments of disability determine what is and can be enacted between siblings, meaning that everyday enactments of the relationship happen in unique ways. Yet in each case, siblings still find some way to engage together, even if that sometimes feels only liminally part of the relationship. That is, even as disability constitutes or creates a unique felt experience within the relationship, it still forms part of a sibling relationship.

6.2.4. Heightened relations

Finally, some relations occurring between siblings with and without disabilities were objectively similar to those occurring between any other siblings, yet felt different because of the presence of disability. In these instances, disability created increased significance or increased intensity to some normative sibling relations.

For Mason and Corey, disability created heightened significance to their talk or chat with their siblings. Mason described the constancy of his trivial chat with his brother Will, who has Cerebral Palsy including unclear speech, compared to other people who do not chat much with Will at all:

[Other people will] be nice, ask Will a few questions like “What do you like to do?” and converse [sic] for a bit and then [the conversation] dies off, like they’ve done their part, you know what I mean? They’ve been nice, they’ve talked to him – because that’s the right thing to do. But me and him, it’s like constant, as if you are with your friends, it’s constant. There’s no difference – something comes up on TV, I’d say something to Will about it and he’ll say something back to me or if he saw something he would tell me or he’d be like “Remember that time”. We can just talk about anything whenever.

Similarly, Corey described the importance of his relationship with his sister, Angie, in a context where he has difficulty communicating with other people:

I have moderately severe autism and don't have speech... Life can be rather difficult as I can't communicate easily⁴... I felt close to [my older sister] Angie since we shared a room... Before going to sleep, she would talk to me about things, what she did at school, what her friends said and some of her ideas about what she wanted to do with her life. I listened... She was my best friend and made me feel accepted and cared for. I was less lonely when we were together. Things started to change as we grew up. When Angie was in Year 10, she met a boy whom she felt attracted to. They started to go out together, spending time during evenings or weekends... I became really resentful of him... Mum said that it was only natural for Angie to grow up and that we all needed to accept that she would become more and more independent. In the meantime, I should spend more time with other people. It was hard for me to see things that way, as I can't make friends easily, not being able to talk... The final straw came when Angie moved into her own room for privacy and more time to do her matriculation. I felt bereft. It was like I lost more than a friend and confidante, I had lost a lifeline to a world I aspired to belong, but without the necessary skills and knowhow, despaired of membership that had been denied.

Here, both Mason and Corey describe highly valuing trivial everyday chat. While this type of trivial chat has a role in many relationships (Duck, 1995) and chat and company are common among siblings (Edwards et al., 2006), both Mason and Corey suggest how, because of disability, this chat and company is all the more significant. Mason counterposed his own frequent chat with Will against other people's more restricted chat with him. Similarly, because he "can't make friends easily, not being able to talk", Corey felt "bereft" when he lost the close relationship he had with Angie where she would chat with him before they went to sleep. Both highlight how when talking with other people is difficult because of an embodiment of disability that affects communication, this may create heightened importance to the chat and company that comes more easily within the sibling relationship, where siblings have

⁴ Corey communicates through facilitated communication comprised of assistance to type. He sent in a written contribution to the study.

built up the skills for communicating with each other throughout their lives. The chat and company Mason and Corey value are normative to many siblings, yet the enactment of it feels different and intensified because of disability.

Other siblings suggested that disability created heightened difficulty within their sibling relationships. Baha and Ruby – each the sibling of a brother with autism and an intellectual disability – spoke about how their respective brothers' disabilities mean that they cannot know what their brother is feeling or thinking:

Baha: We can't really understand what Aakar [is feeling] – because Aakar doesn't really understand... I don't think he knows... It's hard. Not knowing, it's just scary... because we don't know what Aakar is thinking. He could be thinking anything, don't know, it could be anything. Not knowing is scary, well, to me anyway... You want to understand Aakar, but you can't.

Ruby: Luke doesn't understand little things like that... You don't ever know... I don't *ever* know how to make him – look, I want him to know that I really care about him, but... I don't know how to make him know, which is one of the hardest things.

Striving for awareness or understanding of the other is a normative act of relationships (Jordan, 2004) and many people, including siblings, struggle with what they do not know about the people with whom they share close personal relationships (Ayvazian and Tatum, 2004, Kuba, 2011, Rosenblatt and Wieling, 2013). Yet for Baha and Ruby, this experience is magnified because of disability. Because their siblings do not “understand” – that is, because of an embodied experience of intellectual or cognitive disability – Ruby said that she does not “*ever* know” about Luke and that this is “one of the hardest things” and Baha said that he “can't” know about Aakar and that this is “hard” and “scary”. Not “*ever*” knowing and feeling that one “can't” know to the extent of fear are heightened experiences of an inability to know created by the permanence of disability. Disability then creates a particularly heightened experience of not knowing for Baha and Ruby, yet this is a concern that is still fundamental to many relationships.

These examples highlight that disability can create ways in which normative sibling relations come to feel different and intensified because of the embodied presence

of disability within the relationship. While each of the examples above highlights a normative everyday relation among siblings, because of disability there is a different felt experience to it, heightening the emotions and interactions involved.

6.3. Discussion

6.3.1. Disability's everyday presence

This chapter has examined the inter-relationship of disability and the sibling relationship, showing how disability figures in or is part of characterising siblings' everyday relations with each other. Disability can be central to how siblings enact some normative relations of support, talk, banter, shared meaning, disconnection and conflict. Disability can provide ways for siblings to work towards or achieve a purpose for their relationship. Disability is inherent in unique interactions that replace verbal communication or uniquely inflect the tone and level of siblings' relations together. Disability can heighten the significance and difficulty of some normative relations between siblings.

While it is not evident in every relation or interaction between them, this chapter shows how embodiments of disability can either constitute or create some of the relations that siblings enact with each other. Although the examples are different for each pair of siblings, this presence of disability that forms or produces elements of the enactment of the relationship occurs again and again. Sometimes disability is constitutive where relations happen through disability's presence and sometimes disability creates the context for relations to happen because of its presence; the difference between these two roles is further summarised in Figure 3. Either way, disability has a capacity to influence, form and produce some of siblings' relations with each other.

Figure 3: Relational roles of disability for siblings (A)



This presence of disability that has the capacity to form siblings' relations expresses the way that "people make relations with what has made them" (Titchkosky, 2007:18). The siblings in this chapter make their everyday relations with each other by embodying physical, cognitive and emotional elements of disability. The relations between some siblings reflect physical and cognitive embodiments – Olivia and Vicky's physical disabilities, Claire's non-verbal presence, Tara's hearing impairment, Geoff's autism or Thomas and Lucy's intellectual disabilities. Other relations reflect emotional embodiments of disability – Ava's resentment of the experiences she expects Zoe will miss out on. Still other relations reflect embodiments of complex interactions of physical and emotional elements of disability (Shakespeare, 2006) – the emotional intensities of Will and Corey's limited communication. Regardless of whether it is a physical, cognitive, emotional or complex interactive embodiment, disability becomes set within each sibling's own self, identity or corporeal presence – within how they each personally think, act and feel. In turn, as siblings then share everyday relations with each other, those embodiments of disability form some of the ways in which siblings enact their talk, conduct and emotion with each other. In this way, siblings make their relations with each other with, through and because of the physical, cognitive and emotional experiences of disability that have contributed to making them.

Further, this presence of disability that has the capacity to form siblings' relations occurs within the space of 'the everyday'. The siblings in this chapter experience disability in everyday relations that have a very commonplace and often normative character: the presence of disability is experienced in a moment of chat, in a brief hand game or tickling, in silent support, argument or banter or in wonder at the thoughts or feelings of one's brother or sister. While this commonplace character is

sometimes accompanied by heightened or intense emotions, what happens to provoke those emotions – resenting the experiences a brother or sister may miss out on, valuing chatting or striving to understand the other – remain everyday experiences. Given disability's presence within these commonplace everyday relations, siblings' relational experience of disability is then that disability becomes absorbed into everyday life. Its presence in everyday life means that disability is implicated in simply being what they are: being siblings, but doing so with, through and because of the presence of disability within 'the everyday' of their relationship.

Seeing disability as part of 'the everyday' of sibling relationships allows an important relational understanding of disability for siblings. As highlighted in the literature review in Chapter 2, many studies of the role of disability in the sibling relationship have historically tried to measure the impact of disability on the relationship with quantitative measures and control groups (Dallas et al., 1993a, Dallas et al., 1993b, Eisenberg et al., 1998, Kaminsky and Dewey, 2001, Doody et al., 2010, Love et al., 2012) or have offered explanations of factors related to disability that support or negatively influence the development of sibling relationships (Kersh, 2007, Aksoy and Yildirim, 2008, Smith, 2010, Sage and Jegatheesan, 2010, Pollard et al., 2012). These studies have described disability as an external force that *impacts on* the sibling relationship, often finding that it has a negative influence. In counterpoint to this framework of external impact, the findings in this chapter offer an alternate explanation of how disability is an internal presence that *acts within* the sibling relationship, either constituting or creating its relations. In this understanding, disability forms and produces some of siblings' everyday relations – their talk, conduct and emotions with each other – as a natural consequence of being part of each sibling's embodied self. The everyday relations in which disability figures may cover a spectrum from happier to more difficult relational experiences – just as many relationships normatively do. Ultimately, this situated understanding of disability as internal to sibling relationships is important for locating disability *within* 'the everyday', as part of the sibling relationship and as a formative, relational aspect of the lives that siblings share together.

6.3.2. Disability and relationality

The examples in this chapter draw on many of siblings' everyday relations – their behaviour, interactions, emotions and perceptions of each other (Hinde, 1981) – yet together, the presence of disability in these everyday relations also expresses much about siblings' overall relationality. Chapter 3 described relationality as encompassing the overall felt experience of a relationship – a felt experience that is more than the sum of the relationship's parts and that exists at an emergent and deeply contextualised level. Looking across the examples in this chapter highlights two important insights into relationality, each one identifying a particular overall felt experience of disability within the sibling relationship.

Firstly, siblings both with and without disabilities evidenced the presence of disability within their sibling relationships as sometimes an unremarkable or non-descript felt experience and sometimes an intensely emotive felt experience. When disability was the way into conversation for Tara and Erin, a subject of banter for Vicky and Jono or when it inflected the activities shared by Thomas and Sarah, they each spoke of this in an unremarkable and almost incidental way; it did not evoke any particular intensity or strong emotion – rather, it was just the way things are between them. But for other siblings, disability evoked an intense, emotive experience – when disability led to a range of difficult emotions for Ava, caused disconnection for Olivia and Scott or cemented with permanency Baha's feelings of not knowing about his brother, each spoke about this in passionate and evocative ways that revealed the intensity of emotion involved. For some siblings, their experience was both unremarkable *and* intense: for example, Corey and Mason both valued very ordinary, incidental chat with their siblings in very intense ways because of the role of disability in limiting chat with others.

In this sense, the intensity of the overall felt experience of disability within the sibling relationship can vary dramatically. For some siblings, disability is just an embedded, unremarkable aspect of everyday life. However, for others it evokes deep, heightened or intense emotions, and for others still, it can lead to a confusing combination of these two felt experiences. For understanding relationality, it is then important to see that although the siblings in this chapter all enact behaviour,

interactions, emotions and perceptions that are relatively everyday and normative to sibling relationships, the associated overall felt experience of disability within the relationship varies. Disability constitutes and creates very variable, almost contradictory, overall felt experiences for different siblings, with these experiences occurring along a continuum from unremarkable and non-descript to intensely emotive. This variability may be considered fundamental to the relationality of disability for siblings: disability's relationality is that disability is – both simultaneously and contradictorily – intrinsic to some of the most unremarkable relations and some of the most intense relations that siblings share.

Secondly, a subset of the siblings without disabilities in this chapter evidenced how disability contributed to a felt experience of liminality in their sibling relationships. When Mark said that Claire's lack of speech and comprehension both limits their relationship and allows her support to him, he expressed a liminal, contradictory experience. When Ruby spoke about "pretending" and Mark spoke about "play[ing] along" in their interactions with their brothers or sisters with disabilities or when Laura really had to think "Well, what do we do?" to consider her hand game with her brother part of their relationship, each of these are also liminal experiences. In these liminal experiences, there is an overall felt experience where it is either hard to see, understand or place disability within the sibling relationship or disability contributes to relations of talk, support and interaction feeling fabricated or inauthentic, even though these relations may objectively fit the normative functions of many sibling relationships. This experience of liminality is also described in other research, where siblings without disabilities say their sibling relationships are simultaneously familiar and strange (Hwang and Charnley, 2010b), normal and different (Stalker and Connors, 2004) and the same and different (Weisman, 2007) compared to those of other siblings.

Importantly, it was only siblings without disabilities in this study who evidenced liminal relationality – the siblings with disabilities did not suggest a comparable felt experience. This suggests that liminality may be a relationality that is experienced only by siblings without disabilities. Understanding why this may be the case means considering each sibling's positioning, another component of relationality (Carrillo in

Rakes, 2013). By having the disability, siblings with disabilities are positioned so that disability is a presence in *all* of their relationships with everyone, not only their brothers and sisters. However, siblings without disabilities primarily experience disability within their sibling relationship. As such, siblings without disabilities may have more expectations and experience of relationships outside of disability, may be less used to dealing with disability in their relationships or may have a more explicit point of comparison with which to question the place of disability within the relationship. The felt experience of liminality may then be an aspect of their experience precisely because of their more tenuous connection to disability itself. Overall, this means that while both siblings may experience the unremarkable and intense felt experiences described earlier, siblings without disabilities may sometimes also experience an additional liminal relationality. This means that at one level both siblings share the relationality of disability in the sibling relationship, but that beyond this shared experience, siblings without disabilities may also sometimes have a unique experience as well.

Overall, highlighting the roles of disability in constituting or creating siblings' everyday relations is then significant not only for demonstrating how disability can characterise some of the behaviour, interactions, emotions and perceptions that make up the sibling relationship; it is also significant for highlighting that the presence of disability in the sibling relationship also constitutes or creates various relationalities for siblings. These include unremarkable and intense relationalities, that together express how disability can be felt with various intensity in the sibling relationship, and a liminal relationality. These relationalities, summarised in Figure 4, have an important influence on how siblings experience their relationship with each other and experience the presence of disability within it.

Figure 4: Relationalities of disability for siblings (i)



This chapter has focused on how disability constitutes and creates some of the everyday relations and relationalities between siblings. Both constituting and creating highlight a strong role of disability in the sibling relationship. Yet it was not always the case that disability had such a clear role. Sometimes the role of disability was not clear. Here, its influence was present, but in combination with the influence of the other social and temporal factors highlighted in the theoretical framework in Chapter 3: siblings' life-stage and generation in young adulthood and the constellational, ecological and intersectional factors that contextualise sibling relationships. As such, Chapter 7 now turns to detailing a further role of disability in the sibling relationship: a role where rather than creating or constituting siblings' relations, disability instead *contributes* to their relations, just as other influences also simultaneously also contribute to forming those relations.

Chapter 7. Disability in context

Chapter 6 examined the roles of disability in the sibling relationship in a way that singled out its presence and influence. That is, by illustrating how disability constitutes and creates some of siblings' everyday relations, the chapter focused on the examples where disability had a very central role in what happened between them and where its influence could be clearly delineated. Yet in many other examples, the relational role of disability was not as definitive or clear-cut. Many siblings spoke of everyday relations with their brothers or sisters where disability certainly had some role, but where other social and temporal factors were also influential; that is, rather than creating or constituting siblings' relations, disability instead *contributed* to their relations in combination with other influences. Understanding these examples is important for defending against reducing siblings' relations to only disability, but rather accounting for the complexity of factors that may be involved.

Accordingly, this chapter continues to explore the inter-relationship between disability and the sibling relationship, but turns to examining how disability may contribute to sibling relationships also in combination or inter-relationship with a range of other social and temporal influences. These include the young adult, generational, constellational, ecological and intersectional influences outlined in the theoretical framework in Chapter 3. Given the need to detail a greater complexity of factors than in the previous chapter, this chapter focuses on six detailed case examples. The case examples examine how disability is influential in sibling relationships in combination with the contextual, cultural and demographic factors in siblings' families, the services and resources available to them and the other events and changes happening in their young adult lives and in contemporary society. This layering in of context demonstrates that it is not only the physical, cognitive and emotional aspects of disability that form siblings' relations with each

other, but that a range of social and temporal factors also have a role in informing the presence of disability in siblings' lives.

7.1. Disability in social and temporal context

In the study, siblings were asked to give some background to their living arrangements, social and economic engagement, family context and important people in their lives. Other contextual factors also emerged naturally based on what was important to participants' stories. Overall, participants identified the importance of family context, their generation, young adult changes and transitions, birth order, age gaps, gender, cultural background, socio-economic status, geography and resources to their sibling relationships. In many cases, they revealed how these contextual factors combined with disability to influence their everyday relations with each other. These combinations are the subject of this chapter.

The chapter unpacks six case examples that show how social and temporal context influences sibling relationships in combination or inter-relationship with disability. Given the wide variability in participants' contexts, the case examples are not intended to be exhaustive, generalisable or to cover the whole of the sample for the study. Rather, they have been selected to examine some particularly illustrative accounts and to generate thinking about how disability can potentially interact with a range of different contextual experiences for siblings.

7.1.1. Disability in ecological family context

The story of Geoff's relationships with his brother, Trev, and sister, Leah, provides an example of how it is not always possible to separate the relational influence of disability from the other ecological influences present in siblings' families. Geoff, who is on the autism spectrum, described how "it's a bit hard to even want to be in the same place as my siblings" and said that he and his siblings each have "a brick wall built around our own thoughts and emotions". He described a childhood of conflict between them, where "there were arguments, there were tantrums, there was cursing, there was things thrown across the room"; "we fought, we fought".

Now, as young adults – Geoff, 27, Trev, 23 and Leah, 29 – their relations are characterised by what Geoff describes as “estrangement”:

I guess I can just go with the odd ‘Proud of you’ or compliments for my siblings, but we’re not going to have like a deep, open-heart talk around the dining table, if you like, kicking back a few beers like most adults would do.

Geoff went on to describe how Trev and Leah get on “more famously” with each other than with him and that he feels he is “not part of the maverick of the family”. He implied how he and his siblings are incompatible by using an analogy of himself being like a kookaburra and his siblings being like cats:

I’m an annoying chirper and the cats, when they get infuriated by something they don’t like to see, that’s how it is, that weird partnership, because you never expect them to be together.

Overall, Geoff’s description of his sibling relationships reveals everyday relations – including behaviour, interactions, emotions and perceptions – of conflict and “estrangement” and suggests an intense relationality: intense conflict that appears to dominate Geoff’s overall felt experience of the relationship.

When asked why their relations are so difficult and why it is hard to want to spend time with his siblings, Geoff’s answer highlighted a complexity of factors. He described how his own diagnosis on the autism spectrum contributes to their difficult relations along with the ecological family context that he, Trev and Leah grew up in:

Interviewer: So why is it hard to want to spend time together?

Geoff: It all goes to how our childhood was. Ugh. I have to say having a child who has disability, it does nothing to astruliate [sic] that. There is a difference to each human being, and for my brother and my sister, they didn’t know much about the differences or the uniqueness, the actual uniqueness of me being, having a disability, or being born different to them. And another thing is, we grew [up] in a dysfunctional family, heh. My dad, he worked [overseas] a lot... And

the times when he was overseas, my mum had to hold the roost and she had to keep us all in line, and particularly with me, because I – in the early years of me having autism, I couldn't talk, I couldn't communicate, I couldn't go and do these types of things with other people, complete strangers. I had to be reliant on my mum every single day of every hour of every second that I wanted to go out or be able to leave home... The times when Dad was home, he didn't really know how to be around us and there was times where violence and kind of like the actual hindrance of discipline – trying to control us kids, we were hyperactive – we came to a point where he wasn't able to give that much love or affection to us.

In responding to a question about how his relations with his siblings came to be so difficult, Geoff's explanation shifts between accounting for disability and family context and, ultimately, shows the interaction of his disability with the broader context of his family. He acknowledges the role of his disability in contributing to his conflict with his siblings, both by highlighting the challenge of his high level of support needs as a child and the limitations in how Trev and Leah perceived his disability. However, he also described the influence of factors beyond those directly about his disability: the role of his "dysfunctional" family, the violence in their home, his father's absence and difficulty with the children and his mother "hold[ing] the roost" alone; elsewhere in his interview, he also described how his family moved inter-state while he was a child, suggesting an upheaval for each of the siblings.

In this account, Geoff thus acknowledges the contribution of disability to his difficult and "estranged" relations with his siblings, but his explanation also highlights that his disability cannot be seen alone or in isolation in forming that difficulty. Instead, there are many other contextual factors that also contribute. Yet it is not just the presence of other factors alongside disability that forms their difficulty, but rather that disability and their family context actually interact and intensify each other. Geoff suggests that it was their difficult family circumstances that gave such increased significance to his disability in the first place: the high level of his support needs was made all the more significant by his mother "hold[ing] the roost" alone.

In this sense, it is not just disability that forms their difficult relations, but rather disability contributes in interaction with family context.

Geoff's account is important for highlighting that sometimes contextual factors influence and shape disability's role in the sibling relationship. In suggesting that it was their family circumstances that made meeting his support needs particularly difficult, Geoff shows how it is not just that disability alone forms their difficulty, but rather that disability contributes to their relations from within a specific ecological family context – and that that context also simultaneously contributes to the difficulty. Moreover, Geoff's experience also shows that the role of disability cannot be disconnected from the overall complexity of factors influencing his relations with Trev and Leah. It is impossible to disentangle these factors. In this sense, Geoff's experience shows that disability contributes to his sibling relationships but always in combination with the other happenings in his family and so with the other key influences that are formative in his, Trev and Leah's lives.

7.1.2. Disability in intersectional context

While Geoff's story highlighted the interaction between his disability and ecological family context in characterising his relations with his siblings, sometimes the presence of disability manifested through the other intersectional identities or issues in siblings' lives. The story of Quan and Tien's relationship provides an example.

Quan, 19, who has Down Syndrome, and Tien, 17, are from a Vietnamese family. They live with their parents, two other younger siblings, aunt and cousin and – as was evident on the day of their interview – as the oldest child without a disability, Tien has a key role in translating from Vietnamese to English for their parents who have limited English. Many of Quan and Tien's everyday relations reflect an unremarkable, incidental relationality: they see each other at home, sometimes walk to the park or the market together, ask each other everyday questions like “Oh, how was school?” and negotiate over what television shows to watch:

Quan: Like TV Guide stuff, which one I'm watching like tomorrow or day after... Look at channels, so which one Tien wants to do... I'm

asking, 'Do you want to watching...' [sic], you know, like some people like watching *Home and Away*, yeah.

Within this relationality, Quan and Tien gave a picture in their joint interview of the intersection between disability, their cultural background and their servicing context – and of the impact of this intersection on their relationship. Their story began with the identification that Quan is under-serviced, meaning that he has very few disability services to keep him occupied and socially engaged. Quan explained that since he finished school two years ago, he has had little to do:

Quan: I'm still going to [day program].

Interviewer: When do you go?

Quan: Only Monday and Tuesday.

Interviewer: What do you do on Wednesday?

Quan: Stay home.

Interviewer: What do you do on Thursday?

Quan: Wednesday, Thursday, Friday, Saturday, Sunday – stay home and, like, going out [with my family].

Quan emphasised that he wants to “go out” and “see friends” more often, because this is “much more outside”, while he is now “pretty, like, inside”. With his five days a week at home, boredom appears to be a major problem for him.

Tien explained the situation further. First, she described how although Quan received more disability services as a child, “when he got older, it just seemed a lot harder to find places for him”. Yet she also acknowledged, “I think there *are* organisations out there who help older people with disabilities, but I think we lack the knowledge, like we just don't know a lot of how to help him”. In further accounting for why her family does not know how to find adult services for Quan, Tien explained the limitations of their mother mainly receiving service information from just one Vietnamese organisation:

My mum, she goes to this Vietnamese organisation and has meetings with other parents who have children with disabilities and she gets ideas and she learns more about disability and where she can send Quan to during the week, so he doesn't stay home all the time. She gets information and stuff like that from going to [those] meetings, but overall we don't know much.

In having their information source restricted to one organisation, the information-flow to Quan and Tien's family is limited and this is perhaps one reason why they have not accessed more services. This situation reflects a broader context in which bilingual services and service information are not always provided in Australia (Carlson and van Kooten Prasad, 2001). Tien – who translates for her parents – acknowledges their limited information as a problem and says that she herself has “tried to research on the internet to find places for Quan to get involved in”, but that this has been unsuccessful. Overall, while disability contributes to the situation by causing Quan's need for services, the under-servicing they experience is also contributed to by the structural disadvantage of non-English speaking families within the disability service system (Carlson and van Kooten Prasad, 2001). Their under-servicing is then an intersectional disadvantage that includes the contribution of disability but also in intersection with other cultural and systemic factors.

Importantly, this intersectional circumstance has implications for the everyday relations between Quan and Tien. Quan explained what his five days a week at home and his resultant boredom means for his everyday relations with Tien:

If I get bored, nothing to do... my sister gets cross at me... cozzz she gets angry with me... because I did nothing wrong, but I have nothing else to do.

Tien herself said that she gets cross with Quan when he is “stubborn” at home. This type of conflict – being cross at a sibling who is hanging around bored and snapping over small moments of stubbornness – is exactly the type of everyday, incidental conflict that occurs between many siblings irrespective of disability (Punch, 2008). Given the incidental tone of Quan and Tien's relationship, nothing about this conflict between them is unusual, except that for them these small moments of conflict are heightened and likely made more frequent because of their intersectional

disadvantage; that is, how much more often might these small conflicts occur because Quan is under-serviced and hanging around bored at home so often?

Quan and Tien's story is important for highlighting that disability may contribute to the everyday relations between siblings in intersection with other socio-cultural and systemic issues. In these cases, it not sufficient to explain siblings' relations only in terms of disability, but rather there needs to be a view to how a culmination of intersectional circumstances around disability form the relations between siblings. Broadly their relations may be influenced by disability, however the detail of how those relations are formed and experienced is tied up in other socio-cultural issues as well. It is in the combination of disability with these other issues that the relations between siblings emerge. In this sense, the contribution of disability may be almost disguised by the influence of other social identities or issues, but overall, disability contributes along with a range of other factors.

7.1.3. Disability in young adult context

While Geoff, Quan and Tien's stories focused on ecological family and intersectional influences, for other siblings, the role of disability in their relationships was instead set within the context of their life-stage in young adulthood. The story of Ruby and Luke's relationship highlights how disability may be influential in combination with the changes in independence, resources and services that commonly happen for young people during young adulthood and how, for Ruby and Luke, these factors together influenced their relationship.

Ruby, 17, described her relationship with her brother, Luke, 24, detailing the role of his autism and intellectual disability in what he is like to be around. She said Luke has "no real social skills" and can be "aggressive" and "unpredictable", which is "kind of scary sometimes". She went on to explain that because of his disability, he is not "very considerate" in the way he asks for things to be done for him. Ruby said that that is "pretty hard" for her as "I clash with that [lack of consideration] so much". Acknowledging that she herself often did not respond very well and that that was part of the problem between them, Ruby described how up until only a few months before her interview they used to "fight like crazy", "like anything would

make us snap at each other” and how that difficulty spiralled between them because Luke “feeds off emotion, so if I’m angry, he’ll be angry”. Overall, she implied an intense relationality between them: a feeling of intense conflict, emotion and unpredictability.

However, Ruby also explained how her relationship with Luke has recently changed for the better, due to Luke moving out of home:

Luke did live here until a short time ago... he moved out not very long ago. He lives now about three kilometres away, so he’s still close to home. We’re so much better friends now that he’s moved out – it’s a lot better.

Ruby went on to explain more about why and how Luke’s move has improved their relationship:

Before he moved out, he said he never wanted me to come over to his house and I wasn’t allowed in and all this stuff – but then as soon as he moved out, we see each other like once a week and it will just be me and him and we’ll go to [chocolate cafe] or [ice cream store] or I’ll pick him up from work and he loves it – he loves seeing me now and it’s so much better, because we can breathe.

Here, Ruby describes a shift from an intense relationality of conflict and unpredictability towards a more amicable and enjoyable felt experience where they “can breathe”. The key elements in this shift are Luke’s move out home and Ruby and Luke beginning to go out for chocolate and ice cream together. Importantly, both are set within changes in the independence, services and resources Ruby and Luke have available to them as they enter young adulthood. This means that while the unpredictability and lack of consideration caused by Luke’s disability and Ruby’s difficulty in dealing with that contributes to their relations, so too does their context as young people.

Firstly, Luke’s move out of home represents both a transition into more young adult independence and a servicing change. At age 24, it is normative that Luke moves out of the family home to live more independently and such moves have been suggested to improve conflictual sibling relationships, as it does for Ruby and Luke, by giving

siblings more space away from each other (Conger and Little, 2010). Yet, for Luke, this normative change is also facilitated by the service system: he has moved into supported accommodation where, as Ruby says, “he’s got people there 24/7 to do things [for him]” and “that’s what their job is – so he’s just so much happier”. Ruby explained that “he wasn’t happy at home for the last two years”, so his move out of home improved his mood, including removing him from the conflict he had with her. In this sense, the combination of a young adult transition in Luke’s life and the new services that facilitate that transition both also affect change in Ruby and Luke’s relationship.

Secondly, Ruby and Luke’s trips for chocolate and ice cream are facilitated by a milestone of young adult independence for Ruby: she recently received her driver’s license and bought a car, which, among other shifts in her independence, now also allows her to sometimes pick Luke up from work and for them to then go out together. She explains the significance of this:

I started picking him up from work and stuff and he was just so happy to see me, because it was exciting for him, like, it was almost like a little snapshot of someone else getting their licence and something that he would love to do, but he’s never going to do.

Although elsewhere she acknowledged that she also thinks Luke is jealous of her license, given that Ruby suspects that driving is something that Luke “would love to do”, sharing in this “snapshot” of going out with her in the car is also an activity perhaps particularly enjoyable for Luke, precisely because his disability means he will not ever drive himself. With Ruby, he at least gets to share in the experience. Further, now that they live apart and have breathing space, these trips out together allow them to do something new and different outside the space of their family home that had always been their site of conflict. In this way, Ruby’s transition into young adulthood and the resource of her new license also gives a context for changes in her relations with Luke, letting them into new spaces and activities together, outside their previous conflictual pattern.

The changes in Ruby and Luke’s relationship highlight the way that both disability and their young adult context contribute to what happens between them – and that

it only takes a change in one of these factors to prompt new directions for the relationship. Ruby did not suggest that anything about Luke's disability, unpredictability or lack of consideration had changed. However, she did talk about how the way she felt the presence of disability in the relationship had shifted along with the changes in their independence, services and resources as they entered young adulthood. With new services and resources in place, she finally felt like they could each be more independent and so they could "breathe". This highlights that when disability is one factor contributing to siblings' relations within a broader context that also contributes, the changes in the context around disability may in turn also influence or change the role of disability in the relationship and influence or change the type of relations formed between siblings. For young adult siblings normatively undergoing many changes and transitions, this suggests the scope of the changes of this life-stage to also shift the experience of disability in the sibling relationship.

7.1.4. Disability in generational context

As well as disability combining with siblings' young adult context, it also sometimes combined with their generational context. This meant, for example, combining with the policies, politics or technologies of contemporary society. Two smaller case examples from Samuel and Ben and from Emily and Jack illustrate how disability can combine with generational context, with both cases drawing on examples about technology.

Samuel, 21, and Ben, 23, are brothers whose relationship illustrates how disability can contribute to siblings' relations along with the influence of contemporary technological accessibility. Ben, who has a physical and intellectual disability, and Samuel share a relationality somewhere between an incidental relationship and an intense friendship. They mainly see each other incidentally at home, however, like many brothers, they also do activities together (Edwards et al., 2005). Samuel explained, "We go to the movies together and we do bowling together. We love playing Wii together... We go for a drive sometimes".

Within this scope of activities, it was clear that Samuel's favourite activity with Ben is playing Wii. He said, "We play Wii – that's what we love doing together at home" and emphasised this several times during their joint interview. While it was not clear if it was also his *favourite* activity to do with Samuel, it was evident that Ben also enjoys playing Wii – he smiled a lot every time Wii was mentioned and said "Yes" to confirm it was an activity he enjoyed doing with Samuel. Samuel noted that playing Wii together can fix problems between them, explaining that if they are frustrated with each other then "we'll do something that we both enjoy, so we'll both play Wii" to fix the problem. Samuel also spoke about why playing games such as the Wii is important to his experience of their relationship:

In terms of what Ben does for me, it's not a physical thing but it's just laughter and enjoyment and spending time with me... there isn't anything [he] does really that I can think of, nothing like, you know, I give him food – he can't get out of his [wheel]chair that he'd give me food or anything like that, but he can help me by bringing joy, playing games, we'll play games together, spending time with me. He can choose whether or not he does that and he does that, so that's something he does for me.

In this sense, playing Wii is an important relation in maintaining a felt experience of reciprocity; to Samuel, playing Wii means that Ben is returning a chosen, reciprocal act.

While shared activities (Edwards et al., 2005) and gaming (McNamee, 1998) are common between brothers, for Samuel and Ben this normative relation is set within the contemporary context of technological accessibility. The increasing accessibility of mainstream technologies – such as the Wii – allows Samuel and Ben to engage in this normative brotherly activity even though Ben's disability means that he has limited fine motor skills to engage in other less accessible activities with Samuel. Accessibility means that they can both use the Wii and this lets them engage in a way very normative to brothers, while accommodating the presence of disability at the same time. It is a type of sibling interaction that would not however have been possible in a prior generation, when accessible technologies either did not exist or were not readily available. In this sense, both disability and their contemporary

context contribute to the relation between them. On the one hand, disability is perhaps what makes this relation so significant: because the Wii is the activity they can do together in the context of Ben's disability, this perhaps contributes to why it is a favoured activity. Yet on the other hand, their contemporary context also informs the relational role of disability; in an earlier generation, Ben's disability would have had a much more obstructive role in their relationship than it does now when accessibility allows them to get around his physical limitations. In this sense, the contributions of both disability and their generation are key in forming the significance and experience of this relation between them.

Similarly, Emily and Jack engage in a way where contemporary technology combines with disability to form some of their everyday relations. Emily, 19, who has Down Syndrome, and Jack, 16, share an unremarkable, incidental relationality: they "hang around" and "do stuff" together at home; they watch the television shows that Emily likes – which Jack calls "all that crap", but also says "we enjoy that, that's fun"; they walk the dog around the block together; they share inside jokes of Emily doing pigeon impressions; and they have conversations "if we pass by" each other, but not by actively sitting down to talk. Within these everyday relations, Emily and Jack also described the role of "tech support" between them. Emily was the first to mention this, saying:

Emily: Sometimes Jack helps me do stuff like Facebook or something... put in password... Sometimes Jack helps me, sometimes Jack does it, sometimes when my iPod is down, kind of when the power lines went out. For example, there's always no internet, so he made it come back. Jack knows about – about electricity.

Jack: Tech support.

When asked to explain this "tech support" further, Jack gave more details about what happens:

Jack: Emily's iPod runs out of battery every half an hour, because it gets used that much – I've got to go plug it in. If she needs an internet password, I'll type that in

for her. All her passwords for Facebook and stuff are remembered by me.

Interviewer: How did you end up as the rememberer [sic] of the passwords?

Jack: I don't know, they're just complicated and stuff... because some of them words, they're like letters or numbers, like the internet password.

These acts of “tech support” reflect small, mundane moments of everyday life – plugging in an iPod, typing in a password, resetting the internet connection. These acts are thus inherent to both the unremarkable relationality Emily and Jack share and to their young generation who are normatively engaged with technology and live lives online (Australian Government, 2008, Muir et al., 2009). While neither Emily nor Jack directly mentioned disability in these acts of “tech support”, Jack’s description of the complexity of the passwords invokes a sense that the support that Emily needs in using technology is related to her intellectual disability. The “tech support” that happens between them is then premised on a very contemporary disability support need – the need for assistance in using technology – even while it is at the same time perhaps a normative act of assistance among siblings of their young generation.

In this sense, both disability and their shared belonging to a young generation contribute to the relation of “tech support” between Emily and Jack. Emily has a particular need for “tech support” because of disability, yet this support is found in her sibling relationship with Jack (rather than, for example, provided by their parents) perhaps because they are both of the young generation normatively engaged with technology. Viewing only the disability or the support need is then not enough for understanding why “tech support” has become an everyday relation specifically between Emily and Jack. Rather, there is a need to also understand the generational context in which disability exists in order to appreciate the whole of the relation happening between them.

7.1.5. Multi-faceted relational roles of disability

Each of the case examples so far have highlighted how disability contributes to siblings' relations along with other social and temporal influences, including ecological, intersectional, young adult and generational influences. In each case, disability had a partial role in forming or producing the relations between siblings, in counterpoint to the more central roles described in Chapter 6, where it more clearly constituted or created some of siblings' relations. However, in some cases, it was not as clear whether disability constituted, created or contributed to siblings' relations and sometimes it could play more than one of these roles at the same time. For example, Simone and Violet's relationship shows how disability both created and contributed to some of their relations.

Aged 20, twin sisters Simone, who has Cerebral Palsy, and Violet have a sibling relationship that is like an intense friendship. Violet described how they see each other "every single day" and that "basically we do almost everything together"; they "hang out together", "go shopping... to the movies... clubbing" and enjoy "just chatting, we just do that for hours". Simone said they are "supportive" of each other, while Violet added that they "can read each other pretty well". Violet described being "pretty constant in the way that we are towards each other" and Simone said that even though there can be friction between them, they'll always "join together again". Simone's care needs also play a role in their relationship, as Violet has always been very involved in providing care. Overall, the relationality between Simone and Violet is one of intensity, yet unlike Geoff and Ruby earlier in the chapter – who experienced intensity related to conflict – it instead resembles the intensity of a close female friendship (Mauthner, 2002) with the added intensity of the intimacy of care. This relationality is perhaps set up by their constellation as siblings: as twins of the same gender, they are perhaps likely to be like peers and friends.

Through two examples, Simone and Violet highlight how on one level disability creates a support need or conflict that influences their relations with each other, however when this is seen in a broader context, it is evident that disability's creation of the issue is only one contributing part of how they deal with the broader situation between them. This highlights that disability has a complex, multi-faceted role in

their relationship, one that cannot be easily confined to either creating or contributing alone.

In the first example, Simone and Violet highlight how sometimes the presence of disability in their relationship both creates the opportunity for them to do the normative activities of a friendly sibling relationship, but that, within a broader systemic and relational context, disability is still only one factor in contributing to how they do those activities. Simone explained:

Simone: There are some perks to having a disability. For example, I've got a thing called a Companion Card... you get two tickets for the price of one because they understand that you need to take a carer to [public events]. So, for example, I'll buy a ticket to a concert and Violet will pay me half back and she's given the companion ticket. And –

Violet: We're going to Pink in July.

Simone: – that way it's cheaper for both of us.

Here, on the one hand, Simone's disability necessitates that someone go with her to the event; because of disability, she cannot go alone – and, objectively, this creates an opportunity for her to go out with Violet. Yet, at the same time, it is also very normative that friendly sisters might just choose to go out together (Mauthner, 2002) – and this is the interpretation that Simone and Violet appear to prefer in accounting for what happens between them. As in Chapter 6, this is an example in which disability creates a relation that is simultaneously and contradictorily inherently normative to siblings and, to some extent, a product of disability.

Yet understanding the whole context of this relation also depends on seeing disability's creation of the opportunity to go out together as only one contributing part of what happens between them. This is because Simone and Violet also subvert the systemic context around disability to shift what could be understood as only a service-care arrangement into more of an equal sibling-friend relation. Systemically, their use of the Companion Card would normally situate their relation as a care arrangement entirely premised on disability. Yet as Violet "pays [Simone] half back",

Simone and Violet push back against the connotation that Violet is only there to assist Simone and rather imply that they both are attending as equals. In this sense, even as there is a real need for someone to go with Simone, that support need created by disability is only one contributing part of the relation happening between them. The way that Simone and Violet subvert the connotations of the Companion Card shows that while disability contributes, there is more than *only* disability to this relation, because it is also about them spending time together as equal sisters.

In the second example, Simone and Violet highlight how disability can create conflict between them, but that this is only one contribution to how the broader relations of that conflict play out, because their systemic context also provides ways to resolve it. Disability creates what Simone calls their “main disagreement”: when Violet sometimes has to miss a shift at her casual job to cover for one of Simone’s support workers, she “give[s] up [her] only source of income” and this is a financial problem for her; because of disability, support needs and care, this disagreement occurs between them.

Yet while disability creates their conflict, their broader systemic and generational context also contributes a way to resolve it. Simone, who uses a contemporary individualised funding model, described how she went through “a whole process of getting the go ahead from [the department] to employ [Violet] for when I need her care” and how this was one way of resolving their disagreement. In this way, even as disability creates the conflict between them, this is only one factor in the situation, as they also skillfully use their systemic context – including contemporary individualised service approaches, where people with disabilities can choose who they pay for their care – to work towards resolving the issue and so “join together again”, as they say they always do. In this sense, to understand the whole of their relation, it not sufficient to see only the role of disability in creating the conflict, but rather there is also a need to understand how Simone and Violet’s systemic and generational context also contributes ways to resolve the complexities between them.

Simone and Violet’s examples highlight the multi-faceted role of disability in their sibling relationship; disability creates some of their relations, yet simultaneously it

also only contributes to those relations. This points to the need to understand that the role of disability in the sibling relationship can at times be complicated, nuanced and combined, both with other influences and with more than one role. It is sometimes complex to understand what role disability plays in the relationship and, further, its role may not always be completely or readily apparent; it may operate at different levels, in different ways and in many contexts. Yet overall Simone and Violet show that throughout its multi-faceted roles, disability remains a deeply relational experience.

7.2. Discussion

7.2.1. Disability's contextualised presence

This chapter has explored the inter-relationship of disability and the sibling relationship within a broader context. The case examples in this chapter highlight a range of ways in which disability contributes to siblings' everyday relations from within a social and temporal context that also contributes to those relations. In each example, disability combined with other influences to form the behaviour, interactions, perceptions and emotions occurring between siblings. In Geoff's example, family context shaped disability's role in his estranged relations with his siblings and the influence of disability could not be separated from the rest of the complexity of factors happening in his family. In Quan and Tien's experience, disability contributed to their everyday conflicts in intersection with a range of other socio-cultural and systemic issues that combined to form disadvantage. Ruby and Luke's relationship improved when their entry into young adulthood changed the resources and services available to them, in turn influencing a shift in the role of disability in their relationship. Disability formed relations between Samuel, Ben, Emily and Jack that could only exist in a contemporary context. Finally, Simone and Violet's examples highlighted disability's multi-faceted relational roles, where the physicality of disability created support needs and conflicts between them, but where their systemic and generational context also contributed ways of addressing those issues.

Although disability figures differently in each of these examples, all highlight a relational role of disability where it contributes to siblings' relations in combination or inter-relationship with other influential factors. This gives a sense of a more partial and contextualised role of disability in siblings' relations compared to the roles where disability more clearly constituted or created their relations in Chapter 6. The scope of examples in these two chapters then illustrates different ways and strengths with which disability may have a role and presence in the sibling relationship. Further, as Simone and Violet's case example showed, these different relational roles of disability are not always entirely disconnected and instead may sometimes manifest in complicated, multi-faceted and nuanced combinations. This scope of nuanced relational roles of disability is illustrated in Figure 5.

Figure 5: Relational roles of disability for siblings (B)



Further, in detailing how disability contributes in combination or inter-relationship with other influential factors, the case examples in this chapter demonstrate the relevance of a broad range of contextual factors to sibling relationships. The examples highlight the importance and influence of family context, cultural background and disadvantage, services and service systems, other resources, young adult changes and transitions, contemporary context and generation to how sibling relationships are enacted and experienced. Thus there is a broad range of contextual factors that may contribute to siblings' relations alongside and in combination with disability, as was also detailed in the theoretical framework in Chapter 3. Even though the range of contextual factors in this chapter is limited by the need to select and detail case examples, other participants spoke about how education, geography, communities and the in/accessibility of public spaces influenced their sibling relationships. This broad range of contextual factors with which disability combines

signals that siblings' relational experiences of disability are contextualised phenomena.

Understanding that siblings' relational experiences of disability are contextualised is important for giving broad consideration to what informs sibling relationships. In understanding that "people make relations with what has made them" (Titchkosky, 2007:18), this contextualised view reflects acknowledgement that a physically, cognitively or emotionally embodied experience of disability is *one* element with which siblings form their relations with each other (as demonstrated in Chapter 6), but that this embodiment also expresses a social and temporal context that is *also* an element with which siblings form their relations. That is, social context can be drawn into the enactment of the relationship itself. This view of social context as enacted within the relationship reflects Hinde's (1981) inclusion of social context as one of the components of relationships alongside behaviour, interactions, emotions and perceptions. Overall, this contextualised view highlights that while a physically, cognitively or emotionally embodied experience of disability may form or produce siblings' everyday relations, so too does the broader social and temporal context of disability, as detailed in this chapter.

Seeing the role of all of these physical, cognitive, emotional, social and temporal elements in forming siblings' relations also confirms that a relational perspective on disability for siblings implies the critical realist understanding of disability (Danermark, 2002) discussed in the theoretical framework in Chapter 3. The physical, cognitive and emotional embodiment of disability (in Chapter 6) and the broader social and temporal conditions around disability each have a similar influence in forming and informing how siblings' everyday relations with each other are enacted and experienced. This is another way that the presence of disability in sibling relationships is multi-faceted. Recognising this multi-faceted character guards against furthering the individualising view of *only* focusing on siblings without disabilities' psycho-emotional experience (e.g. Abrams, 2009) and adjustment (e.g. Damiani, 1999, Cuskelly, 1999). However, simultaneously it also troubles the alternate position of suggesting that the physical, cognitive or emotional embodiment of disability is not relevant to sibling relationships at all. Instead, a

multi-faceted view of disability ensures a relational perspective that can accommodate and account for all of the many ways that disability may be present and figure in the everyday experience of sibling relationships.

7.2.2. Context and relationality

The case examples also show that context matters to siblings' relationality – that is, context has an influential role in the overall felt experience of the sibling relationship. The relationalities described in Chapter 6 where the intensity of siblings' relationships varied – and so siblings could experience an unremarkable or an intense relationality – was similarly evident in the experiences of the siblings in this chapter, but in a deeply contextualised way. Contextual factors sometimes figured in siblings' relationality; for example, Geoff's ecological family context contributed to his intensely conflictual relationality with Trev and Leah, contemporary technology gave Emily and Jack an opportunity to enact small acts of support that reflect their unremarkable, incidental relationality and Simone and Violet's systemic and generational context allowed them to go out together and "join together again", reflecting the intensity of their relationship which resembles a close female friendship. Contextual factors also sometimes influenced change in siblings' relationality; for example, Ruby and Luke's previous intensity of conflict shifted into a less intense felt experience where they "can breathe" when their resources and services changed during young adulthood. In this sense, the social and temporal context happening around siblings can figure in and influence their relationality.

Understanding that social and temporal context figures in and influences siblings' relationality is important because it shows how the overall felt experience of a relationship includes the felt experience of the relationship's conditions and context. This influence of conditions and context was a key part of the meso-level mapping of relationality in the theoretical framework in Chapter 3, where previous work had suggested that relationality is contextualised by the timing (Edwards and Weller, 2014, Goodley and Roets, 2008), places and spaces (Ward, 2014, Edwards and Weller, 2014, Weller, 2012, Goodley and Roets, 2008) and resources (McCarthy and Prokhovnik, 2014) of the relationship. Based on this conceptualisation, the accounts in this chapter exemplify how a relationship's temporality, spatiality and resources –

as well as its socio-demographic context (e.g. family or culture) – fundamentally figure in and influence the overall felt experience of the relationship. This gives evidence of what the relationally relevant context and conditions might be for siblings and shows how the conceptualisation in the meso-level mapping plays out in the reality of siblings' lives.

Further, acknowledgement of the relational influence of conditions and context is important because it prompts consideration of how to support the sibling relationship itself. Given the capacity of disability to sometimes constitute, create or contribute to difficulty in some sibling relationships, such support may be important for managing the challenges that the presence of disability may bring about in some siblings' lives. While it may not be possible to change the physical, cognitive or emotional presence of disability, Ruby and Luke's example suggests that – given the right circumstances – changing the social and temporal conditions around disability may still effect change in the overall felt experience of disability in some sibling relationships. There is then potential to think about how to adjust resources or services to the benefit of the overall experience of sibling relationships. Ruby and Luke's example further highlights that young adulthood may be a time when such changes may be particularly possible or apparent. While it is important to acknowledge that this conscious support for the relationship may not always be wanted or needed, the possibility of actively adjusting resources or services to shift from an unhappy to a more amicable relationality, as Ruby and Luke do, or to address difficult relations, as Simone and Violet do (or as would benefit Quan and Tien), may benefit at least some siblings.

This chapter and Chapter 6 have offered an analysis of how disability – including its physical, cognitive and emotional elements and the social and temporal factors that surround it – naturally acts within the sibling relationship, constituting, creating or contributing to some of its everyday relations and overall relationality. The analysis in these chapters has focused on examples where disability is largely accepted and drawn in to the sibling relationship; that is, where it becomes part of siblings' relational experiences with each other. However, the siblings in the study were not

always accepting of disability's relational presence. Sometimes they appeared to try to resist its influence. This is subject of Chapter 8.

Chapter 8. Disability-related care

Chapters 6 and 7 focused on how disability is drawn in to siblings' everyday relations and relationality. However, the siblings in the study did not always accept the presence of disability in their relationship and sometimes appeared to resist it. The main place where this happened was in relation to an unwanted influence of disability-related care on their relationship – that is, practical or emotional assistance provided by siblings without disabilities to brothers and sisters with disabilities because of disability-related support needs.

This chapter explores the inter-relationship between the sibling relationship and disability-related care. It looks at the influence of disability-related care on the sibling relationship, detailing both its affect on relationality and the everyday relations siblings use to resist its influence. Through in-depth discussion of two case examples and presentation of a series of briefer examples, the chapter explores how disability-related care can prevent some siblings from feeling like they are siblings by pushing them into unwanted felt experiences characteristic of other relationships. However, the analysis also identifies how, particularly during young adulthood, siblings also sometimes talk and interact in specific ways that appear to resist care's capacity to change the felt experience of the relationship. In this way, the chapter shows how siblings are aware of the presence and influence of disability in their relationships and how, in some situations, they may act in ways that influence that presence.

8.1. The influence of disability-related care

In the study, participants were asked about “what they do for each other” and “what actions they take for each other”. This gave a clear place to talk about disability-related care, but without introducing a framing of it as ‘care’; rather, the intention was to understand how siblings themselves conceptualised care. In

response, siblings described many types of activities that happen between them that signalled the giving and receiving of care based on disability-related support needs.

Some siblings without disabilities spoke about their involvement in personal care:

Sophia: I can relate to all the activities where I'm looking after Anna, be it feeding, changing clothing, showering, toileting.

Samuel: I do a lot for Ben... giving him food for instance and helping him get changed.

Other siblings without disabilities described managing behaviour that could be a risk to their brother or sister or to others:

Baha: [I] just support him if he lashes out.

Raghav: I usually wake up first and I just give him a tablet and then I'll sleep again.

Some described supervising their brother or sister:

Laura: I'd babysit him occasionally or I stay home so that he's okay.

Both siblings with and without disabilities also described the roles of siblings with disabilities in a range of errands, small assistive tasks and situational assistance:

Mark: Mum and Dad don't have to be the only ones, like [with my new license] I can go and get her now as well.

Vicky: You change the DVD, I can't reach that.

Quan: Sometimes I get help from my sister to do stuff... how to learn how to make a food, take-aways.

Steve: He'd be struggling [with rock-climbing] and so I'd help him up because I'd be climbing next to him because I usually do that just to make sure he's all right.

This scope of care tasks shows that one way that the presence of disability manifests in the sibling relationship is in creating a range of care tasks between siblings; that is, disability's presence in the sibling relationship is physically and/or cognitively embodied as either care needs or the capacity to give care and is then experienced

in the everyday relations of siblings giving and receiving care. This fits the description developed in Chapter 6 of some of siblings' everyday relations being created by or happening because of disability – in this case, because of disability-related care.

However, importantly, at the meta-level of their relationality, some siblings also described how disability-related care could also create something else in their sibling relationships: an overall experience where they did not actually feel like siblings. Case examples from Mark and Mia further explain how this could happen.

8.1.1. Keeping care “less serious” and more “fun”

Mark, 18, brother to Claire, 15, who has a physical and intellectual disability, described how doing some “serious” or intimate kinds of disability-related care creates a situation that risks him not feeling like a sibling: these types of care make him feel like he might “lose” the opportunity to “feel like one of the siblings” and, as such, where he can, he keeps his involvement in care to tasks that are “less serious” and more “fun”.

Mark started by describing how his parents do the intimate bodily care for Claire, while he does the tasks that are “less serious”:

My parents do the changing of her... the showering of her and the feeding of her, the basic day-to-day looking after things... I'll turn her TVs on, I'll do all kinds of things to make sure she's comfortable and okay, like if she wants to go outside, I'll take her outside, but I don't do the basic looking after her... I'm kind of less serious.

Mark then went on to explain that his involvement in only these “less serious” care tasks is significant for allowing a “more relaxed” felt experience in their relationship and because it troubles a view of him as really a “carer” for Claire:

Because I don't do the serious things, it's like we're kind of less serious. So even though sometimes it does feel like I'm just a third carer helping out – in a sense, that has to be true, because we all have to work together to look after her – but sometimes I feel like it's less serious between us, that there is a different relationship

between her and Mum and Dad and me and her. You know, that we are kind of more relaxed in the sense that I only do the lighter things, so therefore the relationship between us is more relaxed than say [with] Mum and Dad.

Importantly, Mark suspects that Claire also shares the felt experience of their relationship as “more relaxed” in that he thinks she may find his care more “fun” than from his parents:

I think she’s pleasantly surprised when I do more things. It’s a change for her from Mum and Dad doing everything. If I feed her... I feel like she knows that it’s kind of different in a good but weird way, because I don’t normally do those things, but now I’m doing those things. It’s more kind of – I don’t want to say ‘fun’, because I don’t want to beat my own drum too much – but I mean, it’s different.

However, importantly, Mark also acknowledged that his felt experience of a “relaxed” and “fun” relationship depended on him keeping to only the “less serious” care tasks and that if he took on more of his parents’ role – as he sometimes feels he should – then he would “lose” the opportunity to “feel like one of the siblings”:

I’m torn between wanting to do more, because I feel like I should help out more, and also the idea that by taking on more responsibility it means that I will have to do more long-term and the idea that Mum and Dad have always wanted me to feel like one of the siblings and if I take on more of the caring role then I’ll lose that.

Overall, Mark here describes how taking responsibility for certain types of disability-related care – the intimate, bodily and “serious” tasks of changing, showering and feeding Claire – has the capacity to create an experience where he is shifted out of “feeling like one of the siblings” and towards feeling like “just a third carer”. That is, because of the seriousness of this intimate care, there is a risk of him not feeling like a sibling, a relationship he feels is “more relaxed” and “fun” compared to his parents’ role. In saying that the type of care he does changes his felt experience of the relationship, Mark expresses how some tasks of disability-related care can challenge his relationality by creating a felt experience where he does not quite feel like a sibling. His description reflects the liminal relationality developed in Chapter 6, where some siblings without disabilities experienced a feeling of inauthenticity in

their sibling relationship. Here, Mark highlights that this liminal relationality extends to a challenge to whether he feels like a sibling at all when he does disability-related care that is too intimate or “serious”.

Yet Mark also highlights how, so far, he has managed to mainly keep to feeling like a sibling. He does this by depending on his parents to do the intimate bodily care and so by keeping his role to only the “less serious” and more “fun” tasks, where he can. However, importantly, Mark also highlights that Claire’s demeanour in receiving care also influences *his* felt experience of the relationship: his perception that “she knows it’s different in a good but weird way” and his belief that she finds his care more “fun” both mean that he in turn finds their relationship “more relaxed”. In this way, even though Claire is not able to return or comment on the care between them, she nevertheless has a key role in keeping them to a relationality where they feel like siblings. As Mark and Claire keep to only these “less serious” and more “fun” tasks of care together – an act that depends on their parents doing the more intimate care – they in effect together resist the risk that disability will create a situation where they feel more like “carer”-and-“cared-for” than siblings.

8.1.2. “Adult sisterly relationship” verses care

While Mark has mostly been able to maintain his preferred relationality with Claire, Mia described how disability-related care has on occasion created a situation in which she has not felt like a sibling. Mia, 23, sister to Cara, 19, who has Cerebral Palsy, described how she does not feel like a sibling when her involvement in disability-related care goes beyond the tasks that she feels easily fit within the sibling relationship.

Mia started by making a distinction between the care tasks that are and are not relationally challenging for her, classifying some physical or functional tasks as unproblematic and as just “helping out” and other tasks that implied more moral responsibility for Cara as extensive and as part of “care” itself:

The physical stuff isn’t the stuff that I really look at and go ‘That’s caring’. That’s just helping out, whatever, it’s fine. You know, if your sister has a broken arm, chances are you’d have to cut up her food

for her as well. But when we go out it's [sic] I have to be responsible for myself *and* for her, because there's only so much responsibility that she takes for herself... When we go out, if she runs into something, people look to me, it's 'Well, why didn't *you* control her? You should know better... She's *your* responsibility'... And that's where the distinction comes in that I'm not just taking responsibility for myself or she's not just taking responsibility for herself – I'm taking responsibility for both of us and I think that's where I see the caring role and how that differs from I guess the standard sort of adult sisterly relationship.

Mia also identified how she feels that neither her nor Cara like the relations that her “caring role” creates between them:

She had her wheelchair on too fast and she was nearly running into people and knocking things over. I had to step in and say 'Cara, turn down your wheelchair', 'Cara, do this', 'Cara, do that'. And I don't like that, she doesn't like that... I think that can be a bit trying. I don't like having to do that, but unfortunately sometimes there are situations whereby you do have to step in.

Finally, commenting on these relations between them, Mia said she “couldn't just entirely be [Cara's] sister”, since because of her involvement in this care, what was happening between them also held elements of “management” and of a “parental role”:

At least lately it's been more of taking on a bit more of a carer's role when we've gone out rather than being able to just be a sister... It's almost a management kind of relationship... I couldn't just entirely be her sister, I did have to also take on – I don't want to say a parental role – but it did almost merge into that.

Here, like Mark, Mia feels that some kinds of disability-related care create a disruption to her opportunity to have a “standard sort of adult sisterly relationship”. For Mia, small physical or functional tasks such as cutting up food are unproblematic and not even “care”, because, for her, they are just the type of “helping out” that normatively fits within a sibling relationship. This reflects her acknowledgement that some extent of support and assistance is normative to many sibling relationships irrespective of disability (Eriksen and Gerstel, 2002, Edwards et al., 2006). However,

what is care for her are the more extensive acts of moral responsibility that she believes should be beyond her role in an “adult sisterly relationship”, that is, the times when she must direct Cara’s behaviour. Yet in saying that this responsibility and direction is part of the “caring role”, she sections it off from the sibling relationship entirely and, in so doing, the “caring role” becomes inherently challenging to her sibling relationship.

Importantly however, the specific challenge that disability-related care creates for Mia’s sibling relationship is that it changes the overall felt experience of their relationship; their relationality. Mia’s understanding is that in the “standard sort of adult sisterly relationship” sisters each take responsibility for only themselves; this reflects the largely lateral or horizontal relationship that many siblings do normatively share, where – although there are still power differentials between them, particularly with regard to birth order and gender (Toman, 1994 [1961], Sulloway, 1996, Dunn, 1985) – siblings are *relatively* more equal and egalitarian than vertical family relations, such as parent-child relationships (Branje et al., 2002, Mauthner, 2005, Vivona, 2007, McIntosh and Punch, 2009). While she expects this horizontal relationship, Mia says that, because of disability-related care, she’s actually taking responsibility for both herself and Cara and that this shifts her out of just feeling like a sister – “I couldn’t just entirely be her sister” – because their relationship instead resembles “management” and a “parental role”.

Here, like Mark, Mia implies a liminal experience of feeling like, because of the presence of disability-related care in their relationship, she is not fully a sister, but rather also/instead a manager or a parent; that is, she suggests the liminal relationality where their everyday relations as siblings feel inauthentic. However, for Mia, this liminality is borne of the fact that she expects and desires the normative feeling of equity or horizontality between siblings, yet feels this horizontality is compromised because she is instead edging into the vertical relations of “management” and of a “parental role”. As such, Mia identifies how, for her, the liminal relationality hinges on an elusive felt experience where she expects an equitable, horizontal experience with Cara that does not quite eventuate. This is

then a further relationality created by the presence of disability-related care: a relationality of unclear, elusive horizontality.

These examples from Mark and Mia highlight that the presence of disability-related care may create a liminal and non-horizontal felt experience in the sibling relationship, where siblings do not quite have the felt experience together that they expect siblings should. Overall, Mark and Mia's experiences then reflect the capacity of some types of intimate or power-inflected disability-related care to sometimes undermine the relationality of the sibling relationship, that is, undermine the extent to which siblings feel like siblings. This makes disability-related care a particularly influential aspect of disability, as unlike some of its other aspects that more unproblematically constituted, created or contributed to the everyday relations of the sibling relationship in Chapters 6 and 7, disability-related care instead has the capacity to challenge the overall felt experience of the relationship. This particularly influential nature of disability-related care perhaps gives a sense of why care featured so prominently in the meso-level mapping of relationality in Chapter 3: care is a relational interaction with very significant consequences for relationality.

However, importantly, many other siblings in the study, both those with and without disabilities, evidenced everyday relations – ways of talking and interacting – that can be interpreted as resisting the capacity of disability-related care to create an experience where they do not feel like siblings. These ways of talking and interacting trouble the extent to which care is a normative sibling relation or specific to disability (Eriksen and Gerstel, 2002, Edwards et al., 2006). Ultimately, these relations are important for understanding how some siblings continue to maintain their felt experience as siblings in the presence of disability-related care.

8.2. Resisting disability-related care

As explained through Mark and Mia's accounts, disability-related care can sometimes challenge siblings' relationality. In this context, some siblings displayed particular ways of talking and interacting around disability-related care that resisted its difficult influence on their relationships. These ways of talking and interacting can

be interpreted as managing the affect of care on their relationships by situating it, where possible, within a normative scope of everyday sibling relations.

8.2.1. Different ways to frame care

One of the most common ways that siblings appeared to resist disability-related care's influence was by using a range of different ways to refer to the acts of care that happened between them. Their terms ranged from those that were very low-key and that de-emphasised the significance of care, to terms that implied the traditional responsibilities of care but in everyday language and finally to some explicit references to care. This is explained in the sections below.

Helping out

The siblings in the study most commonly referred to acts of care as “help” and “helping out”. These terms framed the care happening between them in a low-key way that de-emphasised its significance as care and instead situated it within a normative scope of everyday sibling relations.

For example, Will, who has Cerebral Palsy, talked about how his brother, Mason, did errands for him after he had surgery. He described Mason's involvement as about being “helpful” and doing a “favour”:

Interviewer: What role did Mason have when you [were in hospital] and got the pump?

Will: He'd get me things – what I needed from home... I told him [what to bring], clothes, my medication.

Interviewer: What did you think of asking him to do that?

Will: It's a favour.

Interviewer: What do you think he thought of doing it?

Will: Helpful.

Other siblings with disabilities made similar comments. For example, Emily, who has Down Syndrome, said that, as noted in Chapter 7, “sometimes Jack helps me do stuff”

in relation to her support needs with using technology. Her language gives a very low-key feeling to what happens between them.

Importantly, siblings without disabilities also used the low-key framing of “help”. For example, Rachel framed the assistance she gave to her brother, Harry, after his surgery for scoliosis as “helping out”:

Rachel: So with that [surgery], because he couldn’t do much, I was doing his dishes and getting him drinks of water or soft drink and then helping him like cut up his food if he needed me to.

Interviewer: What did you think of that?

Rachel: It was alright, I didn’t mind. I was helping out my brother.

Violet, sister to Simone who has Cerebral Palsy, also framed a scope of care tasks as “help”, even including personal care:

I'll help get Simone up in the morning and I'll get her dressed or I'll say 'Let's go shopping'... and I'll be the one there helping Simone if she needs to go to the toilet while we're there. I'll be there to help her with that. I'll be there to help her get on the bus and things like that.

In this way, both siblings use the low-key framing of “help” to refer to a scope of disability-related care that happens between them, including tasks as diverse as errands, transport, mobility assistance and personal care. Importantly, as some help, support and assistance is normative between many siblings irrespective of disability (Eriksen and Gerstel, 2002, Edwards et al., 2006), this framing perhaps more easily situates disability-related care within the scope of assistance that may normatively happen between many siblings than would a starker description of doing “care”. The framing as “help” means that their actions might equally be situated within everyday sibling relations as in a context of care necessitated by disability. Ultimately, it may allow them to feel like siblings, many of whom “help” each other anyway (Eriksen and Gerstel, 2002, Edwards et al., 2006).

Importantly, in some cases siblings also used the framing of “help” to refer to the assistance offered by siblings with disabilities to brothers and sisters without disabilities. Thus, some siblings use the same framing to refer their assistance to each other. Their language then reflects similarity and reciprocity between them, as in a normative scope of assistance.

Often it was siblings with disabilities who used “help” to describe their actions for their brother or sister. For example, Rachel was quoted above as “helping out” her brother, Harry, by cutting up his food and getting him drinks after he had surgery. Harry then also used the framing of “help” to talk about what he does for Rachel:

When she needs her room changed around, she asked me for some help, yeah, asks me, ‘If you don’t mind, can you please help me with my bed or move my TV?’

Similarly, Emily, also used “help” to describe her assistance to Jack, just as she noted above that Jack “helped” her:

Jack: Who let me in the house today when I was locked out?

Emily: Me... I helped let you in. When I come in the house I opened the house door and then opened the outside door for Jack and [his friend].

Some siblings without disabilities also framed the assistance from their brother or sister with a disability as “help”, although sometimes in intersection with other framings. For example, Baha variously used the terms “help”, “looking after” and sometimes “care” (see sections below) to describe his assistance to his brother Aakar who has autism and an intellectual disability. However, he also used the framing of “help” to refer to the assistance that Aakar offers him and his family:

If we ask him to do something... like just to turn the light off, take the rubbish out or put this plate in the sink, help us out, stuff like that, and he’ll help around the house if we ask him.

Here, although Baha also uses other terms beyond “help” to describe his own assistance to Aakar, which implies that he gives a greater degree of assistance while Aakar gives a lesser degree, “help” is nevertheless one term that he uses for the acts

done by both of them. While not as clear-cut as the examples from Harry and Emily above, this nevertheless implies a degree to which Baha's sometimes uses the same term for the assistance offered by both himself and his brother. It suggests that while some siblings without disabilities may see the exchange of assistance as more complicated or perhaps as less equal than their brothers or sisters with disabilities do, they nevertheless still sometimes use language that invokes a sense of reciprocity.

Using the framing of "help" to refer to the assistance offered by siblings both with and without disabilities to each other furthers the idea of siblings referring to disability-related care in ways that situate it within a normative scope of everyday sibling relations. The use of this low-key framing for both emphasises that both siblings assist each other, sometimes in ways necessitated by disability and sometimes not, yet all are part of normative everyday exchange and reciprocity between them. The terminology is not always consistent and it sometimes implies that one sibling does more than the other. However, the use of the framing of "help" sometimes goes some way to equalising and normalising the power relations of giving and receiving assistance. Even though the acts offered by each may not always be equal in significance or effort, this phrasing nevertheless emphasises a *felt experience* of more equal exchange than would a starker description of "care". The use of "help" for both thus "talk[s] into being" (Duck, 1995:535) the horizontal relationality described earlier, where both siblings offer support to each other and, although indeed experiencing power differentials, are *relatively* equal in power relations (Branje et al., 2002, Mauthner, 2005, Vivona, 2007, McIntosh and Punch, 2009). It may thus be considered a way of resisting the capacity of disability-related care to push them into unequal vertical relations where they do not feel like siblings.

Looking after

Importantly, siblings did not always use terms that were as low-key as "help". Another common framing of care siblings used was "looking after". This term gave more of a sense of a traditional care relationship, with one sibling being responsible for the other, yet significantly, it was still a term that was nuanced within the everyday of siblings' relations, rather than using the starker descriptor of "care".

For example, in addition to his framing of “help” above, Will also described how Mason’s assistance in driving him to an appointment was about the “looking after” that is part of being a brother:

Will: [When I got] the [new] wheelchair, Mason drove me to the appointment. He came in. He lifted me into my [wheel]chair...

Interviewer: What do you think Mason thought of taking you to the appointment?

Will: I don’t know. A brother.

Interviewer: Brother? What do you mean?

Will: He thought he was looking after me.

Here, Will describes Mason taking direct responsibility for the care tasks of transport and lifting, yet he contextualises this as a way of “looking after” that he sees as part of being “a brother”, rather than describing it as an act of “care”. Similarly, Emily said that her brother, Jack – who is younger than her – “wants to look after me”. Here, she appears to be referencing Jack taking some responsibility for her, even though he is younger, in a way that is less low-key than where she referred earlier to Jack’s technological support as “help”. However, she nevertheless expresses this in everyday language that does not reference “care” directly.

Siblings without disabilities also sometimes used the framing of “looking after”. For example, Baha said, “If my mum is somewhere else, then I have to look after Aakar, feed him”. Here, Baha is talking about taking direct responsibility for Aakar, particularly as his mother is not present, yet he refers to this in everyday, nuanced language that does not directly reference “care”, even though, as demonstrated in the section below, overall he acknowledges that care is what he is doing in those circumstances.

While not as low-key as “help”, the framing of “looking after” is also not as stark or formal as referring directly to “care”. Its use highlights that even where siblings do reference the more traditional direct responsibilities of care, they often do so in

ways that do not mention care itself, rather choosing more everyday language. While this may simply be a reflection of the language families or young people use, the participants also suggest that it could be a linguistic device used (either intentionally or unintentionally) to better fit within the scope of siblings' everyday relations.

Talking directly about care

While the siblings in the study mostly referred to disability-related care as “help” or “looking after”, in some circumstances they did use the word “care” directly. Yet the limited and specific nature of these circumstances suggest that this explicit reference is a last resort, used mainly in circumstances beyond their control or introduced by others.

Siblings sometimes referred directly to “care” as an overall framing for times when they took on extensive responsibility for the disability-related care that would usually be provided by their parents, with this often happening in combination with family circumstances outside their control. For example, Baha referred to “care” as an overall framing for when he steps into the more extensive responsibilities usually held by his mother – yet he steps in within a context where his mother is a single parent who is trying to further her education:

We're all trying to help my mum... just helping her, like help Aakar, looking after Aakar when Mum has to go to uni and feeding Aakar and stuff like that – taking care of him (emphasis added).

While, as noted earlier, Baha also uses the low-key framing of “help” and the more everyday framing of “looking after”, here he gives an overall framing to both of these terms as “taking care of him” when he is sometimes the main person providing assistance when his mother, a single parent, cannot. Although he does not say so here, Baha is also the oldest sibling in the family, perhaps meaning that, while all of his brothers assist, he may step into this extensive role of taking over from his mother more often.

In a further example, while earlier Mark and Mia were each troubled by calling themselves ‘carers’, Samuel was the only participant in the study to *comfortably*

refer to himself as a ‘carer’ throughout his interview. However, he used this term not only as the only sibling of Ben, who has a physical and intellectual disability, but also as the son of his mother who has Lupus. When their mother is unwell, Samuel is called on to give extensive assistance to Ben and in this situation he gives an overall framing to his time to “come and help” as about being a “carer”:

Disability for Ben just played a part in knowing that he needs a carer. If Mum and Dad can’t look after him because Dad works full time [and] Mum is sometimes ill as well, she’s got Lupus. Sometimes she’s not well enough to get out of bed. She’s generally okay, but sometimes she’s not, so it’s about me being flexible where I can just take a day off and come and help (emphasis added).

For both Baha and Samuel, the intersections of being the oldest or only other sibling with the circumstances in their families pushes them into the more extensive responsibilities usually held by their parents, which in turn perhaps prompts them to frame their acts of “help” and “looking after” explicitly as “care”. That is, disability combines with their family circumstances to push them into a high level of involvement that can no longer adequately be described as just “help” or “looking after” and so they qualify these terms with an explicit reference to “care”. Like in Chapter 7, the multi-faceted relational role of disability is that disability creates the relations of care that Baha and Samuel are involved in, but this effect of disability also only contributes along with family context to the particular ways that that care is spoken about: because of the broader contexts in Baha and Samuel’s families that limit their parents’ capacity to do care, the disability-related care they do goes beyond what can be accounted for by only the low-key and everyday framings and thus they each use the more direct reference to “care”.

Siblings also referred directly to “care” when other people introduced this language or when they spoke of public perceptions of their role. For example, when talking about supervising her brother, Oliver, who has autism and an intellectual disability, privately at home, Laura did not explicitly refer to “care” and instead used a low-key framing by saying “I stay home so that he’s okay”. Yet when talking about public perception, Laura did reference “care”:

I suppose anyone in a shop or something would see me in the caretaker role, because he'll be kind of doing his own thing. If he wants to get some chips or whatever I'll be standing back and watching and making sure that nothing gets mixed up as far as his interaction with [the shop].

Laura implies how this framing of her being in a “caretaker role” is formed through public perception, rather than being a descriptor that she uses herself when describing her private assistance to Oliver. Again, the role of disability in prompting the act of care contributes in combination with public discourse to form the way she speaks about the care happening between them.

Similarly, Simone, who has Cerebral Palsy, spoke about her sister Violet giving “care” when she described the process – as already noted in Chapter 7 – of getting Violet paid for the times when she steps into the role of a support worker. Simone noted that in the service system there is a “proviso” of family members giving “care” for free and then continued to describe Violet’s assistance as “care”:

The proviso is that you give that care free of charge because you're related to that person... So we had to go through a whole process of getting the go ahead [from the department] to employ my sister for when I need her care, when I'm not able to get it from anyone else.

Here, Simone’s explicit reference to Violet giving “care” flows from the language and “proviso” of the service system, rather than necessarily being the language that originates in their relationship. For both Laura and Simone, while the acts of care happen because of disability, their direct references to “care” are contributed from the outside – from public perception and the service system – rather than from the low-key language that many siblings commonly appear to choose themselves. This is again a way that, as in Chapter 7, social context influences the presence of disability-related care in sibling relationships: public discourse and the language of others influences how they describe their relations as siblings.

Seeing these places where the siblings in the study refer directly to “care” gives a sense of how they only use the starker and more formal descriptor of “care” when they are pushed to do so by extensive involvement borne of family circumstances

beyond their control, by public discourse or by the language of others. While disability creates the relation of care, it appears to be social context that contributes to when siblings choose to call it “care” itself. Overall, this suggests that while the siblings in the study must navigate private and public codings of care – *where possible* and within the limits of their family, social and contextual circumstances – they mainly keep to the low-key and/or everyday language that gives them a felt experience of being siblings with normative reciprocity and horizontality. Overall, this suggests that the siblings here resist using the explicit language of “care”, except when they really have to and so suggests how they use language to maintain a felt experience of being in a normative sibling relationship.

8.2.2. Setting and breaking boundaries

Siblings also appeared to maintain a feeling of being in a sibling relationship by, as Mark’s earlier example showed, invoking boundaries in the disability-related care that they were willing to have happen between them. Siblings invoked boundaries both implicitly and explicitly and both set and broke boundaries.

Some siblings were explicit about the boundaries that they set on disability-related care. For example, Sarah and Ava specifically set boundaries on assisting their siblings with disabilities with personal care:

Sarah: I’ll feed him occasionally – help Mum and Dad out. I don’t do toileting, that’s the only thing that I won’t do anymore, did when he was little and then grew up.

Ava: I refuse to help toilet her, I used to do that when I was a bit younger and I might help her sometimes now, but as a generalised rule I don’t, I refuse to do that, I don’t want to do that, I shouldn’t have to do that.

While Sarah and Ava’s boundaries might be about cultural reservations around waste and excrement (Hughes et al., 2005), there is also a sense in which they are setting a boundary against the more “serious”, intimate care that earlier Mark identified would risk his opportunity to “feel like one of the siblings”. In this context, while neither Sarah nor Ava directly give a reason, one possible interpretation of

their boundaries is that as they have aged they have become more conscious of the difficult relational implications of these intimate care tasks and have stepped back from them.

Other siblings were implicit about their boundaries on disability-related care. For example, while not talking directly about boundaries, Macy, who has an intellectual disability, commented that she asks her mother for assistance with “putting on [her] shoes”, but asks her brother, Joshua, and sister, Cally, for assistance with tidying her room – assistance she sometimes repays when she helps them tidy their rooms. Macy thus implicitly describes keeping her requests for disability-related care for her parents, while participating in a more normative, equal exchange with her siblings. Macy’s choice about who to ask for which kind of assistance gives a sense of her implicitly maintaining a felt experience of exchange and reciprocity – that is, of horizontal relationality – with her siblings by not asking them to provide disability-related care.

Siblings also sometimes broke their usual boundaries on disability-related care in a way that allowed them to feel like siblings. For example, Fleur, who has Cerebral Palsy, described how her sister, Petra, and brother, James, do not usually do her personal care, but how they did one time in order to go on holiday together:

I don’t really go on holidays a lot or if I do, it’s with my parents... [which is] not really ideal when you’re 22... And so James and Petra, they got their friends together... and took me on a holiday... we got a house... we stayed there for a weekend and they did all the personal care and stuff, which is not something that they normally do, but in order to make it work and get me away from the normal way that we do things, like I didn’t have a support worker down there, and I think that was something that was really good, because the whole point of a holiday is to get away from your daily life, so that’s what they did.

Here, James, Petra and Fleur reverse their usual boundary on personal care and enact a vertical care relationship in order to – contradictorily – have a shared experience as horizontal peers or equals where they together “get away from... daily life”. Making this exception to their usual practices of care perhaps allows them to feel like siblings going away together as equals, rather than having a support worker

there who might disrupt the shared tone of the holiday. That is, the reversal actually allows them to maintain an equitable, shared and horizontal felt experience as siblings.

These examples demonstrate that within disability-related care siblings can invoke and adapt boundaries to enable them to feel like siblings, engaged together in the right level of “seriousness” of care and in a horizontal relationality. Importantly, this way of maintaining their relationality depends on someone else, usually a parent, being there to do the care that they are not prepared to do. Thus by considering which kinds of care they will enact together and by depending on the care given by others, some siblings in the study resist disability-related care creating a feeling of being unlike siblings, by engaging, where they can, only in care which augments, rather than challenges, their overall felt experience as siblings.

8.2.3. Inter-personal negotiations

Finally, where siblings already had close relationships with each other, they also sometimes negotiated about disability-related care in ways that let them maintain their felt experience as siblings. In such negotiations, siblings found ways of accommodating each other’s perspectives about disability-related care.

For example, Simone and Violet actively negotiated about disability-related care. Their solution of paying Violet for her role in Simone’s care was already discussed in Chapter 7; the use of this payment allowed them to find a way to “join together again” in the manner characteristic of their relationship and, ultimately, to negotiate a way through their “main disagreement”. Simone and Violet also negotiated in another way over Simone’s concerns about care. Violet explained:

For instance, [we’re planning on] moving out [together and] Simone was worried about me helping her... it took her a while to come out and say... ‘What if you just decide one day that I’m on the toilet and you decide that you’re just sick of it and you walk out?’ And she was really worried about that. She didn’t want to bring it up because she thought I’d get upset. And of course I did get upset and I denied it as much as I possibly could. But we still talked it through. And knowing

how we felt about it helped us move forward and then deal with the next thing that came up.

Here, in the close relationship they share, Simone and Violet negotiate disability-related care between them: they “talk it through”, know how each other feel about it and use the experience to deal with the next issue that comes up. This negotiation expresses both the product and production of a horizontal relationality: even though their horizontal relations sometimes feel in danger because Violet might “walk out”, they nevertheless enact the relations of equitable, horizontal siblings who collaboratively deal with complex issues together.

Similarly, Craig and Jess showed that where disability-related care is negotiated, this in itself may lead to a horizontal relationality. Craig has Cerebral Palsy and sometimes uses a wheelchair. Carrying on from explaining his interaction with taxi drivers, he and Jess said:

Craig: ... if I do get out of a [wheel]chair and get into a car, I know that I’m not that glamorous... it looks like I’m struggling, but that’s just the way I do it. So I have had people grab me and hoist me up somewhere when I don’t necessarily need that help, so that’s that personal barrier being crossed and you have to let that be known... you have to let people know that that’s –

Jess: I just let you do it [laughs].

Craig: Yeah, so that’s the thing – [Jess] won’t intervene in that way to come into my personal space and do something that would, you know, because that’s invasion of me, where she wouldn’t do that because she knows what I’m like.

Here, whereas others fall into a vertical relation of making assumptions about disability-related care, Jess knows Craig well and so “just lets [him] do it” – and, importantly, Craig experiences this as a trusting relationship with someone who will not challenge him: Jess “won’t intervene” and will not be an “invasion” and this helps to create a comfortable, horizontal relationality between them. This suggests that, at least where they are already close and where the functional impact of

disability allows them to have the necessary discussions, some siblings are able to negotiate about each other's preferences with regard to disability-related care, allowing them to together maintain their horizontal felt experience as siblings.

The siblings in this chapter highlight that in a context where the presence of disability-related care can risk creating relationalities of liminality and elusive horizontality between them, some siblings talk and act in ways that keep the care between them situated within a scope of everyday sibling relations and that attempt to maintain their horizontal relationality. While siblings' efforts may be more or less successful at different times, in different family, social and contextual circumstances and in different private or public domains, the ways that the siblings in this study use language, set and break boundaries and undertake inter-personal negotiations are in themselves relational acts that either explicitly or implicitly resist disability-related care jeopardising their felt experience as siblings. In this way, they attempt to keep to the overall felt experience of being in a sibling relationship.

8.3. Discussion

8.3.1. Disability's presence in the life course

This chapter has explored the inter-relationship between the sibling relationship and disability-related care. While it is embodied and enacted in their everyday relations, the experiences of the siblings in this chapter show how disability-related care also has the capacity to create a relational experience in which they do not feel like siblings. By creating liminal experiences of feeling like a carer, manager or parent rather than (only) a sibling and/or by challenging the relatively equitable, horizontal relations that are characteristic between siblings (Branje et al., 2002, Mauthner, 2005, Vivona, 2007, McIntosh and Punch, 2009), some types of "serious" or intimate disability-related care run the risk of undermining the overall experience of feeling like siblings. Yet, importantly, many siblings also had ways of talking and interacting that allowed them to – *where possible* and within the limits of their family, social and contextual circumstances – resist and so maintain the feeling of being siblings.

On one level, siblings' ways of resisting highlight that in considering the role of disability in the sibling relationship, it is not just that disability constitutes, creates or contributes to siblings' everyday relations and relationality – but that siblings also influence disability's relational presence themselves. Just as disability can influence their everyday relations, so too can the everyday relations of how siblings talk and interact also influence the presence of disability. When siblings with and without disabilities talk in low-key or everyday ways about care, set boundaries and/or negotiate, they influence the role and effect of disability in their relationship. This means that the sibling relationship also influences the relational experience of disability and thus that the relational presence of disability goes two ways: it can *influence* or it can *be influenced*. Appreciating this bi-directionality is important for understanding that siblings' everyday relations and relationality cannot be reduced to *only* the effect of disability on the relationship, but rather siblings also have some agency in influencing disability's relational presence as well.

However, at a further level, a bigger picture temporal analysis suggests that the possibility of exerting this agency and maintaining their felt experience as siblings in the particular ways documented in this chapter may be unique to the stage in the life course that the young adult siblings in this study are in. As young adults, all study participants were in a life-stage where siblings without disabilities were old enough to take on a substantive role in disability-related care, but their parents were still young enough that they provided the majority of care and, where it was necessary, acted as primary carer. This meant that the roles in disability-related care of all of the siblings without disabilities in this study were supplementary, even though those supplementary roles were characterised by differing extents of autonomy and responsibility based on siblings' family, social and contextual circumstances. The supplementary nature of these roles is thus contingent on parents' primary roles, but is also what affords siblings the opportunity to resist the risk that disability will create an experience of feeling unlike siblings. In supplementary roles, siblings can pick and choose what disability-related care they are willing to have happen between them and can set boundaries precisely because their parents are there to do the care that they do not wish to do. Further, siblings can frame disability-related care as low-key and everyday, because, ultimately, siblings do not have the final or

“serious” responsibility. It is then the intergenerational structure of the family as a whole that affords the siblings in this study the opportunity to think critically about disability-related care and to determine their engagement in it by prioritising their relationship and felt experience as siblings.

However, intergenerational family structures shift over time and over the life course. Adult siblings without disabilities commonly take over the main role in care from ageing parents (Dew et al., 2004, Kramer, 2009, Heller and Kramer, 2009), whether by providing direct care (Seltzer et al., 2005) or by becoming the main contact with service providers (Bigby et al., 2014). This means that young adult siblings’ “less serious” and bounded roles in care may not hold over time. There is then a question about how siblings’ everyday relations around disability-related care may change over the life course and about how siblings’ care relationships in later life are built on their earlier histories. If up to the point of the transition of care, siblings without disabilities’ roles have been premised on being supplementary, what happens if/when they are required to move into a primary care role? Could they then have less agency in how they talk and interact around care? Could a new felt experience be created between them? How might the relationship and power relations between the siblings change? How might they struggle to maintain a felt experience as siblings? These questions suggest that young adulthood is a time when many siblings may have more agency in care and a more unencumbered sibling relationship – with the opportunity to ‘just be’ or feel like siblings – than they may share later in life.

One key question emerging from these insights for policy, service providers, families and siblings is about how to support siblings in maintaining their agency in care and their felt experience as siblings over time and over the life course. Sibling relationships are likely to inevitably change to some degree after a transition of care – some siblings without disabilities may take on more extensive direct care roles, while others may broker and safeguard care that is provided beyond the family, for example, through formal services. In either case, if the service system can act as the third-party that siblings rely on to do the “serious” care, then the relational impact of the transition may be minimised and siblings may be better able to maintain their

agency and their lower-key felt experience together. In this sense, flexible and personalised services for people with disabilities are relationally significant for *both* siblings: if personalised support can be put in place in a way that allows siblings to keep as much of a supplementary care relationship as possible, then both siblings may be better able to maintain the felt experience of a lifelong sibling relationship.

8.3.2. Care and relationality

Reflecting the prominence of care within the meso-level mapping of relationality developed in the theoretical framework in Chapter 3, this chapter also highlights that care is an aspect of disability that has very significant consequences for siblings' relationality. Its consequences are so significant because it can lead to the liminal relationality described in Chapter 6 where the sibling relationship feels inauthentic. In the experience of liminal relationality in this chapter, some siblings without disabilities did not completely feel like siblings, because their engagement in "serious", intimate and/or primary care meant they felt like they were instead edging into a carer, manager or parent relationship. Accordingly, disability-related care is so significant because it can undermine the overall experience of feeling like a sibling.

Further, this chapter highlights that the move away from feeling like a sibling also expresses another relationality: elusive horizontality. Here the equitable, horizontal felt experience expected by some siblings feels challenged or some siblings maintain horizontality by specifically using low-key or everyday language, invoking boundaries or negotiating. As such, the presence of disability-related care is also significant because it is linked to an unsettling of the overall experience of the relationship: while they objectively *are* siblings, disability-related care means that a need to talk and interact in ways that reinforce the horizontal felt experience of being siblings also becomes a feature of siblings' everyday relations. For some siblings, these ways of talking and interacting indeed allow them to maintain more of a horizontal experience, while for others horizontality may still feel more elusive and challenged. Either way, while siblings may not always be horizontal in relationality or may not be perfectly horizontal, these ways of talking and interacting allow at least some

siblings to maintain more of the overall felt experience of relative horizontality, even if the details are contested or unclear.

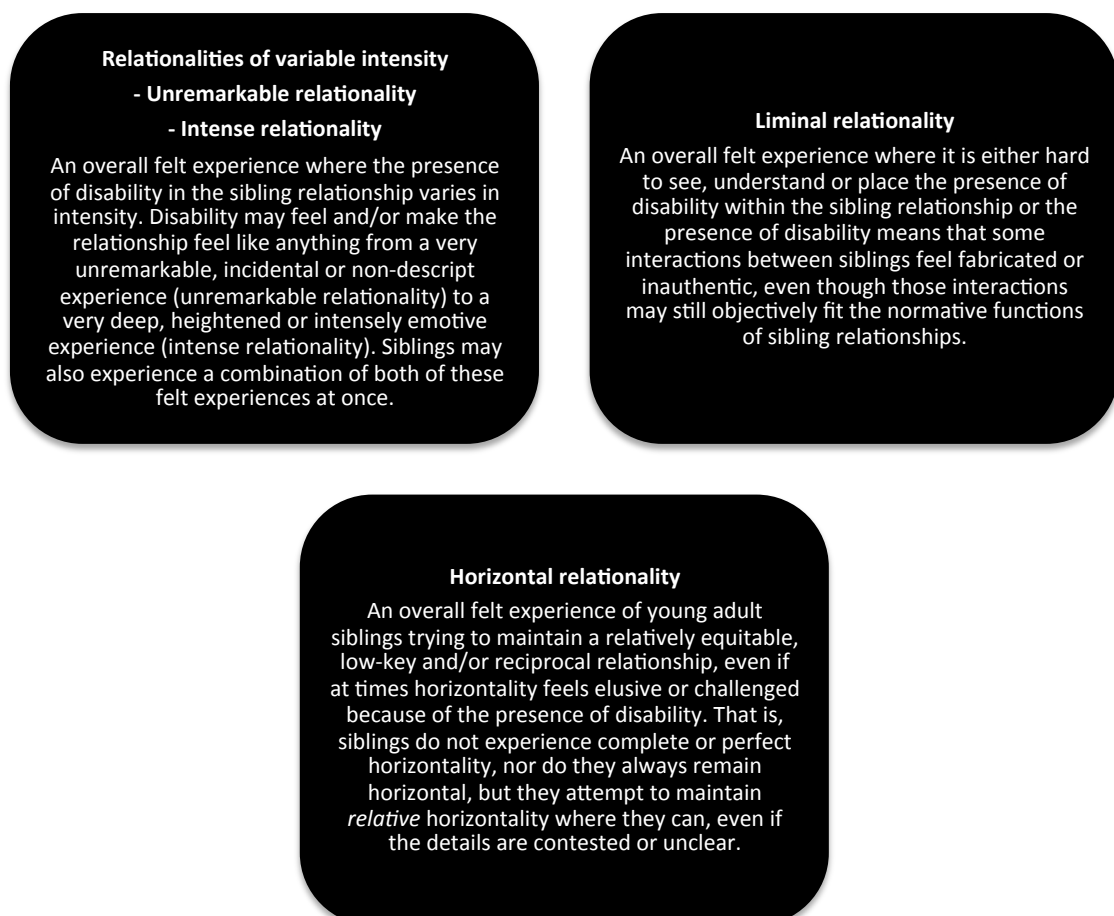
Importantly, elusive horizontality is a felt experience where the presence of disability heightens power complexities that are normative between many siblings. In saying that siblings with and without disabilities expect horizontality because some level of equity is normative to siblings (Branje et al., 2002, Mauthner, 2005, Vivona, 2007, McIntosh and Punch, 2009), it is important to acknowledge that such equity is contested and incomplete between many siblings irrespective of disability. While siblings are *relatively* more equal and egalitarian than, for example, parent-child relationships, siblings still experience power inequalities. The differential responsibility and power associated with birth order has, for example, been a major focus of sibling research (Toman, 1994 [1961], Sulloway, 1996, Dunn, 1985, Furman and Buhrmester, 1985, Edwards et al., 2006). In this way, the experience of challenged or incomplete horizontality is also normative to many siblings. This chapter however highlights that disability-related care can create additional challenges to horizontality for siblings with and without disabilities and that these challenges may feel particularly acute. As in Chapter 6, the relationality of elusive horizontality then expresses how the presence of disability heightens relations normative to siblings: it heightens the complexities of normative sibling power relations.

Further, it is important to note that while, consistent with Chapter 6, it was only siblings without disabilities who expressed liminal experiences, siblings both with and without disabilities talk and interact in ways that can maintain the feeling of horizontality. Maintaining horizontality is thus co-produced. Extent of support needs can affect *how* siblings with disabilities contribute: for example, it was more common for siblings with low support needs who could offer their own assistance to brothers or sisters without disabilities to reflect similarity in the language of “help” and “helping out”, whereas Claire, with higher support needs, contributed by her demeanour in also appearing to find care from her brother, Mark, “more relaxed” and “fun”. Either way, siblings’ co-production of horizontality highlights that both siblings may play a role in determining their relationality despite their level of

support needs, although the contributions of siblings with high support needs may be subtler and, at times, harder to recognise.

Overall, the liminal and elusive horizontal relationalities found here further develop the set of relationalities begun in Chapter 6. Chapter 6 discussed how the sibling relationship might feel more or less intense, thus forming unremarkable and intense relationalities, as well as sometimes feel fabricated or inauthentic, forming a liminal relationality. This chapter again finds the liminal relationality and newly highlights the possibility of an elusive horizontal relationality. This develops a more extended set of relationalities, as summarised in Figure 6. In this more extended set, the liminal and elusive horizontal relationalities together reflect some of the complexities of disability's relational presence.

Figure 6: Relationalities of disability for siblings (ii)



The complexities that disability-related care creates through the liminal and elusive horizontal relationalities have policy implications. For example, in Australia young adult siblings without disabilities are often framed as or coupled with ‘young carers’ in policy and public discourse (Commonwealth of Australia, 2009, Australian Government, 2011a, 2011b). Yet the evidence from the siblings both with and without disabilities in this study suggests that this is not how they see or perhaps wish to see themselves and that this framing may in fact present complexities and challenges in the extent to which they can maintain a felt experience as siblings. The implication for policy-makers is about re-considering how siblings without disabilities are framed so that services, policy and public discourse can better support and augment the ways that both siblings experience their own relationships. These implications are discussed further in Chapter 10 in examining how relational evidence, policy and practice might be developed for siblings with and without disabilities.

This chapter and Chapters 6 and 7 have accounted for siblings with and without disabilities’ experiences as largely similar to each other. The analysis has shown how both siblings share similar experiences of disability figuring in their everyday relations with each other. However, siblings with disabilities and siblings without disabilities also had some different views to each other about how disability influenced their lives and sibling relationships. This was particularly evident where they spoke about the influence of the relational presence and role of disability upon their individual life experiences. This is the subject of Chapter 9, drawing on a discussion of each sibling’s individual experiences during young adulthood.

Chapter 9. Disability and sibling relationships in young adulthood

Attention has so far been given to the everyday relations enacted between both siblings – for example, the ways they talk, interact, argue or share activities, as well as the disability-related care enacted between them. However, beyond these shared relations, the presence of disability in the sibling relationship could also influence each sibling's individual life experiences. Accordingly, this chapter explores siblings with and without disabilities' individual experiences of the changes and transitions of young adulthood. The focus is on identifying and discussing the extent and ways in which the inter-relationship between disability and the sibling relationship (and thus the relational presence and roles of disability) influenced how each sibling perceived their own young adult experiences. The chapter first looks at siblings without disabilities, then siblings with disabilities and finally at the comparisons they make between themselves.

The chapter reveals the different ways that the siblings with and without disabilities in the study each understood the relational presence and role of disability in their young adult lives. The siblings without disabilities perceived that the relational presence of disability was a significant and prominent influence for them, often either constituting or creating some of their individual young adult experiences. In comparison, siblings with disabilities more commonly perceived that the relational presence of disability more unclearly or partially contributed to their young adult experiences. The end of the chapter draws on these insights to discuss how disability's relational presence is to some extent a product of each sibling's positioning and perception.

9.1. Relational experiences of disability during young adulthood

Participants were asked about ‘important things’ that had happened in their lives during young adulthood. This could include important events or experiences that had made them feel like an adult. They were then asked if and how disability had played a role in these experiences and if and how these experiences had influenced their sibling relationship. The purpose was to gain a sense of the inter-relationship between their experiences as siblings, of disability and of young adulthood, particularly the extent and ways in which the inter-relationship between disability and the sibling relationship influenced their young adult experiences. Importantly, the analysis showed differences between siblings with and without disabilities in this area. This is discussed in the sections below.

9.1.1. Siblings without disabilities: Relational presence of disability either constitutes or creates young adult experiences

When asked about their important experiences during young adulthood, the siblings without disabilities in the study commonly reflected on many of the changes, transitions and other experiences that the youth studies literature has highlighted as characteristic for young people. For example, they spoke about the actions, decisions and new reflections, thoughts and perceptions that they had as they progressed through school, moved into work, made steps towards independence, had new experiences, such as travel or driving, or formulated more of their identity and worldviews (Settersson and Ray, 2010, Lowe et al., 2013, Arnett, 2000, Worth, 2009).

When siblings without disabilities spoke about these experiences, they commonly did so in two ways. Firstly, *not all* of their young adult experiences had a connection to either disability or their brothers and sisters and there were many influences on their young adult lives and experiences they had that did not relate to either disability or their sibling relationships at all. However, when they *did* speak about the influence of either disability or of their siblings on their young adult experiences, disability and the sibling relationship were commonly very much connected. That is,

siblings without disabilities inherently spoke about the influence of the presence of disability in the sibling relationship on their young adult lives, not just about the influence of either disability or the sibling relationship separately. Secondly, they identified that the presence of disability in the sibling relationship was not only *an* influence on their lives, but a significant and prominent influence – it felt significant in what happened to and for them. Thus, as documented in the following sections, the way they spoke about the relational role of disability suggested that it often had one of the two stronger roles of either *creating* or *constituting* some their key experiences as young people. This is demonstrated in the examples below.

Actions and decisions

Several siblings without disabilities showed how some key elements of their young adult actions and decisions could be seen as created by the inter-relationship between disability and their sibling relationship – that is, the outcome of their action or decision could be understood as informed by or happening because of the presence of disability in their sibling relationship, even though the action or decision itself was normative to young adult life and would have happened anyway.

One way in which this happened was where some siblings without disabilities made life decisions that clearly reflected disability's relational presence. In moving into partnership and property ownership, Jess planned an accessible wedding and bought an accessible house, because:

I wouldn't have wanted to buy a house that Craig couldn't access or get into, because, you know, I like him to come over and visit and house-sit if we need him.

Similarly, in deciding where she would live in the future, Sarah described her brother's disability as "keeping me in [this city]"; she said, "I think if Thomas wasn't so special, I probably wouldn't stay". In each example, Jess and Sarah's young adult choices of where to live are normative, but they explain that the actual choices they make are informed by the relational presence of disability.

For others, the presence of disability in the sibling relationship clearly influenced their decisions as they moved into tertiary study or work. Baha explained that he was studying disability because of his experience with this brother:

Because of Aakar, I started studying. I did Disability first, Cert III, and then now I'm doing Aged Care Cert III... Because I look after Aakar my whole life, I want to – life experience – and I want to help other people who have been in my situation.

Currently a medical student, Sophia similarly commented:

Having no answer or having no name for Anna's condition is really intriguing to me. I think that's a really big player in my interest in medicine, because there is so much that we just don't know.

Others made employment decisions that were because of the relational presence of disability. For example, Samuel's decision about where to accept his first job hinged on his care role for his brother, Ben:

[My employer] understand[s] the caring role... They have flexible hours... if the [paid] carer doesn't turn up, I can just come in later to work and then stay later... [When I was looking for work], I just picked the companies that I knew would be able to support me in that and that's why I picked this company, because I knew they promoted flexible working hours. It's the reason why I picked them as opposed to other companies definitely 100 per cent.

Baha, Sophia and Samuel would each have had to make these decisions about study and work irrespective of disability, yet for each, what they actually decide is informed by and because of the presence of disability in their sibling relationships. They thus show how the relational presence of disability has a key and formative influence on what they do as they undergo the changes and transitions of young adulthood.

In each of these examples, siblings without disabilities make decisions characteristic of young adult life: where to live or work and what to study (Setterson and Ray, 2010, Lowe et al., 2013). Yet, as they enact actions and make decisions that are normative for young people, they show the presence of disability in the sibling

relationship as a clear influence informing how they do that: the outcomes of their actions and decisions happen to some degree because of disability's presence in their sibling relationship. Importantly, there may be other factors at play as well, meaning that the relational presence of disability may contribute along with other influences rather than completely creating the experience. Yet, each of the siblings quoted here give prominence to disability in their explanation, implying its role in creating their experiences. While the prominence given to disability may be amplified here by the research process that asked about connections between disability and young adult experiences, these siblings' accounts nevertheless give a sense of the relational presence of disability as having a central role in informing some of their young adult actions and decisions.

Significance of young adult experiences

For some siblings without disabilities, the presence of disability in the sibling relationship created heightened significance or particular forms of significance to some of the experiences they had during young adulthood. These siblings had experiences characteristic of many young people, yet the way they felt and explained some of the importance of these experiences was because of the relational presence of disability.

For example, Mark spoke about the implications of receiving his driver's license:

Now that I have my licence... I can drive Claire places and it's that extra flexibility. Admittedly my car is too small to fit both her walker and her wheelchair, which limits that... if I could fit both those things then if Mum and Dad were busy then I would be able to take her more and more places. But then again, I think that's a good thing. I like having more responsibility, because otherwise if it's not on me then either Mum or Dad have to make plans that hinder them... I feel like that I would like to be able to take care of Claire herself, like kind of take care of everything – because I can take care of most things... But then again, I also realise that if I was able to do that then I would have to do that more often and kind of, whether long-term whether I'd want to be still doing that, depending on where I want my life to go.

Receiving a license is a key young adult milestone irrespective of disability (Lowe et al., 2013). Yet when Mark explains what this meant for him personally, he explains that receiving his license was significant because of the relational presence of disability: his new license brought him close to being able to do “everything” to support Claire and, while he values the assistance he can now give his parents, he also recognises that it potentially has implications for his future.

Similarly, Mia spoke about how her study trip overseas had heightened significance in light of her sister, Cara’s, disability:

Going overseas for a year when I studied in [location]... that was my first time essentially living out of home and that was wonderful... it was really nice for the first time in my life not to feel like Cara or her disability was shaping what I was doing... I just had to take responsibility for myself... I really got to be myself. I wasn’t defined by ‘This is Mia with a sister with a disability’.

Going overseas, living out of home and developing a persona independent of family are all significant young adult experiences irrespective of disability (Arnett, 2000, Aquilino, 2006, Lowe et al., 2013). However, for Mia, these experiences were made all the more significant because of the presence of disability in her sibling relationship that, through travel, she had her first opportunity to be more distant from.

These examples show that for some siblings without disabilities, some of their young adult experiences feel particularly notable because of the presence of disability in their sibling relationships. Even as Mark and Mia’s experiences of driving and travel are important new experiences for many young people (Lowe et al., 2013), the presence of disability in their sibling relationships creates heightened significance or some of the reasons why these experiences feel important for them.

Thoughts and perceptions

For other siblings without disabilities, the relational presence of disability constituted some of their thoughts and perceptions as they entered adulthood. That is, some of the thoughts and perceptions they had as young people were expressed

through the presence of disability in their sibling relationship.

One place where this constitutive influence occurred was where disability's presence in the relationship formed some of siblings without disabilities' conceptualisations of what adulthood itself meant. For example, when Rachel was asked what adulthood meant to her, one answer she gave was about what it meant to have a responsible reaction to her brother, Harry, being called 'robot' because of his tracheostomy and 'spine boy' because of his scoliosis:

[Adulthood means] responsibility – say recently my brother's been picked on, teased, and I'm like, 'Look bro, I'd love to go and thump the kid for you, but I can't, because I can be charged for assaulting minors, so as much as I'd love to help you out with this, I can't help you out at my age'.

Here, Rachel's expresses a notion of adult responsibility that is formed through her response to and experience of her brother's disability. While she may also have other notions of what responsibility means in other contexts, her relational experience of disability thus constitutes part of what responsibility means for her.

Similarly, disability constituted some of Ruby's thoughts about adult responsibility and choice. Ruby said that for herself adulthood means "you're not going to get anything handed to you anymore", whereas for her brother, Luke, who has autism and an intellectual disability, "it's almost the opposite, because it's kind of like someone's always going to be there holding his hand". She reflected on how Luke's choices to play UNO or go fishing with his support worker "aren't influenced by anything", whereas her own choices are increasingly influenced by cost, household responsibilities and her own and her friends' work schedules. However, she also said, "I think he's got it easy, but it's not worth what he has to miss out on". Here, her understanding of the interplay between what Luke "miss[es] out on" in the context of his disability with his easier choices forms a way that Ruby appears to come to terms with her own adult responsibilities and choices. In this way, her acceptance of her adult responsibility is expressed through and constituted by the presence of disability in her sibling relationship, where she has the opportunity to make comparisons between herself and Luke.

For others, the presence of disability in the sibling relationship constituted a basis for expanding their social consciousness during young adulthood. Alex, brother to Jeremy who has Cerebral Palsy, demonstrates this in his shift from thinking about Jeremy's transition to work to considering issues of disability and inclusion in society:

Alex: Jeremy went to have a look at a supported workplace. It was mainly for people with intellectual disabilities... And I think it's just the whole idea of being together... everyone with a disability just goes together. Same thing with group homes – I've been thinking about it a bit more when we've been looking at transition to work... I suppose Jeremy has a very good set up. I suppose we're a supportive family and everything's good at school now, and I've been thinking about the people who it's not that good for and they'll just get put in a group home... [Group homes] are probably good for some people, but I think that it would probably be better if they were just sort of included in just everything and they, as Jeremy said, try and live a life as if they hadn't [had a disability]. But I realise that if they don't have the support, like their family and friends and everything and haven't had like a good set up from early childhood, that's not possible, but [a group home is] definitely not for Jeremy.

Interviewer: So why were you thinking about that? What brought that up?

Alex: Well, probably all the thinking about Jeremy going to work and life after school and where he'll be living and things like that.

Here, as Alex develops more of a social consciousness during young adulthood, one of the ways he does this is through his opportunity, as Jeremy's brother, to observe and learn from Jeremy's experiences. That is, the presence of disability in his sibling relationship constitutes an opportunity for him to develop and extend his thoughts and perceptions about society.

While young adulthood is a time of expanding identity, responsibility, thought and sometimes social consciousness for many young people (Erikson, 1968, Worth, 2009), the siblings without disabilities here show how disability constitutes some of their new thoughts and perceptions. That is, some of their thoughts and perceptions are expressed *through* their relational experience of disability and disability becomes embedded in their expanded and matured thinking.

Together these examples from the siblings without disabilities in the study show that, even at an individual level, they find disability a relational experience. Whether it is through creating elements of their actions and decisions, creating heightened or particular significance to their young adult experiences or constituting some of their thoughts and perceptions, the presence of disability within the sibling relationship is a significant and prominent influence upon their young adult lives; each of their examples point to the two stronger roles documented in this thesis of disability either creating or constituting some of their experiences. For the remainder of this chapter, these two relational roles – constituting and creating – are thus used together to refer to the scope of ways that disability might figure in siblings' without disabilities young adult lives, yet it is important to remember that each refers to a different way that disability might figure in their experiences. Importantly, these two relational roles of disability are also used together to show how siblings without disabilities' experiences were different to those of their brothers or sisters with disabilities, as, for siblings with disabilities, the relational presence of disability instead *contributed* more partially to their young adult lives.

9.1.2. Siblings with disabilities: Relational presence of disability contributes to young adult experiences

Like siblings without disabilities, siblings with disabilities also spoke about their young adult experiences in education, work, of moving into independence, having new experiences and formulating their identity and worldviews (Setterson and Ray, 2010, Lowe et al., 2013, Arnett, 2000, Worth, 2009). Similarly, they also spoke about how disability and their sibling relationships influenced these experiences.

Importantly however, while both disability and their brothers and sisters separately influenced siblings with disabilities' young adult experiences, the *inter-relationship between* disability and the sibling relationship appeared less influential for them than it did for their brothers and sisters. This was for two reasons. Firstly, not all of their young adult experiences of disability featured their siblings – sometimes disability influenced siblings with disabilities' young adult lives without their brothers and sisters being part of the experience at all⁵. Secondly, where their young adult experiences were influenced by both disability and their sibling relationship, siblings with disabilities very often emphasised one of these aspects over the other: that is, either they described disability as far more key to their young adult experience than their siblings or they described their siblings as far more key than disability. The effect was that the inter-relationship between disability and their sibling relationship came across as a more partial and less prominent influence on young adulthood for siblings with disabilities than it did for their brothers and sisters. Thus, as documented in the following sections, the way siblings with disabilities spoke about the relational presence and role of disability suggested that it only partially *contributed* to their young adult experiences, rather than more strongly creating or constituting their experiences, as was the case for siblings without disabilities. This is explored in the sections below.

Siblings have a marginal influence

For some siblings with disabilities, their brothers and sisters had a marginal influence upon their young adult experiences of disability. Here, their brothers and sisters'

⁵ As these young adult experiences do not include siblings with disabilities' brothers and sisters, they are outside the scope of the thesis. However, for reference, siblings with disabilities spoke about many ways that disability affected their young adult lives. These areas are detailed with quoted evidence in Appendix 9, but in summary included:

- Disability's impact on their social and economic engagement as young people – for example, changing schools or choosing subjects because of disability, experiencing disability-related employment discrimination, entering disability-related jobs or using disability services as a form of engagement.
- Disability's impact on friendships and socialising – for example, dealing with other people's perceptions of disability when making friends, socialising through disability groups or planning for accessibility or support workers when socialising.
- Disability's influence on their subjective young adult experiences – for example, getting more of a say about services or using new disability services as forms of independence or the impact of experiences of inclusion or stigma on identity and belonging.

role was present and definable, but it was only one small contribution to a much broader experience.

For example, Nathan commented that a significant experience during young adulthood for him had been having major surgery to correct his walking: “I had multi-level surgery in about 2004... There was all sorts of things that they did, sort of lengthening muscles and rotating my foot out and things like that”. This surgery not only involved the medical procedure itself, but going inter-state for the operation and an extensive recovery. Within this broader experience, he identified how his siblings, Alicia and Jesse, had an important but ultimately small role:

Even when I was [inter-state] they would ring up, probably it was about twice a week and see how I was and keep me updated on how things were going.

They’d sort of help out in a way, even if it was just a bit of motivation, it might have just been spending a bit of time with me, because I was pretty much on the couch for a while.

Here, although Alicia and Jesse only have a small role in Nathan’s broader experience of disability during young adulthood, their presence contributes to keeping Nathan connected to home during a stressful time and to encouraging him through his recovery. While their presence and support is only one small factor in the broader experience, it nevertheless plays a role.

Similarly, Zoe, who has Cerebral Palsy, commented on developing more independence during young adulthood through receiving an attendant care package. She explained how, “It’s given me independence for myself... I can wash up dishes or I can decide to go places”. Yet as one of four siblings, she also commented:

The attendant care package was a big thing because we’ve already got six people in the house, so having extra people coming all the time creates havoc, I guess, and it just made things a bit harder.

Zoe’s experience is primarily about developing her own young adult independence, facilitated through new disability services. Yet marginally, her siblings contribute something to the experience: their intersection in the home with her support

workers means that her independence also sometimes feels like “havoc”. In this way, her siblings have some influence on Zoe’s predominantly individual experience, making it more complicated than it might otherwise have been.

Other siblings with disabilities gave similar examples. Harry spoke about the difficulty of finding a casual job because of his disability. He said he had come up against the attitude that “people won’t take disability people to work, they’ll say, ‘He won’t know what he’s doing’”. Yet Harry also commented on one option for help with getting a job:

If I needed help, I’d ask Rachel, ‘Can you try to help me get into this job, because I really like this job?’ So she’ll help me out.

Here, the possibility of his sister Rachel’s help forms only one component of Harry’s broader experience of finding a job as a young person and of disability-related employment difficulties, yet her presence offers an important form of support.

The siblings with disabilities here show that their brothers and sisters contribute to their young adult experiences of disability, yet have only a marginal role. However, while marginal, their siblings still contextualise the experience, provide support or become a complicating factor. In this way, while marginal, the inter-relationship between disability and the sibling relationship contributes to their experiences – albeit to the nuances and details of the experience, rather than being a primary influence.

[Disability’s influence is secondary to the influence of siblings](#)

In other cases, siblings with disabilities clearly identified the role of their brothers and sisters in their young adult lives, but spoke of the role of disability as secondary. This meant that disability was framed as a background contributing factor, as even though it might have a significant role in what happened, siblings with disabilities described their interactions with their brothers and sisters as more prominent.

For example, Fleur described a “good night” out with her brother, James. Her account gave an explanation of how their night out together only even occurred

because of her disability, yet in describing what happened, the chance to spend enjoyable time with James was far more her central focus:

Just recently I was invited to a friend's birthday party and I couldn't find a support worker to take me. I don't often go out with James, because often James goes out drinking or to parties or whatever and that's just not my thing. But in this instance, he was like 'Oh no, me and [my girlfriend] will take you!'... So we went and that was an incredible – I had *such* a good night... we don't get to spend that much time together and so yeah, it was really nice.

Here, disability creates an excuse for James and Fleur to go out together when they do not do so usually. Yet when Fleur talks about it, this influence of disability comes across as just a secondary factor contributing to the situation. Instead, Fleur's experience is much more prominently about socialising and having a fun night out with her brother and his girlfriend.

In other cases, other people – including brothers or sisters without disabilities – might see siblings with disabilities' young adult experiences as primarily about disability, yet this was not the experience of siblings with disabilities themselves. This was the case in a disagreement between Lucy, who has Down Syndrome, and her sister Allegra about whether Lucy should take up a package of independent living funding to move out of home. For Allegra, the importance of Lucy moving out is because of disability: already living out of home herself and focused on the importance of inclusion, self-advocacy and creating opportunities for people with disabilities, Allegra wants Lucy to use the funding to move out because "it's about community connections, it's about home skills, it's about creating a life" and "I just want her to have the same life as I have". Here, Allegra values her own lifestyle and wants the best opportunities for Lucy as well, especially in light of the risk she might not have them due to her disability.

Yet, for Lucy, these considerations with regard to inclusion and her status as a young person with a disability do not figure so prominently. Instead, her views are centred on the difficulty of the transition out of home and, at least for the moment, wanting to maintain her current lifestyle. She said: "Actually, I just want to stay here at home. I have a wonderful life here with [my family]". When asked what she wants from

Allegra, she said, “I want to stay here” and she struggles with Allegra’s perspective on the situation:

Allegra: I [applied for the funding package] without really your full support, because I knew it was the right thing, our family did –

Lucy: Sometimes you hurt people’s feelings.

Allegra: And that’s been really hard for me emotionally, because Lucy will say she doesn’t [want to move out] – like, we know that you’ll come around... But I hope you’re not angry at me?

Lucy: No, I’m not angry – I just don’t feel like giving up on these things.

Here, Lucy’s sees disability as a more secondary factor than what Allegra perceives; for Lucy, disability at best contributes to the situation or perhaps does not figure in it at all. Allegra’s influence is important and may one day encourage Lucy to broach new experiences, but at this moment, for Lucy, her young adult decision of whether to move out of home is experienced much more in terms of her disagreement with Allegra – an argument in the sibling relationship – than it is in terms of disability. Their example highlights that siblings with and without disabilities may have different views and experiences of the role and prominence of disability in the situations they encounter together during young adulthood and that that difference of view may itself be influential in their relational experiences.

In this sense, while disability may objectively or in the views of others have a role in creating siblings with disabilities’ young adult experiences, for siblings with disabilities themselves, disability may be perceived as only a secondary contributing factor. Fleur and Lucy show that it may be the time spent together or the disagreements had with one’s siblings in the context of disability that are more influential than disability is itself. That is, while disability contributes to and contextualises what happens, their relations with their siblings are the more significant influence.

Disability's influence is unclear

Finally, some siblings with disabilities gave accounts of young adult experiences with their brothers and sisters where it was not clear what role disability played – yet there was still a sense that disability might be contributing in some way. In these cases, siblings with disabilities gave information about their siblings and about disability in separate parts of their interviews, which, when juxtaposed, raised questions about the role of disability in their young adult experiences with their siblings.

For example, Eric, who has a physical and intellectual disability, spoke about the importance of his older sister Jacqui's young adult transitions for his own experience as a young person. He described some of the changes that have recently happened in her life: "My sister got married... I felt happy for her that she found the right man. And they had a baby [girl]... so I'm an uncle". Eric explained the relationship he now has with his new brother-in-law, Tom:

Facilitator⁶: What's the fun things you like to do with your family?

Eric: Play video games with my brother-in-law, [Tom]. It's called 'A Duty'. His game tag is – I can't say it, because he'll delete me.

Facilitator: Does your brother, Zac, play with you?

Eric: No. Tom. Tom helps me out when I get up to the really hard part, he helps me out.

Here, Jacqui's young adult transitions of moving into partnership and parenthood also give Eric a new identity as an uncle and a new relationship with a trusted adult, Tom, his brother-in-law. These are changes that are characteristic for many young people, for example, who commonly develop relationships with trusted adults (Beam et al., 2002). Eric really values these relationships, particularly emphasising his trust of and fun with his brother-in-law.

⁶ Eric contributed to the study via a documented contribution where a third-party facilitator asked him questions on video. The facilitator is thus not the researcher.

Nowhere in his account of these relationships does Eric mention disability. Yet in his broader contribution to the study, he spoke about how up until recently he stayed at home all the time because he was unhappy at his day program, how he has trouble getting around due to unsteady walking and how he has experienced teasing from his other siblings and cousins. This is a context that hints at social exclusion linked to disability. Juxtaposed against this context, a question arises about whether he perhaps values the new relationships that Jacqui's young adult transitions have brought to his life so much precisely because he is socially isolated by disability. While Eric does not draw this conclusion himself, the juxtaposition of these different parts of his account suggests that disability might be contributing to how much he values Jacqui, his brother-in-law and niece.

Similarly, Maria, who has a vision impairment and learning disability, commented on how her sisters had been a particularly appropriate source of advice about what to do after school, compared to her parents:

I asked my both younger sisters and then they suggested to me to go to an employment agency or to do a TAFE course... [I asked them] because my sisters were younger than my mum and dad... they had something in mind when I was going to ask them, they knew what I could do maybe because my sisters were a younger generation, where my mum and dad were an older generation.

Here, Maria describes a normative experience of seeking advice from her sisters who are closer to her own experience and age in the education system than their parents (Gillies and Lucey, 2006). There is nothing she says here that suggests a role of disability in this experience. Yet in other parts of her interview, Maria hinted at some of the complexity that disability created for her education, describing how she started at a mainstream high school but then "someone recommended me to a special ed school". This past history to her education raises a question about whether her transition out of school might also have been complicated by disability and about whether this may have contextualised a need for her to seek extra advice from her sisters. Similarly to Eric, the juxtaposition of the different parts of her account suggests that disability might have contributed to how and why she sought advice from her sisters.

Eric and Maria's examples highlight that while they do not draw the conclusion themselves, for some siblings with disabilities there is a sense that disability might still contribute to their young adult experiences with their brothers and sisters. Yet even if disability does contribute, it is backgrounded to the extent that the experience becomes entirely centred on only their young adult experiences with their siblings. Like the earlier examples from Fleur and Lucy, this suggests that disability contributes to and contextualises what happens to these siblings with disabilities during young adulthood, but that their brothers and sisters nevertheless are felt to be the more significant influence.

For a small number of siblings with disabilities, it was not possible to even draw these kinds of tentative conclusions about the relational role that disability might have. Instead, for these siblings, disability and their sibling relationship did not appear to feel inter-related at all and thus did not together have a relational role. For example, while each talking separately about their experiences with their brothers or sisters and about their experiences of disability during young adulthood, Danielle, who has a hearing impairment, and Jeremy, who has Cerebral Palsy, each did not draw *any* links between their experiences as siblings and of disability, suggesting that in their experience disability was not perceived to have a relational presence or role. Danielle and Jeremy represent the minority of cases where the inter-relationship of these two experiences completely does not figure in their lives. This highlights that for some siblings with disabilities, disability is not a relational experience.

Taking all of the examples thus far together, this chapter shows that – at the level of their individual experience during young adulthood – siblings with and without disabilities perceive and experience the relational presence and role of disability differently to each other. Many of the siblings without disabilities in the study perceived that the presence of disability in the sibling relationship either created or constituted some of their young adult experiences. In comparison, many siblings with disabilities perceived that it only more marginally or secondarily contributed to their experiences in young adulthood or occasionally did not figure in their experiences at all.

Contrasting these two alternatives shows that disability's relational role is not static or self-contained. That is, disability's relational role is not determined only by the influence of disability itself, but rather it is also subject to positioning and perception of each sibling. When it comes to how a sibling perceives – that is, understands or interprets – the influence of the relational presence of disability on their experiences during young adulthood, it matters whether they are a sibling with a disability or a sibling without a disability to what they perceive and experience. Based on either position, there is a tendency to see the inter-relationship between disability and the sibling relationship (and thus the relational presence and role of disability) as either more or less prominent and significant. Once again, this highlights that siblings' experiences are not reducible to only the role of disability, because their other characteristics also influence how they understand, interpret and experience its role. The impact of positioning and perception is further evident in considering the comparisons that siblings with and without disabilities make between their respective experiences during young adulthood.

9.1.3. Comparisons

Evidence that positioning and perception matters to how siblings with and without disabilities each understand and interpret the relational role of disability is also seen in how they frame comparisons between their respective young adult experiences. While comparing similarities and differences is common among siblings (Edwards et al., 2006), the siblings in the study gave a particular range of insights about how disability figured in the comparisons between them.

Given the prominence of disability's presence in the sibling relationship for siblings without disabilities, it perhaps follows that they mainly focused on disability when comparing their own and their brother or sister's young adult experiences. A few did not focus on disability in this way and instead identified similarities and minimised the influence of disability. For example, Isla felt that while she goes to university and her brother, Oliver, to supported employment, and while she focuses on developing new friendships and he on developing independent living skills, they are still both in a time of "figuring stuff out" in their lives:

We're both in the time of our lives where we're figuring stuff out essentially. And we might be figuring slightly different things out, but it just kind of reminds me that it's a time of change, it's a time of development... it's definitely similar things going on on different scales.

Similarly, Mia felt that for herself adulthood was about having "entire financial responsibility" and for her sister, Cara, "it's actually quite similar" in also taking increased financial responsibility, even though Cara's finances would be managed through trusts and guardianship. In this way, both Isla and Mia perceived commonalities in their own and their brother or sister's experiences.

However, more commonly, siblings without disabilities focused on disability and perceived differences and inequalities between themselves and their brothers and sisters as a result. Sometimes they felt their own experiences were more difficult; for example, Jack said that he expected his last two years of high school to be "stressful", while he felt that those of his sister, Emily, who has Down Syndrome and attended a special education program, had been "pretty chill". However, the comparison led many more siblings without disabilities to focus on the disadvantage they perceived was experienced by their brothers and sisters because of disability. For example, Jess spoke about the ease of her process of learning to drive compared to that of her brother, Craig:

I got my Ls, I got my Ps and went driving. And Craig's been trying to get his license and getting the hand controls for the car, being assessed – it's a huge process for them – and then money just to get the car converted with the hand controls and then there's only a few people that teach hand controls, so you know, sourcing an instructor and things like that – where it was so easy for me to do... It's so much harder for him to just be able to drive, where I probably took that for granted at the time, did my lessons and just went out driving in Dad's car. He can't do that.

Similarly, Ava felt that her sister, Zoe, would not get to experience the same things as "us normal people", such as marriage, children, working, moving out or driving. Mason said that he has "every option that I can possibly want" for the future, whereas his brother, Will, has "not much options". Sarah highlighted that for her

brother, Thomas, “adulthood won’t be an opportunity for learning for him, as it is for me”, because the staff at Day Options where he will go are “not educators, they’re carers”. Rachel compared her experience of getting a job with that of her brother, Harry, saying “he has it harder than what I do”, because “not many people take him on board because of his disability”. In each case, siblings without disabilities make comparisons where disability features prominently and figures as inequality and disadvantage.

However, in contrast, siblings with disabilities more commonly did not perceive disability as an issue in their comparisons or otherwise they normalised disability, set their comparisons in the context of other influences or saw benefits for themselves in the comparison. This perhaps reflects their perception, as demonstrated in the earlier sections of this chapter, of disability having a less prominent relational role. Each of their responses mean that their comparisons also appeared more embedded and subtle within the broader context of the sibling relationship.

Some siblings with disabilities simply did not see disability as an issue in their comparisons. This was the case for Brett, who has a physical and intellectual disability and contributed to the study via a video where a third-party facilitator asked him questions on camera. Brett described how he missed his high school graduation as “I was in the hospital” because “I had a collapsed lung”, also saying that “in the hospital, I had a dance with the nurses” as an alternate celebration. Brett then explained his brother, Dean, and sister, Beth’s, graduations, saying that “[Dean] wore a suit” and Beth wore a dress. Here, the facilitator prompted: “So Dean got to go to his graduation?” Despite the opportunity – and possibly the facilitator’s intention – for Brett to here make the comparison between himself missing and Dean attending graduation, Brett simply responded with “That’s right”. That is, he noted the difference, but did not make a big issue of it, even when prompted.

Others normalised disability in their comparisons. Maria, who has a vision impairment and learning disability, did this by specifically discounting disability when asked how she felt about her younger sisters being married when she, as the

older sister, was not. She did this first by referencing her own preferences and personality:

Interviewer: You mentioned that your [sisters] are both married...
What do you think about getting married?

Maria: I've thought of this and I don't have much patience. I find that being single is that you don't have to listen to anyone, you can go anywhere you want, you don't have much responsibilities... So I've decided that maybe I have a lot of men that are friends, but I haven't thought of getting married.

However, she then specifically followed this up by adding a reference to disability:

I just wanted to say on marriage with people with disabilities – I've got some friends that are in wheelchairs, and [one], he recently got married, so it doesn't matter if you've got a disability, because you still have all the [same] rights as an able-bodied person.

Maria here normalises the difference between herself and her sisters by focusing on preference and personality and specifically discounting disability. Others normalised the comparison in other ways. For example, Craig emphasised birth order:

When it comes to doing life things, like learning to drive and moving out and stuff – I've always known that it takes me longer to do things [than Jess], but I've always been cool with that, like I've never felt like 'Why?' other than the fact that you're older than me – you've always been ahead of me anyway.

Similarly, Zoe normalised the comparison by emphasising that both siblings may simply find different things difficult and by instead focusing on making sure that both are happy:

So you might have a sibling with [a] disability [who] might find these things harder to do, the person without a disability might find other things harder. I suppose coming out with an outcome would be good... like a good outcome, like achieving things and moving forward and being happy in yourself.

In each case, siblings with disabilities embed their differences from their brothers and sisters within normative differences, rather than focusing on disability or inequality. The effect is to also contextualise the differences between them within normative features of the sibling relationship.

Other siblings with disabilities acknowledged or alluded to disability in their comparisons, but, even so, this did not lead to the same perceptions of inequality as their brothers and sisters. Sometimes siblings with disabilities acknowledged disadvantage, but did not focus on feeling too unhappy about it. For example, Fleur admitted that she was jealous of her sister Petra's travels, but also balanced this with being happy for her:

I'm very jealous of my sister because she can go overseas, she can pick up and go 'Yeah, I'm going to take some time off my job and go overseas for six months'. I can't do that. So I'm not jealous of her in some sort of evil sister jealousy thing – I'm happy for her, but I'm also like, 'Oh my goodness, I wish I could do that'.

At other times, siblings with disabilities felt that the discrepancy between their own and their brother or sisters' experiences benefited them. For example, Fleur also commented that the comparison with Petra means that other family members are reminded that they have to "treat me like an equal", that is, treat her as an autonomous young person as they would treat Petra. Other siblings identified how the comparison could reflect well on them. For example, Melanie suggested that disability shows her in a good academic light compared to her brother, Jason:

My brother hates Maths and always 'run[s] away' from doing his Maths homework. I like doing Maths and I am doing things that he runs away from like algebra, trigonometry and number systems. I am disabled and can't use my hands to write and I am still doing Maths.

These examples highlight that positioning and perception matter to how siblings with and without disabilities each view the relational role of disability in the comparisons they make between their respective young adult experiences. For siblings without disabilities who see the relational role of disability with prominence, it appears that it is often hard for them to ignore the inequality and disadvantage

they perceive in their brothers and sisters' experiences compared to their own. Yet for siblings with disabilities who see the relational role of disability less prominently, it is much easier to situate the comparisons and differences between themselves and their brothers and sisters as less of an issue, more normalised or with benefits. Again, this shows that the relational role of disability is not static or self-contained, but rather is subject to the positioning and perception of each sibling.

9.2. Discussion

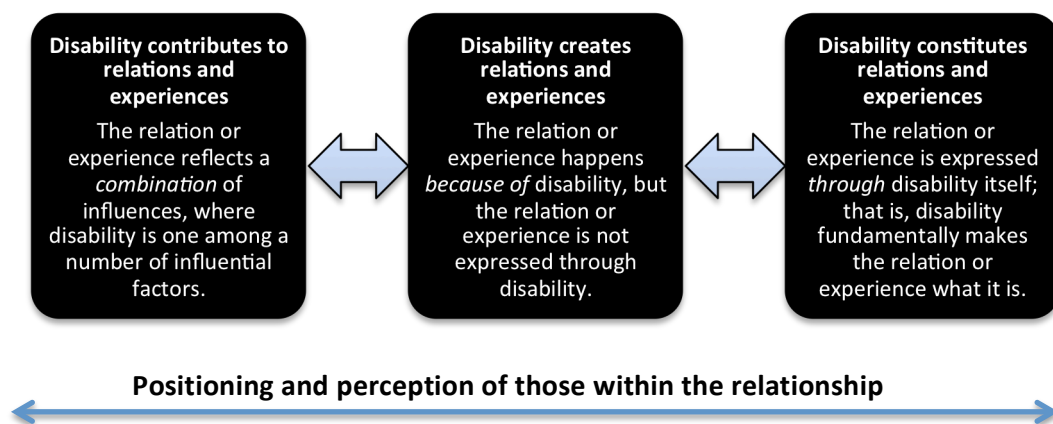
9.2.1. Disability's positioned presence

The previous chapters discussed how disability's presence and roles in the sibling relationship have an everyday and contextualised quality and how disability is influential in constituting, creating and contributing to siblings' relations and relationality. They also discussed how the relations between siblings (for example, the ways they talk and interact around disability-related care) can influence their experience of the relational presence of disability itself. This chapter adds the insight that disability's relational presence and role is also subject to positioning and perception. That is, in perceiving and experiencing the relational presence and roles of disability, it matters whether one is a sibling with or without a disability. Siblings without disabilities perceive – that is, understand or interpret – disability's relational presence as having the capacity to formatively create or constitute some of their individual young adult experiences. However, siblings with disabilities more commonly suggested that the relational presence of disability only contributed to their young adult experiences in ways that were often marginal, secondary or unclear or occasionally perceived that it did not figure in their experiences at all.

This means that disability's relational presence is 'positioned' – that is, the way its presence is experienced depends very much on who perceives it, what their characteristics are and what their relationship is to disability itself. This reflects the acknowledgement in the theoretical framework in Chapter 3 that the positioning of people within a relationship affects their experience of the relationship. Disability's positioned presence also means that disability's role in the sibling relationship is not static or self-contained. Rather, the relational presence of disability can be perceived

as constituting, creating or contributing to siblings' individual experiences depending on who is looking and what they think or see is happening. In this way, this chapter provides a key qualification to the typology of roles of disability developed throughout the thesis, acknowledging that views of disability's presence and role are influenced by the positioning and perceptions of each sibling; this is depicted in Figure 7.

Figure 7: Relational roles of disability for siblings (C)



For siblings themselves, understanding the role of positioning and perception is important for allowing each to understand the other's experience. To some siblings with disabilities, it may seem that their brothers and sisters over-emphasise the influence of disability's presence in the relationship, while siblings without disabilities could feel that their brothers and sisters with disabilities under-emphasise it. Cultivating an understanding of why their experiences are different and of how this depends on their respective positions is then important for fostering relational understanding between siblings themselves.

9.2.2. Positioning and relationality

Further, this chapter highlights that positioning also influenced a final relationality evident in siblings' experiences. Based on their position as either a sibling with a disability or a sibling without a disability, the siblings in this chapter demonstrate a variable felt experience related to the extent to which the sibling relationship feels inherently connected to disability or not.

In the accounts of siblings without disabilities, the influence of disability and of their sibling relationship on their young adult experiences were almost always inherently connected – one did not appear without the other and, further, it was what was emergent in the connection between the two that was influential. Yet, for siblings with disabilities, only some of their young adult experiences of disability involved their siblings and even where disability and the sibling relationship were connected, one was usually emphasised over the other – either disability or the sibling relationship was more prominent and the other marginal, secondary or unclear. The extent to which disability and the sibling relationship *feel* inherently connected or not is then an important relationality that varies by position and perception.

Alongside the unremarkable, intense, liminal and elusive horizontal relationalities already developed earlier in the thesis and shown in Figure 8, this ‘interconnected relationality’ of the extent to which disability and the sibling relationship feel interconnected or not rounds out a picture of some of the ways that disability’s relational presence may influence the overall felt experience of the sibling relationship.

Figure 8: Relationalities of disability for siblings (iii)



Once again, for siblings with and without disabilities themselves, each understanding that the other may have a different perception to him or herself of the level of connection of the sibling relationship to disability is important for fostering relational understanding. Where each sibling may have a different felt experience here to the other, better articulating what their experiences are and how they differ by position is important for allowing siblings to think about and appreciate the relationality experienced by their brother or sister.

9.2.3. Siblings, disability and young adulthood

Beyond disability's positioned presence and siblings' relationalities, this chapter also demonstrates that understanding the inter-relationship of experiences as siblings, of

disability and of young adulthood is complex. Yet irrespective of the extent to which the three experiences are inter-related or not, this chapter highlights a number of important points about how both disability and sibling relationships are separate significant influences on both siblings' experiences of young adulthood.

Firstly, the chapter shows that siblings both with and without disabilities identify the influence of their brothers and sisters on the changes, transitions and other experiences they have as they progress through school, move into work, make steps towards independence and formulate more of their social consciousness, identity and worldviews (Settersson and Ray, 2010, Lowe et al., 2013, Arnett, 2000, Worth, 2009). As the literature has often highlighted young adulthood as a time when young people begin to move away from family (Aquilino, 2006) and develop stronger relationships with friends, peers and partners (Collins and van Dulmen, 2006, Conger and Little, 2010), understanding the continued influence that siblings have during young adulthood is important for seeing that even as young people may normatively move away from family, their sibling relationships may still remain a formative influence on their young adult lives.

Secondly, the chapter shows that siblings with and without disabilities both find that disability itself is a significant influence on their lives during young adulthood, even though they experience its inter-relationship with the sibling relationship differently to each other. Both siblings identify ways that disability influences their changes, transitions and other young adult experiences. The literature has rarely recognised that disability is an influential factor in *both* siblings' lives, only identifying this as a by-product of work that acknowledges that disability may be a 'risk factor' for both young people with disabilities and 'young carers' (Hudson, 2006, Stewart et al., 2010, Smyth et al., 2011, Hamilton and Adamson, 2013). As such, it is important that the accounts here show that beyond being a risk factor, disability is also a formative individual and relational influence within the young adult lives of siblings *both* with and without disabilities – not necessarily implying risk, but rather just being a basis for experience, thought and change for both siblings. This means that even while their experiences are different to each other, both siblings nevertheless share an essential commonality in experiencing disability while making young adult changes

and transitions, especially when compared to peers who do not have disability in their lives at all.

Finally then, this view from the lens of young adulthood highlights that the extent to which siblings' experiences of sibling relationships and of disability are inter-related or not during young adulthood is only one part of their broader experience as siblings, of disability and of this life-stage. Whilst important for the argument mounted in this thesis, the inter-relationship of these three experiences is only one component of how each of the three manifest in siblings' lives. It is just as significant that each of these three experiences are separately evident for siblings. Mapping the extent to which these experiences are inter-related is then significant for understanding siblings' relational experiences of disability during young adulthood, yet it is important not to forget that each experience is also important in its own right too.

Chapter 10. Discussion

The aims of this study were to develop a relational perspective on disability for young adult siblings with and without disabilities, as well as connect scholarship from disability studies and youth studies with that about siblings and disability; expand the theoretical approaches used in research about siblings and disability; and contribute to methodological development in how to do research that includes both siblings. In following these aims, the central research question asked what the everyday relational experience of disability is for young adult siblings with and without disabilities and how that reflects the inter-relationship of their experiences as siblings, of disability and of young adulthood.

The previous chapters examined two streams of findings that addressed this research question. Firstly, some roles of disability in the sibling relationship were identified and exemplified, highlighting how disability might constitute, create or contribute to some of siblings' everyday relations with each other and overall relationality (see Figure 7 in Chapter 9). These roles of disability are everyday, contextualised by social and temporal factors, sometimes influenced by the ways siblings talk and interact (for example, about disability-related care) and subject to the positioning and perception of each sibling. Secondly, a set of relationalities was also identified – overall felt experiences of disability's presence in the sibling relationship. Disability's presence in the relationship could feel unremarkable, intense, liminal, could feel like a challenge to horizontal power relations or could feel like it had a variable level of connection between disability and the sibling relationship (see Figure 8 in Chapter 9). These relationalities reflect meta-level relational experiences that are emergent from more than the sum of the relationship's parts.

In drawing these two streams of findings together, a number of key insights can be detailed that further answer the aims and research questions of the study. These insights firstly develop a relational perspective on disability for young adult siblings,

detailing how disability is relationally formative for siblings, but not in isolation. The insights also contribute to theory, scholarship and methodology in sibling-disability research, through exemplifying the relevance of the concept of relationality, the importance of scholarship on life-stage and generation for siblings and the criticality of recognising the two-way nature of sibling relationships for the methodologies of sibling-disability research. Together these insights develop a set of contributions to sibling-disability research that reflect the inter-relationship between experiences as siblings, of disability and of young adulthood, fill gaps in the existing literature and are different to the majority existing research. The end of this chapter applies these new insights to discuss how to further extend relational knowledge, evidence, policy and practice about siblings and disability.

10.1. Relational insights and contributions

10.1.1. Disability's role is relationally formative, but not in isolation

Most centrally, this thesis has found that disability is a formative presence and influence within the sibling relationship, but that disability is simultaneously also subject to the specificity of the relationship being enacted and to the conditions and context of the relationship. That is, disability is relationally formative for siblings, but not in isolation and not in a way where siblings' everyday relations or relationality can be reduced to *only* the influence of disability. This insight develops a key relational perspective on disability for young adult siblings with and without disabilities.

Disability may have a number of formative roles in sibling relationships – roles that express different strengths of influence. As it is embodied and enacted in their everyday relations, disability may form siblings' relations (constitute; strongest role), be causative of why some relations happen (create; middle role) or may contribute to their relations along with other influences (contribute; weakest role). Thus, whilst in each case being relationally formative, disability's influence does not always manifest in the same way or with the same strength in the relationship. Nevertheless, in each case, disability has a role in forming and informing what happens within the relationship and what is enacted between siblings.

Each of these roles of disability are not isolated or reducible to only disability. That is, there are a number of other factors that are also formative alongside or in interaction with disability. This means that disability's formative role must always be qualified with acknowledgement that disability is also relationally *influenced* even as it also *influences* sibling relationships. This is seen when acknowledging three important factors that mediate the influence of disability on sibling relationships.

Firstly, disability's relational presence and role reflects normative sibling relations. Even as disability forms some of siblings' everyday relations or forms their relationality, what happens between siblings very often still reflects moments of enjoyment, argument, assistance and everyday talk and activities that are normative between many siblings irrespective of disability, only occasionally threatening to push them out of normative relations (for example, when it creates unique relations or pushes them too far out of normative horizontality). This means that even as disability is formative within the relationship, it becomes present in and informs the behaviour, interactions, perceptions and emotions that are characteristic among many siblings anyway. In this sense, whilst formative, disability is nevertheless largely bounded to forming and informing normative sibling relations by virtue of its presence within a sibling relationship.

Secondly, the relational presence and role of disability is not divorced from social and temporal context. The more personal physical, cognitive and emotional elements of disability certainly have a role in forming and informing the sibling relationship, but the social and temporal context of disability is equally as formative in siblings' relations and relationality. This multi-faceted and contextualised role of disability means that, for example, ecological (e.g. family context, policy, services), intersectional (e.g. cultural background) and temporal (e.g. young adult experiences of life-stage and generation) influences are also relationally formative for siblings and mediate how disability's formative presence and influence appears within the sibling relationship.

Finally, disability's relational presence and role is not uni-directional, static or self-contained. While disability has a clear role in forming and informing sibling relations, disability's presence in the sibling relationship is also influenced *by* those relations,

as in the examples where siblings talked and interacted in ways that resisted disability-related care. Further, an individual sibling's views and understandings of disability's relational presence and role are subject to positioning and perception, with one's position, views and experiences as either a sibling with or without a disability influencing how disability's relational presence is understood and interpreted and the extent to which it is a focus of their experience. This means that even whilst disability is formative, siblings' relations and experiences are not reducible to *only* the effect of disability, because the other personal and relational characteristics are also influential.

Overall, disability's formative but not isolated presence and role in the sibling relationship highlights that – as noted in the theoretical framework in Chapter 3 – disability, sibling relationships and context all inter-relate; all influence and, to some extent, become part of each other. Disability informs the enactment of relationships, relationships inform one's understanding of the role of disability and context circumscribes all of this, becoming embedded in siblings' relational experiences of disability. In this way, this thesis argues for acknowledging the formative relational roles of disability, whilst also seeing that these roles exist bi-directionally: disability inscribes *but is also subject to* the specific relationship being enacted – the sibling relationship.

Further, disability's relational presence and roles are nuanced and often intangible. At different times, in different situations and with different positions, siblings with and without disabilities may (choose to) notice or read disability into the relationship or not. Understanding this intangibility and the potential to focus on disability or not is central to seeing that disability is a significant presence in and inflection to the sibling relationship, but one that is variously seen or foregrounded.

This acknowledgement of disability's relational presence and role is important for developing the relational perspective on disability that was an aim of this study and for addressing gaps in sibling-disability research, as identified in Chapter 2. There is a need to expand beyond psycho-emotional studies of siblings without disabilities to learn more about how disability figures in both siblings' enactment of their shared relationship. Understanding the relational presence and roles of disability, as

described by both siblings, and the conditions that mediate these roles begins to develop this more experiential, relational approach, thereby offering a key perspective for and contribution to widening the scope of knowledge about siblings and disability. The findings and argument here highlight that there is a whole level of relational experience that has not been a focus of previous sibling-disability research.

10.1.2. Relationality is important for expressing relational depth

This thesis has also demonstrated the importance of the concept of relationality, which is a key contribution to expanding the theoretical approaches used in research about siblings and disability. Chapter 3 mapped references to relationality in a wide scope of previous works and came to a working definition of the concept as the overall felt experience of a relationship, as it is contextualised through care, positioning and conditions/context. The later chapters then applied this definition empirically with data from siblings, coming to a set of relationalities that the participants experienced. This conceptual and empirical work demonstrates the importance of relationality for a number of reasons.

Firstly, the concept of relationality is important for offering a way to express the relational depth of siblings' experiences. Rather than describing only the presence and role of disability in forming separate or discrete relations between siblings (e.g. disability figuring in one instance of talk or activity between them), the concept of relationality importantly reflects a deeper and more abstract level of emergent relational experience. Thus, using the concept of relationality prevents the fragmentation of the relationship into separate relations and accounts for a deeper understanding of the felt experience of disability within the relationship. Conceptually, relationality is then an important new theoretical approach for understanding the depth of siblings' more complex relational experiences that are harder to articulate.

Secondly, the particular relationalities identified in this work are important for showing the depth and complexity of what disability may feel like specifically within sibling relationships. The analysis demonstrated ways that the presence of disability within the sibling relationship could vary between feeling more or less intense, thus

either unremarkable or intense; more or less liminal; could feel like a challenge to horizontal power relations; or could feel like disability had more or less of an inherent connection to the sibling relationship (see Figure 8 in Chapter 9). Each of these relationalities capture an overall sense of what being a sibling is about and then of the role of disability in influencing the felt experience of being a sibling. As each of these relationalities express a possible variety of experience, they also show how siblings' experiences exist on a continuum where disability may feel like it has more or less of an overall presence in the relationship and where siblings may feel like the relationship is functioning more or less as they perceive it should. It suggests that where siblings are struggling with the relational presence of disability, this may be because their overall felt experience tends towards the more challenging end of the continuum on some or all of the relationalities identified.

Further, the identification of these relationalities above as a *set* is important for giving a way to empirically come to relational depth. The identification of the set is a new empirical application of the concept of relationality that has not featured in any previous work. This new manner of identifying a set of relationalities offers a way to conceptualise a series of overall felt experiences to the relationship that may happen along various continuums, sometimes separately and sometimes in combination with each other. The set thus allows a way to explore and describe a complexity of felt experiences either happening at once or happening for siblings in different situations or with different relational circumstances.

The set of relationalities identified in this work thus gives a deeper sense of siblings' relational experiences of disability and with each other and of what is emergent within disability's relational presence. Representing this deeper and emergent experience makes an important theoretical contribution in giving a concept and vocabulary for articulating more of the complex and subtle ways that disability influences sibling relationships. The depth that relationality expresses is also important for beginning to address a further gap identified by the literature review in Chapter 2, that is, identifying how disability figures in the overall experience of sibling relationships. Relationality is thus an important concept both for siblings

themselves and for the practice of research and theory in developing further knowledge about siblings.

10.1.3. Life-stage and generation are central to relational experience

In connecting scholarship from disability studies and youth studies with that about siblings and disability, the thesis has also shown that life-stage and generation are central in understanding young adult siblings' relational experiences of disability and with each other. While social and temporal context was already acknowledged as one of the key mediators of disability's formative influence on the sibling relationship, it is worth specifically drawing out a number of points that highlight the particular centrality of young adulthood and young adult siblings' contemporary generation to their relational experiences of disability.

Firstly, life-stage is significant to relational experiences as the findings in this study suggest that siblings have experiences as young people that may not continue into their later lives. Chapter 8 highlighted that young adulthood is a time when the sibling relationship is relatively unencumbered by care, allowing siblings to feel like siblings and, to the degree possible, to maintain the horizontal relationality normative to brothers and sisters. As this experience may shift into a more vertical care relationship later in life, life-stage is then a central factor influencing what relations and relationalities are possible between siblings at different stages of the life course. This insight indicates the need to acknowledge siblings' experiences as temporally-specific and the importance of not treating siblings as a homogenous group unaffected by time.

Secondly, life-stage is important because young adulthood is a time of change and transition, not only at an individual level, but also at a relational level. Chapter 7 demonstrated that the new resources, services and life experiences often obtained during young adulthood can also affect change in the sibling relationship. Chapter 9 showed how the presence of disability in the sibling relationship could (more or less prominently) influence the changes and transitions that each sibling experienced individually, which in turn influenced how they thought about the sibling

relationship. In this sense, the changes and transitions of this life-stage have significant implications for how the sibling relationship is experienced.

Thirdly, generational influences were also significant for some of the young adult siblings in this study. Chapter 7 demonstrated that the policies, service models and technologies related to disability in contemporary society all had a significant influence on how some siblings in the study enact their relationships, including on how disability figured in their everyday relations with each other. In this sense, the generation that siblings belong to matters to their relational experiences of disability. This again speaks to the importance of avoiding the homogenisation of siblings, in this case across generations.

Finally, generation is also important because the whole premise of siblings with and without disabilities sharing everyday relations in which disability might figure is a recent phenomenon. The young adult siblings in this study are one of the first generations to live completely without a history of institutionalisation in their lifetimes, thus enabling them to share everyday talk, activities, arguments or other moments together. For many siblings who were young adults in earlier decades, these everyday relations would not have happened, because the sibling with the disability would have been institutionalised and so the pair would not have shared their day-to-day lives. In this sense, the argument of this thesis is a contemporary phenomenon.

Overall, the insight that life-stage and generation are so central to siblings' relational experiences of disability is important for connecting scholarship on siblings, disability and young people and for addressing a gap identified by the literature review in Chapter 2 with regard to siblings' experiences of young adulthood. Based on the existing literature, there is a need for greater exploration of how the young adult experiences of both siblings interact with their sibling relationships, including how their relational experiences might be specific to their life-stage. The findings here explore these areas, identifying how both life-stage and generation have a central role in creating a context for how disability is experienced by young adult siblings.

10.1.4. Methodological implications of two-way sibling relationships

Finally, the thesis has operated from the perspective that sibling relationships are inherently a two-way phenomenon: that is, the relationship always includes both the sibling without the disability *and* the sibling with the disability. Whilst this might seem self-evident, it is not. Given the history of sibling-disability research so rarely including the perspectives of siblings with disabilities and so often looking at disability from only a psycho-emotional or caregiving perspective, acknowledgement of the co-production of the relationship between both siblings and of both siblings' perspectives is rare.

In including both siblings together, the work here argues for a new relational conception that acknowledges that it is not possible to study the enacted, co-produced sibling relationship without including siblings both with and without disabilities. This forms a key contribution to methodological development in how to do research that includes both siblings. The insights about siblings' joint relational experiences and about their comparative individual experiences – each so fundamental to the relational analysis featured here – would not have been possible without both siblings' perspectives. In this sense, depiction of the sibling relationship inherently implies and relies on the accounts of both siblings. It may not always be both siblings in a *specific pair* contributing together, but it is important to include *some* participants from each group overall.

This acknowledgement of the two-way nature of sibling relationships has important implications for the methodological development of sibling-disability research. If it is not possible to study the enacted sibling relationship without both siblings, then there is a necessity to develop the methodologies of sibling-disability research to be better able to accommodate the sibling relationship as well as accommodate the accessibility requirements of some siblings with disabilities, so that they can have strong voices in research alongside their brothers and sisters without disabilities.

The accessible and relationally informed approach of this study, explained in Chapter 4, begins to develop the necessary methods. Particular developments included providing choice to siblings about whether to participate together,

separately or alone; offering the supports in the ‘accessibility toolbox’ for participants with intellectual disabilities or complex communication needs; and searching for ways to manage the power relations of communication to acknowledge the risk of siblings without disabilities speaking over or for those with disabilities, yet also acknowledge the subtleties of differential communication within the sibling relationship itself. Other areas are yet to be developed and refined. For example, as outlined in Chapter 4, questions remain as to how to do research that is ethical, thorough and that respects and represents the perspectives of both siblings where complex issues of disclosure are at play.

In arguing that there is a need to develop knowledge about the level of relational experience that this thesis newly draws attention to, this work thus simultaneously makes an argument for the importance of continuing to develop the methodologies of sibling-disability research to better accommodate the sibling relationship and better cater to the accessibility considerations that have featured in other areas of disability studies. This is not only a methodological and ethical imperative, but, as demonstrated here, it is critical to the knowledge that can be produced in sibling-disability research. Without developing these methodologies, research about siblings and disability will not develop a deeper understanding of the relational experiences of both siblings, which is vital for knowing more about the sibling relationship itself.

Together these four relational insights – about disability’s formative but not isolated relational role, the importance of relationality, the centrality of temporal context and the methodological significance of recognising sibling relationships as two-way – detail the overall findings of the study that answer to its aims and research questions. Together these insights extend scholarship, theory and methodology with regard to siblings with and without disabilities, particularly identifying a relational perspective on disability for siblings with attention to the inter-relationship between their experiences as siblings, of disability and of young adulthood. Overall, this extends sibling-disability research and knowledge about siblings and disability.

10.2. Relational evidence, policy and practice for siblings

As highlighted above, this work has built new knowledge about siblings and disability. However, there remains a question about how and where this knowledge can be applied. What are its implications for policy, service provision, families and siblings? What might it mean for how siblings are thought about in policy and practice? What can be taken from it for understanding what policy and practice can do for siblings? These questions are important as the research questions for the study also asked about the implications of recognising a relational perspective on disability for siblings.

The following sections thus explore the implications of the insights and contributions outlined above for the evidence base around the issue of siblings and disability used to inform policy and practice. As explained below, based on the findings of the thesis, there is a case for diversifying how sibling-disability issues are understood and acted on.

10.2.1. Assessing the existing evidence base

One way of using the knowledge generated by research is to apply it as an evidence base for policy and practice. Here, research – or evidence – is used to mount a case to take action upon issues or problems (Bacchi, 2009, 2012). Evidence may contribute to how a problem is represented, to what the problem is conceived to be, to how resolutions are sought and to the framing with which different parties act on issues. In treating research as evidence in this way, there is opportunity to understand how the relational perspective developed in this thesis can question and make a case for diversifying the existing evidence base for policy and practice around the issue of siblings and disability.

Firstly, the relational perspective developed here questions the dominance of medicalised evidence about siblings and disability. In writing of the process of using evidence, van Toorn and Dowse (2015:6) explain that “if mobilised effectively, evidence allows a particular problem representation to take shape and assume dominance over contending representations”. With regard to siblings and disability,

the research that has been mobilised most effectively and thus the dominant representation of the 'problem' to be addressed both reflect a focus on the prevention of psycho-emotional problems among siblings without disabilities. The long-term emphasis on researching psycho-emotional risks to siblings without disabilities, discussed in Chapter 2, has led to an evidence base – and also, relatedly, support models (Strohm and Nesa, 2005, Strobel, 2011, McCartney, 2008), evaluations (Evans et al., 2001, D'Arcy et al., 2005, Giallo and Gavidia-Payne, 2008, Roberts et al., 2015) and recommendations for policy (RANZCP, 2011) – variously premised on therapeutic principles for improving emotional and behavioural functioning, psychometric testing and/or based on mitigating the risks of disability leading to mental health problems for siblings without disabilities. This focus reflects the frequent dominance of formal, often medical, research in framing human policy issues (Glasby et al., 2007).

While protecting psycho-emotional wellbeing is indeed very important, it may not however be all that policy and practice can do for siblings. The relational perspective developed here prompts a question about diversifying the medicalised evidence base. Is it possible that the psycho-emotional framing has taken shape and assumed such dominance because, due to the long history of psycho-emotional studies, this is the only evidence that has been mobilised effectively? How might an understanding of what policy and practice can do for siblings expand if the evidence base were to diversify? In critiquing the dominance of overly-medicalised evidence, Glasby et al (2007:325) propose the idea of “knowledge-based practice” as an alternative, which includes the lived experience of the people to which policy and practice refer. Glasby et al's (2007) alternative of knowledge and lived experience better reflects the relational and phenomenological account included in this study and thus poses a question about how extending this kind of experiential evidence might prompt an expansion of what policy and practice can do for siblings.

Secondly, in beginning to provide some experiential evidence, the experiences of the siblings in this study also suggest that the other common way that young adult siblings are seen in policy and practice in Australia – as 'young carers' – may be problematic from the perspective of lived experience. The challenge lies with what van Toorn and

Dowse (2015:12) call a 'frame conflict' – where different parties have different framings of the problem they think needs to be addressed. On the one hand, while acknowledging that they may not see themselves as 'carers', government (Commonwealth of Australia, 2009, Australian Government, 2011a, 2011b) and much social policy research (Moore and McArthur, 2007, Cass et al., 2009, Smyth et al., 2011, Hamilton and Adamson, 2013) either frames young adult siblings without disabilities as 'young carers' or clusters them together with 'young carers' in policy, thereby assigning the issue of siblings and disability to carer policies. While inclusion in carer policies and services may be important for some adult siblings who take up extensive roles in care or for those siblings who identify as 'carers', the young adult siblings in this study show that, for them, in a younger life-stage, they did not commonly identify as 'carers' and, furthermore, this label has the potential to damage the extent to which they can feel like siblings. From the experiential perspective above (Glasby et al., 2007), there is then a 'frame conflict'.

In such 'frame conflicts', van Toorn and Dowse (2015:12) highlight that the role of evidence is "to help construct a common 'frame' through which meaning is applied and resolution sought" (van Toorn and Dowse, 2015:12). In an experiential or "knowledge-based" approach to siblings (Glasby et al., 2007:325), this would mean using evidence to come to a policy 'frame' that goes beyond young adult siblings with and without disabilities as 'young carers' and care recipients and that reflects the experiences expressed by siblings both with and without disabilities themselves. This implies the need for new experiential evidence to inform the ways that policy and practice can conceptualise siblings and address supports that are grounded in their own perspectives. Again, this means that the evidence base around siblings and disability must diversify.

By identifying a new relational perspective, this thesis begins to provide some of the experiential evidence that is needed. That is, it provides evidence about the experience of the sibling relationship itself, which can lead to an understanding of what policy and practice can do for siblings from a relational perspective. As detailed in the sections below, the evidence drawn from the work here can assist in conceptualising a relational 'frame' that better reflects siblings' own experiences, yet there is still further work to be done to fill out the 'frame' and operationalise it for policy and practice.

10.2.2. Advancing evidence towards relationality as a policy 'frame'

The work in this thesis suggests that there is potential to treat relationality as an experiential 'frame' for understanding the issue of siblings and disability. That is, a 'problem' to be addressed in policy and practice could be how to keep siblings feeling like siblings in the presence of disability or, stated another way, how to keep sibling relationships feeling natural in disability's presence. The findings from this study show that disability can sometimes risk leading to a relationality of elusive or challenged horizontality to the extent that some siblings feel like they are in a parent, carer or manager role rather than a sibling relationship. For others, it may create a liminal relationality where they are unsure how disability fits into their relationship as siblings. These relationalities suggest that some siblings with and without disabilities may benefit from being set within systems that actively support them to feel like siblings or that support them to understand and/or accept the more unique elements of their relationships. In this sense, a 'frame' of protecting siblings' relationality gives an important additional way to conceptualise the purpose of work with regard to sibling-disability issues.

There are several benefits of treating relationality as a 'frame' for siblings. Firstly, it expands away from a deficit focus towards a positive goal – that is, rather than preventing psycho-emotional problems, it has the positive goal of keeping sibling relationships feeling natural and appropriate. Secondly, the 'frame' of relationality could encompass some existing policy and practice issues, but in a way premised on protecting sibling relationships. For example, using relationality as a 'frame' moves away from treating siblings without disabilities as 'young carers' – which both siblings say feels inappropriate – but would still address the provision of care as one of the key issues that need to be dealt with in order to support siblings to feel like siblings. Finally, relationality could potentially be addressed through many existing areas of policy and practice, making it flexible for practical application. Planning ways to keep relationships feeling natural could potentially be overlaid into many existing service planning practices, for example, as a component of what people with disabilities think about as they self-direct their supports, as a rationale for providing flexible care or as an objective of the education provided to families of

people with disabilities. In this sense, a 'frame' of relationality is beneficial for mainly encompassing a re-framing of the thinking required for using services and supports that already exist. This is important in that it does not necessarily require new resources in a policy area that already has limited capacity.

One challenge of using relationality as a 'frame' for siblings is that relationships often fall on the personal side of a public-private divide and, thus, are not always seen as a legitimate domain of policy. Relationships are instead usually seen as a private matter. Yet, in principle, a focus on keeping relationships feeling natural in the presence of disability is not inconsistent with some current policy focuses. For example, the United Nations Convention on the Rights of Persons with Disabilities acknowledges that "the family is the natural and fundamental group unit of society and is entitled to protection" (UNCRPD, section x), implying a need to protect family relationships in the context of disability. Models of relational service practice (Furlong, 2013) and relational rights applications (Muir and Goldblatt, 2011) are also beginning to feature in some discussions of disability and other human service policies, as is systems thinking which acknowledges the relational context in which people with disabilities live (Muir et al., 2014). Further, there has also been greater recognition of the need for disability policies for families outside the 'carer' framework (Fyffe et al., 2015). In this sense, the foundation for using relationality as a policy 'frame' for siblings exists – there is just a need to extend in the relational thinking to achieve it.

Internationally, extending in the relational thinking needed to use relationality as a 'frame' for siblings requires addressing the way in which many contemporary concepts of disability support focus on an individualistic rather than relational framing. Across the service systems of many developed nations, including Australia, the United States, Canada, the United Kingdom and some European Union nations, there has been a movement towards and, in some cases, a fundamental restructuring of disability support to foster personal choice, control, autonomy, self-direction and person-centredness for people with disabilities through programs of personalisation, individualised funding, direct funding or personal budgets (Foster et al., 2012, NDIS Rules, 2013, Purcal et al., 2014, Power et al., 2013, Pearson et al.,

2005, Sims and Cabrita Gulyurtlu, 2014, Hutchison et al., 2006, Wehmeyer and Abery, 2013, Stainton et al., 2013, European Platform for Rehabilitation, 2013). This movement has been very beneficial for people with disabilities, allowing greater flexibility and individuality within daily life. Yet it is also an approach which foregrounds a range of concepts (such as personal choice, control and autonomy) that have been critiqued as “antagonistic to the workings of secure, equitable relationships” (Furlong, 2013:95), as all relationships require “a degree of surrender” (Furlong, 2013:95) and “operations of inter-dependency” (Furlong, 2013:95) which are challenging to advocates of personal choice and control. In this sense, a relational ‘frame’ may seem at odds with what appears as an individualistic tone to contemporary notions of disability support.

However, it is possible to overlay a deeper relational understanding to these concepts that, at the surface level, appear to be individualistic. For example, autonomy is usually seen as an individual attribute associated with self-sufficiency and rational independence. Yet in a re-conceptualisation as ‘relational autonomy’, autonomy can be seen as enacted within a system of relationships, where different people’s wants and needs are enmeshed together and where, ideally, people act with a shared concern for everyone involved (Mackenzie and Stoljar, 2000). While idealistic, this re-framing nevertheless suggests that a ‘frame’ of relationality can dovetail with, and add nuance to, the existing concepts of contemporary disability support, but only where relational conceptualisations are specifically foregrounded. Overall, this highlights that in order to use a ‘frame’ of relationality for siblings within contemporary disability policy and service provision, there is a need to specifically consider how existing concepts, frames of thinking and service models, policies and practices can accommodate a relational perspective.

The new evidence provided in this thesis suggests the pertinence of relationality as a new ‘frame’ for siblings, but re-considering all of the issues, concepts, thinking and service models, policies and practices in the ways needed to operationalise the ‘frame’ is beyond its scope. Further, this thesis has explored relationality for one group of young adult siblings, but there are other siblings, beyond those in the sample, whose experiences must also be accounted for in a relational policy ‘frame’.

The work here thus begins a larger project of diversifying what policy and practice can do for siblings, but there is further research to be done and more evidence to be built. Some options for how to progress future research are outlined in the section below.

10.2.3. Thesis limitations, scope and areas for future research

In order to operationalise relationality as a policy 'frame', there is a need for future research to extend the relational evidence base begun in this work. While this study gives a robust account of the relational experiences of a group of young adult siblings with and without disabilities, there are nevertheless a number of limitations to the work presented here and a number of areas that were outside the scope of this research, but which could be usefully addressed by future studies.

Firstly, there is a need to extend the demographic coverage of the relational perspective. As participants self-selected to take part in this study, some demographic characteristics were not as well-represented as others. Although purposive sampling was used, the number of participants who experienced socio-economic disadvantage, cultural or linguistic diversity, very conflictual relationships, extensive psycho-emotional difficulty and challenging behaviour was small. The under-representation of these groups is a limitation of this study. As these are characteristics that are likely to affect the enactment of sibling relationships and several of these groups have been identified as hard-to-reach populations for research (Brackertz, 2007), there is a specific need to know more about their experiences in order to extend the relational evidence base to those who experience challenging circumstances. This is an understanding that could be developed through future research.

Secondly, the intersectional focuses that were a less developed component of the theoretical framework and analysis in this work require a more substantive and central exploration. Due to the sample limitations in cultural and socio-economic diversity, this substantive exploration did not feature in the analysis, although was the subject of one case example in Chapter 7. This is a limitation of the study. Future research could more thoroughly explore an intersectional relational approach, which,

through a focus on disability and relationality's intersection with gender, class, age, sexuality and/or culture, could detail how these characteristics influence siblings' relational experiences. This substantive intersectional approach is important for building the relational evidence base about siblings in ways that can further consider complexity and further deepen the understanding of how disability is not isolated from social context.

Thirdly, the analysis was focused on the enacted relationship between a sibling pair and thus it was beyond scope to give a thorough analysis of the location of the sibling relationship within a broader family context or within specific sibling constellations. For example, it was not within scope to determine how the total number or quality of relationships between all siblings in the family influences the relationship between each pair; how each sibling's relationship with their parents influences their sibling relationships; how different family structures influence siblings; or how some siblings without disabilities engage in disability-related care to help their parents. Additionally, siblings' constellations – birth order, age spacing, gender pairings and family size – were implicit in the analysis, rather than foregrounded. These family systems and constellational approaches are however key overlays to a relational perspective for siblings (Minuchin, 1974, Toman, 1994 [1961], Sanders, 2004) and should be incorporated in future research. They are included in the theoretical framework in Chapter 3 to show how they fit into the model developed here, but there is a need to further understand their influence.

Fourthly, this study was about young adulthood and other life-stages were outside its scope. To extend the appreciation of the centrality of temporal context to relational experience, future research should extend knowledge about the experiences of siblings in other life-stages. In particular, Chapter 8 showed that young adult siblings attempt to keep to “less serious” care that is not challenging to their horizontal power relations. However, in later life siblings without disabilities commonly take over the main role in care from ageing parents (Dew et al., 2004, Kramer, 2009, Heller and Kramer, 2009). There is then a need to understand more about the implications of this shift in care role. Longitudinal research that explores siblings' relationality before, during and after the transition of care is important for

giving capacity to understand relationality over time, in different care contexts and at different life-stages. In addition, there is a role for future research to develop further knowledge about the relational experiences and relationalities of older generations of siblings who may have been separated by institutionalisation or experienced other past social attitudes and policies towards disability. This is an area that has so far only been addressed in a minority of studies (Dew, 2010, Dew et al., 2011) or anecdotally (Meyer, 2009), yet this historical-intergenerational work is important for understanding more about the temporal and generational context of sibling relationships.

An additional key task for future research is to develop further knowledge about how to apply relationality. As outlined earlier, this includes work to conceptualise how relationality works with the individualistically-leaning concepts of choice, control, self-direction, autonomy and person-centredness (Furlong, 2013, Mackenzie and Stoljar, 2000), which have currency in many countries' contemporary restructuring of disability support. However, it would also include work about how to conceptualise, design, implement and evaluate applications of relational principles in policy, services and supports for siblings both with and without disabilities. The discussion above suggested that relationality could be overlaid into existing services and service planning practices. Future research is however needed to understand which services or planning it might be overlaid into, how this might happen and how it might relate to other policy and service developments. For example, in Australia, research could be undertaken into the place of relationality within current service restructuring under the National Disability Insurance Scheme and the role that relationality might play as people with disabilities plan under the Scheme for their engagement in social, economic and community life.

In applying relationality, it will also be important to understand its relationship to existing models of 'sibling support'. Internationally, sibling support is currently focused on siblings without disabilities and offers individual-level supports such as psycho-emotional support, peer support, respite and assistance with advocacy, while also offering education for parents and service providers about the experiences of siblings without disabilities (Meyer and Vadasy, 1994, Strohm and

Nesa, 2005, Caplan, 2011, Welch et al., 2012, Sibling Leadership Network, 2013). Understanding what the 'frame' of relationality – which includes siblings both with and without disabilities and focuses on relational (rather than individual) experience – brings to these existing models will be important for conceptualising how 'sibling support' can cohesively include different individual- and relational-level components.

In this way, this study provides a first step. The findings demonstrate that disability is an everyday, formative – but not isolated – relational experience for both siblings during young adulthood, but that there are also elements within its relational presence that mean that siblings' experience as siblings must be protected. Understanding how to protect siblings' relationality, including for a much broader range of siblings than were included in this study, is a task begun in this work, but that can and should continue to be developed through future research that premises a relational perspective.

Chapter 11. Conclusion

The relational perspective developed in this thesis has progressed knowledge about siblings with and without disabilities' relational experiences of disability during young adulthood. It has extended the literature by showing that disability is an everyday, formative – but not isolated – relational experience for both siblings. Further, this work has, for the first time, focused on both the enactment and overall emergent experience of disability within the sibling relationship, in the process developing a typology of roles that disability may play in forming and informing sibling relationships (see Figure 7 in Chapter 9) and articulating a set of relationalities that siblings may experience (see Figure 8 in Chapter 9). Together, the detailing of the enactment and overall experience of disability in the sibling relationship offers a key approach for understanding how disability is experienced in everyday life. Finally, the thesis has demonstrated that the everyday relational experience of disability is, for the group of young adult siblings in this study, also contextualised by normative sibling relations, social and temporal context and by positioning and perception. Thus it importantly shows that disability's relational influence is a contextualised phenomenon. Together these findings articulate a level of relational experience that has not been described in previous sibling-disability research. This is important for extending knowledge, but also for furthering the depth, concepts and vocabulary with which siblings with and without disabilities' more complex and intangible experiences together can be understood.

Further, the relational perspective developed here is significant because it has been drawn from the perspectives of siblings *both* with and without disabilities. This is important in a field that has usually been based on siblings without disabilities' perspectives only. This study has extended the small literature base on both siblings' perspectives. In the process of doing so, it has progressed the accessible and relationally informed methodologies needed to include both siblings and has been

able to explore a level of shared experience between both siblings that has rarely featured in previous sibling-disability research.

When applied, this new level of relational experience also contributes to diversifying understandings about what research, evidence, policy and practice can do for siblings with and without disabilities. Understanding that, through a relational perspective, evidence, policy and practice should focus on protecting siblings' relationality – that is, keeping them feeling like siblings even when disability risks pushing them into other felt experiences – is important for contributing back to the lives and relationships of siblings and for honouring the sibling relationship itself.

Ultimately, this thesis is important because relationships matter. Relationships are key elements of everyday life, affecting individuals, pairs and families. Knowledge that helps to articulate and understand the shared and individual experiences that happen within relationships can foster understanding between people, provide support and influence or improve life experiences. It is thus important to consider a relational perspective on disability as contemporary attitudes to disability progress and as a fundamental restructuring of disability support happens around the developed world. With a focus on relational experience, there is potential to foster people – *siblings* – with and without disabilities in working together to share good lives and relationships.

Appendices

Appendix 1. Sampling frame

Projected sampling frame

		Total	Total divided	
			Siblings with disabilities	Siblings without disabilities
Any disability (e.g. physical or sensory)	Male, 15-18	20	10	10
	Female, 15-18	20	10	10
	Male, 19-29	20	10	10
	Female, 19-29	20	10	10
	Sub-total	80	40	40
Intellectual disability	Male, 15-18	10	5	5
	Female, 15-18	10	5	5
	Male, 19-29	10	5	5
	Female, 19-29	10	5	5
	Sub-total	40	20	20
Complex communication needs	Male, 15-18	10	5	5
	Female, 15-18	10	5	5
	Male, 19-29	10	5	5
	Female, 19-29	10	5	5
	Sub-total	40	20	20
Overall total		160	80	80

Final sample

		Total	Total divided	
			Siblings with disabilities	Siblings without disabilities
Any disability (e.g. physical or sensory)	Male, 15-18	4	2	2
	Female, 15-18	4	3	1
	Male, 19-29	3	3	
	Female, 19-29	7	4	3
	Sub-total	18	12	6
Intellectual disability	Male, 15-18	4	1	3
	Female, 15-18	4	1	3
	Male, 19-29	4	3	1
	Female, 19-29	8	3	5
	Sub-total	20	8	12
Complex communication needs	Male, 15-18	4	3	1
	Female, 15-18	1	1	0
	Male, 19-29	3	1	2
	Female, 19-29	0	0	0
	Sub-total	8	5	3
Overall total		46	25	21

Appendix 2. Recruitment materials

Newsletter blurb

Standard newsletter blurb	<p>Looking for people to take part in a research study about siblings, disability and young adulthood</p> <p>In this study happening at the Social Policy Research Centre, researchers are talking to <u>both</u> young people with disabilities <u>and</u> their siblings without disabilities (both aged 15-25) about how disability affects or plays a role in their sibling relationship and affects what happens in their lives during young adulthood.</p> <p>If either you <u>or</u> your brother or sister have a disability and you are <u>both</u> aged 15-25, you can take part in an interview or by your own creative response. Accessibility and communication supports available.</p> <p>For details, see www.siblingsanddisability.com or contact Ariella Meltzer at the Social Policy Research Centre (University of New South Wales): a.meltzer@unsw.edu.au or (02) 9385 3747.</p>
Easy Read newsletter blurb	<p>Research study about siblings, disability and being a young person</p> <p>In this study, we are talking to:</p> <ul style="list-style-type: none">• People with disabilities.• Their brothers and sisters without disabilities. <p>We are asking them about how disability plays a role in:</p> <ul style="list-style-type: none">• Their sibling relationship.• What happens in their lives during young adulthood (about ages 15 to 25). <p>You can take part if:</p> <ul style="list-style-type: none">• Either you <u>or</u> your brother or sister have a disability.• Both of you are aged 15 to 25.

-
- You live in Australia.

You can take part in:

- An interview – this is talking and answering questions.
- A ‘creative contribution’ – you send in something you write, a picture or something technological (like a recording or something from the internet).

If you want, you can have someone help you for either an interview or for a ‘creative contribution’.

To find out more, go to: www.siblingsanddisability.com There is a page with easy info there. There is also an Easy Read consent form with pictures.

To take part, get in touch with Ariella Meltzer (at the Social Policy Research Centre): Phone: (02) 9385 3747 Email: a.meltzer@unsw.edu.au

RESEARCH STUDY ABOUT SIBLINGS, DISABILITY AND YOUNG PEOPLE

What?

We are talking to **both** siblings with **and** without disabilities about how disability affects their sibling relationship and affects what happens in their lives during young adulthood.

Who?

Both people with and without disabilities are taking part.

You can take part if:

- You have a brother or sister
- Either you **or** your brother or sister have a disability
- Both you **and** your brother or sister are aged 15 to 25, **AND**
- You live in Australia

How?

You can take part in:

- An interview
- A creative contribution (something you make that is written, a picture or technological).



For all the information about the study, see:

www.siblingsanddisability.com

Please get in touch with Ariella Meltzer at a.meltzer@unsw.edu.au or on (02) 9385 3747 with any questions.

This research study is being undertaken at the Social Policy Research Centre at the University of New South Wales as PhD research.

SPRC
Social Policy Research Centre




Appendix 3. Example screenshot of website

Siblings, young people and disability study

[Home](#)[What is the study about?](#)[Who can take part?](#)[What ways are there to take part?](#)[Should siblings take part together or separately?](#)[Arranging an interview](#)[Doing a creative contribution](#)[Consent forms and information sheets](#)[FAQs](#)[Contacts](#)[Easy info](#)

What is the study about?



Accessible RTF of website content

Go to
Easy info

This is a research study about siblings, disability and young adulthood.

We are talking to **both** siblings with **and** without disabilities about how disability affects their sibling relationship and affects what happens in their lives during young adulthood.

The study will ask about:

- . What you and your brother or sister do together and feel about each other.
- . How disability affects the important events in your life from your mid teens to your mid twenties and the ways you feel like an adult.
- . What your relationship together is like and how disability affects that.
- . The kinds of things you feel, say or do when you deal with all of this together.

This study is being conducted at the [Social Policy Research Centre](#) at the University of New South Wales as PhD research.

Appendix 4. Consent forms

Standard sibling consent form



Participant Information and Consent Form **Siblings, young people and relational experiences of disability** **HREC: HC12370**

What is this study about?

This study is about siblings with and without disabilities' experiences of disability during young adulthood (ages 15-25). It is looking at how the social issues of disability in this time of life affect sibling relationships for both siblings with and without disabilities.

Who can take part in the study?

You can take part in the study if:

- You have a brother or sister
- Either you **or** your brother or sister have a lifelong* disability
- Both you **and** your brother or sister are aged 15-25.
- You live in Australia. See below for information on the specific locations where the research will take place.

*Lifelong disability means a physical, intellectual or sensory disability from birth or under 2 years of age.

Who is doing this study, and why?

This study is being undertaken at the Social Policy Research Centre at the University of New South Wales, as research for a PhD. The study is to contribute to understandings of how siblings experience disability.

If I decide to take part, what will I need to do?

There are two ways to take part:

1. An interview

You can make a time for a researcher to come and speak to you. This will take about half an hour to meet and discuss the study and then an hour to do the interview. Interviews will be done in urban areas in New South Wales, Victoria and South Australia. You will receive a \$30 gift voucher to thank you for your time.

2. A creative contribution

You can respond to a short set of questions in any way you like from within the following options:

- Something **written** (for example, an email, letter or short comment).
- Something **pictorial or visual**, with a comment explaining what is shown (for example, a photo, mindmap, collage or Compic symbols).
- Something **technological** (for example, an audio or video recording or internet link).

Creative contributions can come from people living anywhere in Australia. You will go in the draw to win one of two \$150 gift vouchers (prize drawn in August 2013).

Should siblings take part together or separately?

It is your choice. You can take part together with your sibling in the same interview or creative contribution **or** each of you can do your own interview or creative contribution separately from each other. If your sibling doesn't want to take part, you can take part in the study by yourself. You could also do a combination – for example, an interview together and separate creative contributions.

What will the information be used for?

The information from the interviews and creative contributions will be used in a PhD thesis, seminars, conference presentations and other publications, such as in academic journals and books.

What happens to my information? Will it be confidential?

Yes, all information about you will be confidential, except as required by law. Your name and any information about you that can identify you will not be shared. Pictorial/visual data will only be used and re-produced in an anonymous and de-identified way (e.g. selecting images that don't show identifiable people, blurring, pixelating, other edited changes). Pictorial/visual data that shows participants' identities will not be published.

Do I have to take part? What if I change my mind about taking part?

Taking part is voluntary – it is your choice. Whether or not you take part has no impact on any disability or carer services you receive or on any relationship you have with UNSW. You can also choose to leave the study at any time with no penalty.

What if taking part is upsetting?

If you find taking part upsetting, there are people you can get in touch with:

- You can call Lifeline Counselling if you are upset – phone: 13 11 14.
- You can contact *eheadspace* if you need advice about problems with your brother or sister or if you are upset. *eheadspace* has email, online chat and telephone support options – see: www.eheadspace.org.au.

You also have the choice to leave the study if it is too difficult.

What if I have complaints about the study?

If you have complaints about the study you can contact the Ethics Secretariat the University of New South Wales on (02) 9385 4234 or ethics.sec@unsw.edu.au. You will need to give them this number: HC12370.

What if I have more questions?

If you have any other questions, feel free to contact one of the researchers, who will be happy to answer them.

- Ariella Meltzer (main researcher): (02) 9385 3747 or a.meltzer@unsw.edu.au.
- Kristy Muir (chief investigator): (02) 9385 7818 or k.muir@unsw.edu.au.

Participant Information and Consent Form

**Siblings, young people and relational experiences of disability
HREC: HC12370**

Participant consent

By signing this consent form, I am confirming that I have read the information provided and based on this information, I agree to participate.

.....
Your signature

.....
Your name (PRINT)

.....
Signature of witness

.....
Name of witness (PRINT)

.....
Date

Return this form to: Ariella Meltzer
Social Policy Research Centre
John Goodsell Building, University of New South Wales
Kensington, 2052, NSW
Email: a.meltzer@unsw.edu.au

Participant Information and Consent Form

**Siblings, young people and relational experiences of disability
HREC: HC12370**

Participant withdrawal of consent

By signing this consent form, I am confirming that I no longer consent to take part in the study. I want the information I have provided to be discounted.

.....
Your signature

.....
Your name (PRINT)

.....
Signature of witness

.....
Name of witness (PRINT)

.....
Date

Return this form to: Ariella Meltzer
Social Policy Research Centre
John Goodsell Building, University of New South Wales
Kensington, 2052, NSW
Email: a.meltzer@unsw.edu.au

Easy Read sibling consent form

Study: Siblings, young people and relational experiences of disability



HREC: HC12370

Easy Read Information and Consent Form

Siblings, young people and relational experiences of disability

About the study and who can take part



This study asks brothers and sisters what they think of disability, of being a young person and of their relationship together.

You can take part if:

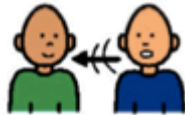
- You have a brother or sister
- Either you **or** your brother or sister have a disability
- Both you **and** your brother or sister are 15 to 25 years old
- You live in Australia

You can take part:

- Together with your brother or sister
- Separately from them (you both take part, but not together)
- If they don't want to take part, you can do it by yourself

About how to take part

You can take part by:



- **An interview**

This means you talk and answer questions for about an hour.

You can do this if you live in New South Wales, Victoria or South Australia.

You get a \$30 gift voucher to say thank you.

or



- **Send in something**

- Written down
- A picture or recording
- Something from the internet

You can do this if you live anywhere in Australia.

You go in the draw to win a \$150 gift voucher (prize drawn in August 2013).

About using the information and your choices

The information will be used for books, talks and papers that researchers read.



All information that could give away who you are will always be a secret.

This means that the researchers:

- Don't use your name
- Make sure pictures don't show who you are

You should only take part if you want to. It is **your choice**.

Whether or not you take part does not change any disability services you get.

If you change your mind about taking part, that is OK too.



If you need help to take part, that is OK. You can ask someone you trust to help you.

You can also talk with the researchers about what they can do to make taking part easy for you.

People to get in touch with



These are some people you can get in touch with about the study.

If you feel **upset** by the study or want to talk to someone about problems with your brother or sister, you can:

- Talk to someone at Lifeline. The number is 13 11 14.
- Email, chat online or talk to someone at *eheadspace*. The website is www.eheadspace.org.au.

If you want to **complain** about the study, you can get in touch with the Ethics Secretariat:

- (02) 9385 4234 or ethics.sec@unsw.edu.au
- You will need to give them this number: HC12370

The Ethics Secretariat are there to make sure researchers do a good job for you.

If you have more **questions** about the study, you can get in touch with one of the researchers:

- **Ariella Meltzer** – the main researcher
(02) 9385 3747 or a.meltzer@unsw.edu.au
- **Kristy Muir** – in charge of the research
(02) 9385 7818 or k.muir@unsw.edu.au

Participant Information and Consent Form

Siblings, young people and relational experiences of disability

HREC: HC12370

I want to take part



I am signing this form because:

- I understand about the study
- I want to take part

.....
Your signature

.....
Your name (PRINT)

.....
Signature of witness

.....
Name of witness (PRINT)

.....
Date

Send this form to:

Ariella Meltzer
Social Policy Research Centre
John Goodsell Building, University of New South Wales
Kensington, 2052, NSW
Email: a.meltzer@unsw.edu.au

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Participant Information and Consent Form

Siblings, young people and relational experiences of disability

HREC: HC12370

I don't want to take part anymore



I am signing this form because:

- I don't want to take part anymore
- I don't want my information to be used

.....
Your signature

.....
Your name (PRINT)

.....
Signature of witness

.....
Name of witness (PRINT)

.....
Date

Send this form to: Ariella Meltzer
Social Policy Research Centre
John Goodsell Building, University of New South Wales
Kensington, 2052, NSW
Email: a.meltzer@unsw.edu.au

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Guardian Information and Consent
Siblings, young people and relational experiences of disability
HREC: HC12370

This form is for parents/guardians of 15, 16 or 17 year olds wishing to take part in this study or guardians of people with a disability under a legal guardianship arrangement who are wishing to take part.

What is this study about?

This study is about siblings with and without disabilities' experiences of disability during young adulthood (ages 15-25). It is looking at how the social issues of disability in this time of life affect sibling relationships for both siblings with and without disabilities.

Who is doing this study, and why?

This study is being undertaken at the Social Policy Research Centre at the University of New South Wales, as research for a PhD. The study is to contribute to understandings of how siblings experience disability.

Who can take part?

To take part, participants need to fill the following criteria:

- Participants have a brother or sister
- Either the participant **or** their brother or sister have a lifelong* disability
- **Both** siblings are aged 15-25.
- Participants live in Australia. See below for information on the specific locations where the research will take place.

*Lifelong disability means a physical, intellectual or sensory disability from birth or under 2 years of age.

How do siblings take part in the study?

Participation can be by interview (half hour preparation, 1 hour interview) or by a creative contribution (a written, pictorial/visual or technological contribution). Interviews will be in urban areas in New South Wales, Victoria and South Australia, and participants will receive a \$30 gift voucher to thank them for their time. Creative contributions can be from anywhere in Australia, and participants will go in the draw to win one of two \$150 gift vouchers (prize drawn in August 2013).

Should siblings take part together or separately?

Siblings can choose to take part together in the same interview or creative contribution or each can take part separately. If one sibling does not want to take part, the other sibling can participate by him or herself in the study.

What will the information be used for?

The information from the study will be used in a PhD thesis, seminars, conference presentations and other publications, such as in academic journals and books.

Is participation voluntary?

Participation is voluntary and can be revoked at any time without penalty. Participation and revocation have no impact on any disability or carer services siblings may receive and no impact on any relationship with UNSW.

What happens to the information? Will it be confidential?

Yes, all information about participants will be confidential, except as required by law. Participants' names and any information that could identify them will not be shared. Pictorial/visual data will only be used and re-produced in an anonymous and de-identified way (e.g. selecting images that don't show identifiable people, blurring, pixelating, other edited changes). Pictorial/visual data that shows participants' identities will not be published.

What if taking part is upsetting?

If participants find taking part upsetting, there are people they can get in touch with:

- They can call Lifeline Counselling if they are upset – phone: 13 11 14.
- They can contact *eheadspace* if they need advice about problems with their brother or sister or if they are upset. *eheadspace* has email, online chat and telephone support options – see: www.eheadspace.org.au.

Participants also have the choice to leave the study if it is too difficult.

What if I have complaints about the study?

If you have complaints about the study you can contact the Ethics Secretariat the University of New South Wales on (02) 9385 4234 or ethics.sec@unsw.edu.au. You will need to give them this number: HC12370.

What if I have more questions?

If you have any other questions, feel free to contact one of the researchers, who will be happy to answer them.

- Ariella Meltzer (main researcher): (02) 9385 3747 or a.meltzer@unsw.edu.au.
- Kristy Muir (chief investigator) (02) 9385 7818 or k.muir@unsw.edu.au.

Siblings, young people and relational experiences of disability
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Consent from guardian

By signing this form I am confirming that (please tick all that apply):

- ☐ I am the guardian of the study participant indicated below.
 - ☐ This participant has an intellectual or cognitive disability.
 - ☐ This participant is aged 15, 16 or 17 years old.
- ☐ I give consent for their participation in the study.

.....
Name of the person for which you are guardian

.....
Your signature

.....
Your name (PRINT)

.....
Signature of witness

.....
Name of witness (PRINT)

.....
Date

Return this form to: Ariella Meltzer
Social Policy Research Centre
John Goodsell Building, University of New South Wales
Kensington, 2052, NSW
Email: a.meltzer@unsw.edu.au

Participant Information and Consent From

**Siblings, young people and relational experiences of disability
HREC: HC12370**

Withdrawal of consent from guardian

By signing this consent form, I am confirming that I no longer consent to the person for which I am guardian taking part in the study and I want their information to be discounted.

.....
Name of the person for which you are guardian

.....
Your signature

.....
Your name (PRINT)

.....
Signature of witness

.....
Name of witness (PRINT)

.....
Date

Return this form to: Ariella Meltzer
Social Policy Research Centre
John Goodsell Building, University of New South Wales
Kensington, 2052, NSW
Email: a.meltzer@unsw.edu.au

Supporter consent form



Supporter Information and Consent **Siblings, young people and relational experiences of disability** **HREC: HC12370**

This form is for those who act as supporters to people with a disability taking part in the research.

What is this study about?

This study is about siblings with and without disabilities' experiences of disability during young adulthood (ages 15-25). It is looking at how the social issues of disability in this time of life affect sibling relationships for both siblings with and without disabilities.

Who is doing this study, and why?

This study is being undertaken at the Social Policy Research Centre at the University of New South Wales, as research for a PhD. The study is to contribute to understandings of how siblings experience disability.

Who can take part, and how?

People who either have a lifelong disability or who have a brother or sister with a lifelong disability can take part in the research. They must be between the ages of 15-25 and live in Australia. Participation can be via an interview (half hour preparation, 1 hour interview) or by a creative contribution (a written, pictorial/visual or technological contribution). Siblings can take part jointly, separately or just one may take part in the research alone.

What is my role as a supporter?

Your role as a supporter is to assist a person with a disability to take part in the study. This involves assisting them with communication: e.g. facilitating, explaining, contextualising or interpreting speech and communication; asking or rephrasing questions in language participants will understand; or acting in a role that is motivating, reassuring or otherwise facilitating. This assistance could be provided either in an interview or for a creative contribution. While the research focus is on the information provided by the participant with a disability, by taking part as a supporter you understand that your contributions (e.g. comments in an interview, input to a creative contribution) may be included and used in the research to contextualise and explain the responses given by these participants themselves.

What will the information be used for?

The information from the study will be used in a PhD thesis, seminars, conference presentations and other publications, such as in academic journals and books.

Is participation as a supporter voluntary?

Participation as a supporter is voluntary and can be revoked at any time without penalty. If you revoke your consent, this means that you cannot be quoted in the research, but this does not affect the participation of the person you have supported and he or she may still be quoted without your contributions being identified.

Participation and revocation have no impact on any disability or carer services yourself or the participant may receive and no impact on any relationship with UNSW.

What happens to the information? Will it be confidential?

Yes, all information will be confidential, except as required by law. Participants' and supporters' names and any information that could identify them will not be shared. Pictorial/visual data will only be used and re-produced in an anonymous and de-identified way (e.g. selecting images that don't show identifiable people, blurring, pixelating, other edited changes). Pictorial/visual data that shows participants' or supporters' identities will not be published.

What if taking part is upsetting?

If you find taking part upsetting, there are people you can get in touch with:

- You can call Lifeline Counselling if you are upset – phone: 13 11 14.
- You can contact *eheadspace*. *eheadspace* has email, online chat and telephone support options – see: www.eheadspace.org.au.

You also have the choice to leave the study if it is too difficult.

What if I have complaints about the study?

If you have complaints about the study you can contact the Ethics Secretariat the University of New South Wales on (02) 9385 4234 or ethics.sec@unsw.edu.au. You will need to give them this number: HC12370.

What if I have more questions?

If you have any other questions, feel free to contact one of the researchers, who will be happy to answer them.

- Ariella Meltzer (main researcher): (02) 9385 3747 or a.meltzer@unsw.edu.au.
- Kristy Muir (chief investigator) (02) 9385 7818 or k.muir@unsw.edu.au.

Siblings, young people and relational experiences of disability
HREC: HC12370

Consent from supporter

By signing this consent form, I am confirming that I have read the information provided and based on this information, I agree to participate as a supporter.

.....
Name of the person for which you are supporter

.....
Your signature

.....
Your name (PRINT)

.....
Signature of witness

.....
Name of witness (PRINT)

.....
Date

Return this form to: Ariella Meltzer
Social Policy Research Centre
John Goodsell Building, University of New South Wales
Kensington, 2052, NSW
Email: a.meltzer@unsw.edu.au

Siblings, young people and relational experiences of disability
HREC: HC12370

Withdrawal of consent from supporter

By signing this consent form, I am confirming that I no longer consent to take part in the study as a supporter.

.....
Name of the person for which you are supporter

.....
Your signature

.....
Your name (PRINT)

.....
Signature of witness

.....
Name of witness (PRINT)

.....
Date

Return this form to: Ariella Meltzer
Social Policy Research Centre
John Goodsell Building, University of New South Wales
Kensington, 2052, NSW
Email: a.meltzer@unsw.edu.au

Appendix 5. Interview schedule

Interview questions

* Bold sections asked of each sibling separately before proceeding to joint discussion.

Section A: Who you are and what you do together
So, to start off, because we're going to be talking about the two of you today, I'd like to begin by just getting a sense of who each of you are. So things like what you're each interested in, what you do during the week, where you live, the important people in your life – that kind of thing, but you can add anything really that you think it's important for me to know about you.
1. So could you tell me a bit about these kinds of things for each of you? And can you please tell me a bit about [your/your sibling's] disability as well?
OK, so that's a bit about each of you separately, but I also want to know what you're like together. So things like the kinds of things you do together, what you agree on or argue about, what kinds of things you feel or find good or hard with each other.
2. So can you start off by telling me a bit about the kinds of things you do together and what it's like when you do them? Has that changed over time? How is that different now to when you were kids?
3. What about what you agree on or maybe argue about or find good or hard with each other? Has that changed over time? How is that different now to when you were kids?

Section B: Disability during young adulthood
I want to move on now and talk about how you both experience disability as you enter adulthood. I'm going to ask a bunch of questions about important things that have happened for each of you in the last few years, how disability played a role in those and what that's been like for each of you.

<p>4. [Joint]</p> <p>What are some important things that have happened for each of you since your mid teens?</p> <p>[Separate/alone]</p> <p>What are some important things that have happened for you since your mid teens, and what <u>do you think</u> are important things that have happened for your brother or sister during this time.</p> <p>This is could be:</p> <ul style="list-style-type: none"> - <u>Important events</u> (so things like finishing school or starting study/work) <p>BUT IT COULD ALSO BE</p> <ul style="list-style-type: none"> - <u>Things that have made you feel like an adult</u> (so things like getting more independent or new responsibilities).
<p>5. I'm interested now to find out a bit more about how those things have happened for each of you.</p> <ul style="list-style-type: none"> • How did disability play a role in how those important things have happened? • How did those important things affect your relationship? • What do you think when you compare the important things for the two of you?
<p>6. Did any of those important things for either of you make you think about circumstances for people with and without disabilities more widely than yourselves, and how?</p>
<p>7. If you had to explain disability to someone who didn't know anything about it, what would you say?</p>
<p>8. What do you think are your similarities and differences?</p>
<p>9. [Joint]</p> <p>What does being an adult mean for each of you?</p> <p>[Separate/alone]</p> <p>What does being an adult mean for you, and what <u>do you think</u> it means for</p>

your brother or sister?
Section C: Siblings' relational processes
In this last bit, I want to try and get a sense of what you <i>do</i> about these kinds of things we've just spoken about, about what they <i>mean</i> for how you feel about each other and act together.
10. When these important things are happening, how aware would you be of what each other was feeling about that and how would you know?
11. When these important things are happening, how would you talk or communicate about it? What would you say? When would you say it? <ul style="list-style-type: none"> • Do you talk about disability together? What do you say? • Do you talk about disability with others? What do you say?
12. When these important things are happening – or just in general – what would you expect of each other and of yourselves in relation to each other?
13. When these important things are happening – or just in general – what actions would you both take for each other? What would you actually <i>do</i> for each other?
14. What do you do to fix a difficult situation between you or make things good between you?
15. This is the last question in the main part of the interview – we're almost there now! [Creative] If you were going to compare the two of you to something to explain what you're like together – so make an analogy about your relationship – what would you compare to and why? [Back up] How do you think other people see you two? Would you agree with them?

Section D: Endings
That's all the questions I have today. Before we finish though, I just have a few things to check with you.
16. First, is there anything else we didn't talk about that you wanted to say today?
17. The second thing is that I said to you at the beginning of the interview that I would check to see if there's anything more sensitive or that you are worried about having told me, so that I can be particularly careful when I write about it. Is there anything like that?
18. Why did you take part today and did it make you think of anything new?

Appendix 6. Demographic information sheet

About you and your sibling

Information about you and your brother or sister

Everyone who is taking part in this study needs to fill in this form. If you and your sibling are both taking part, please fill in a form each.

If you need help to fill in this form, please ask someone you trust to help you.



1. About the way you are taking part

I am taking part in a (tick all that apply):

Interview: ☐ Yes / ☐ No

Creative contribution: ☐ Yes / ☐ No

I did this interview and/or creative contribution:

☐ Jointly with my sibling (we spoke/made it together)

☐ By myself, but my sibling did a separate interview

☐ By myself, but my sibling did a separate creative contribution

☐ By myself, and my sibling didn't take part in the study at all

☐ A combination (please specify) _____

2. About you

My FIRST name: _____

My gender: ☐ Male / ☐ Female

My date of birth (dd/mm/yyyy): _____

My postcode: _____ State/territory: _____

My highest level of education:

☐ Year 9 or below

☐ Year 10

☐ Year 11

☐ Year 12

☐ Vocational certificate, diploma or course

☐ University degree

Do you have a disability? ☐ Yes / ☐ No (If 'yes', go to Q3. If 'no', go to Q4).

3. About your disability

Name of disability: _____

Describe the impact of the disability on what you can do (e.g. physical impact; intellectual impact; impact on communication etc; extent of impact – how mild or severe?): _____

Intellectual disability: ☐ Yes / ☐ No

Disability that affects speech: ☐ Yes / ☐ No

4. About your family

Do you have other siblings (aside from the one you have answered about)? ☐ Yes / ☐ No

If yes, how many other siblings do you have? _____

5. About how you spend your time

How do you spend most of your time during the week? (tick all that apply)

	Full time	Part time	Casual/ occasional	I don't do this
High School	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Tertiary education (e.g. uni or college)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Vocational education/training (e.g. apprenticeship, transition to work, certificate course)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Paid work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Volunteering	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Attending a disability service	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
No activity	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Other activity (please specify) _____

6. About where you live

Where are you living? (tick all that apply)

With your parents: ☐ Yes / ☐ No

With your sibling: ☐ Yes / ☐ No

At supported accommodation for people with a disability: ☐ Yes / ☐ No

Independently (without older family members): ☐ Yes / ☐ No

Other (please specify): _____

7. About your brother or sister

Gender: ☐ Male / ☐ Female

Date of birth (dd/mm/yyyy): _____

Does your brother or sister have a disability? ☐ Yes / ☐ No (if 'yes', answer below)

Name of disability: _____

Describe the impact of the disability on what your brother or sister can do (e.g. physical impact; intellectual impact; impact on communication etc; extent of impact – how mild or severe?):

Intellectual disability: ☐ Yes / ☐ No

Disability that affects speech: ☐ Yes / ☐ No

Is your brother or sister taking part in this study? ☐ Yes / ☐ No / ☐ Don't know

If you answered 'No' or 'Don't know', **go to Question 8.**

If you answered 'Yes', what is his or her FIRST name? _____

8. Contacting you (this is optional – you don't have to fill this part out if you don't want to)

My FIRST name: _____

My phone number: __ (____) _____

My email address: _____

This contact information can be used (tick all that apply):

- ☐ To ask me any further questions
- ☐ To send me a summary of the study's findings
- ☐ I would prefer not to be contacted

Researcher use only

Participant ID: _____

Date/time of interview: _____

Location: _____

Linked sibling participating: ☐ Yes / ☐ No

Linked sibling ID: _____

OR

Non-participating sibling ID: _____

Appendix 7. Accessibility toolbox

Easy Read questions

Option 1 – very easy

Intro

- Can you tell me a bit about you? And about your brother or sister? (activities, interests, family)
- What do you think of being a brother or sister?
- Tell me about a time when you had fun together.
- Tell me about a time when there was a problem between you and you were angry or sad.

Relational disability experience during young adulthood and relational processes

- What is something that has happened in the last few years that has either:
(a) changed things for you and your brother/sister? OR
(b) made you think more about how things are between you and your brother or sister?

[prompt for important events or things that have made you feel grown up]

- What was the thing that happened?
- What was that like for you?
- *[Judge if possible/appropriate]* How did having a disability affect that?
- What changed? OR What did you think about?
- What did you do about it? *[prompt for knowing, talking, expecting, acting]*
- What did your brother or sister do about it? *[prompt for knowing, talking, expecting, acting]*
- What are things like for you both now?

Endings

- Is there anything else you want to say?

- Is there anything you said that you are nervous about your brother/sister or family knowing you said?
- Can we fill in this form together? It asks some questions about you.

Option 2 – a bit harder

Intro

I'm going to start off by asking a bit about you and your brother or sister.

- Can you tell me a little about you:
 - What you do during the week
 - What you're interested in
 - Where and who you live with
- Can you tell me a little about your brother or sister:
 - What s/he does during the week
 - What s/he is interested in
 - Where and who s/he lives with
- What do you think of being a brother or sister?
 - What do you do together? What's this like for you?
 - What do you feel about each other? What do you agree or argue about? What's this like for you?

Relational disability experience during young adulthood and relational processes

Now I'm going to ask some questions about important things that have happened to you in the last few years and how having a disability plays a role in that and what that's been like for you and your brother or sister.

When I ask you about important things that have happened, can you think about:

- Things that have changed things for you and your brother or sister.
 - Things that have made you think about how things are between you and your brother or sister.
- What is something important that has happened to you [in the last few years/since your mid teens]?

It could be:

- An important event (like finishing school, getting a job, a new program, changing where you live)
- Something that has made you feel like an adult (like being more independent, new responsibilities)
 - What was that like for you?
 - What do you think it was like for your brother or sister?
 - How did having a disability affect that? (For you? For your brother or sister?)
 - Did it change anything between you two? What?
 - What new thing did it make you think about? [*prompt for thoughts on disability*]
 - How did you know what each other was feeling about that?
 - How did you talk about it? What did you both say?
 - What did you want your brother/sister to do when that happened? What did they want you to do?
 - What did you two *actually* do about it?
 - What are things like for you both now?
- What is something important that's happened for your brother or sister [in the last few years/since their mid teens]?
 - Repeat other questions.
- How do you think you and your brother or sister are similar or different?
- What does being an adult mean to you, and what do you think it means for your brother or sister?

Endings

- Is there anything else you want to say?
- Is there anything you said that you are nervous about your brother or sister or family knowing you said?
- Can we fill in this form together? It asks some questions about you.

Yes/no questions

My job is to find out what *you really think*. I don't mind whether you say 'yes' or 'no' to my questions. The most important thing is that it's what *you really think*. OK?

Quick questions about you and your brother/sister

These questions are just to let me know a little bit about you and your brother or sister.

<ul style="list-style-type: none">• What do you like? What's your favourite thing? [open-ended]• I heard that you do XXXX during the week. What do you think of that?<ul style="list-style-type: none">○ Good○ Bad○ Just OK	
<ul style="list-style-type: none">• What do you do with your brother/sister?<ul style="list-style-type: none">○ Fun things like games or activities○ Things in the house – housework○ Things with the family○ Getting help○ Something else○ Nothing	<ul style="list-style-type: none">• What is it like with your brother/sister? Most of the time do have fun or argue?<ul style="list-style-type: none">○ Have fun○ Argue○ Both – half and half○ Neither
<ul style="list-style-type: none">• Would you say you and your brother/sister are kind of the same or mostly different?<ul style="list-style-type: none">○ Kind of the same○ Mostly different○ Both – half and half	<ul style="list-style-type: none">• What is [kind of the same/different] about you?<ul style="list-style-type: none">○ The kind of things we like (interests)○ The kinds of things we do (activities)○ Our moods and what we find funny (personality)

	<ul style="list-style-type: none"> ○ Having or not having a disability ○ How much help we need
--	--

Questions about you

I want to find out what are some important things that have happened for *you* in the last few years. I've got a list of ideas. Can you tell me if each one is important for you? If none of them are important for you, that's ok, you should just tell me that and we can think of something else that is.

<ul style="list-style-type: none"> • Moving house / moving out • Going on holiday / traveling • Being at school • Finishing school • Starting work • Earning money • Driving • Having new activities to do • Changing or getting new services or carers 	<ul style="list-style-type: none"> • Changing or having new relationships or friends • Meeting new people • More independent <ul style="list-style-type: none"> ○ Doing more things yourself ○ Making more choices • More responsibilities / things you need to do • Having more of a say • Having new ideas
--	---

Now I want to know how *you* felt about that. I've got a list of ideas. Can you tell me if each one is how you felt? You can say 'yes' to more than one, but you don't have to say 'yes' to any if they're not how you felt.

I also want to know how you think *your brother/sister* felt about that. Lets use the same list of ideas. Can you tell me if each one is how you think your brother/sister felt? You can say 'yes' to more than one, but you don't have to say 'yes' to any if they're not how you think your brother/sister felt.

<ul style="list-style-type: none"> • Happy • OK with it • Excited • Proud 	<ul style="list-style-type: none"> • Surprised • Confused • Worried • Scared • Didn't care / didn't mind 	<ul style="list-style-type: none"> • Hurt / disappointed • Sad • Angry • Jealous
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Now I want to find out what happened about that. I've got some questions about it. You can say 'yes' or 'no' to each one. Some of the questions have more than one option. I'll tell you all the options and then you can choose.

<ul style="list-style-type: none"> • You said that you thought your brother/sister was feeling XXXX. <ul style="list-style-type: none"> ○ How did you know they were feeling that? <ul style="list-style-type: none"> ▪ They told you ▪ Someone else told you ▪ You guessed ▪ You could tell from what they did or said • You said that you felt XXXX. Do you think your brother/sister knew you were feeling that? <ul style="list-style-type: none"> ○ How do you think they knew? <ul style="list-style-type: none"> ▪ You told them ▪ Someone else told them ▪ They guessed ▪ They could tell from what you did or said • Did you talk about it? <ul style="list-style-type: none"> ○ Who did the talking? <ul style="list-style-type: none"> ▪ You ▪ Your brother/sister ▪ Both of you ▪ Someone else ○ What did you say? <ul style="list-style-type: none"> ▪ Explaining what was happening
--

- About what you felt
- About what you were going to do about it
- Did you actually *do* something about it?
 - Who did something about it?
 - You
 - Your brother/sister
 - Someone else
 - What did you/they do?

Questions about your brother/sister

Now I'm going to ask you questions that are almost the same again, but this time, they're about what you and your brother/sister think of what's been happening in *their* life, not *yours*. OK?

I want to know what you think are some important things that have happened for *your brother/sister* in the last few years. I've got a list of ideas. Can you tell me if you think each one is important for them? If you don't think any are important for them, that's ok, you should just tell me that and we can think of something else that is.

<ul style="list-style-type: none"> • Moving house / moving out • Going on holiday / traveling • Being at school • Finishing school • Starting work • Earning money • Driving • Having new activities to do • Changing or getting new services or carers 	<ul style="list-style-type: none"> • Changing or having new relationships and/or friends • Meeting new people • More independent (doing more things yourself or making more choices) • More responsibilities / things you need to do • Having more of a say • Having new ideas
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Now I want to know how *you* felt about that. I've got a list of ideas. Can you tell me if each one is how you felt? You can say 'yes' to more than one, but you don't have to say 'yes' to any if they're not how you felt.

I also want to know how you think *your brother/sister* felt about that. Lets use the same list of ideas. Can you tell me if each one is how you think your brother/sister felt? You can say 'yes' to more than one, but you don't have to say 'yes' to any if they're not how you think your brother/sister felt.

<ul style="list-style-type: none"> • Happy • OK with it • Excited • Proud 	<ul style="list-style-type: none"> • Surprised • Confused • Worried • Scared • Didn't care / didn't mind 	<ul style="list-style-type: none"> • Hurt / disappointed • Sad • Angry • Jealous
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Now I want to find out what happened about that. I've got some questions about it. You can say 'yes' or 'no' to each one. Some of the questions have more than one option. I'll tell you all the options and then you can choose.

<ul style="list-style-type: none"> • You said that you thought your brother/sister was feeling XXXX. <ul style="list-style-type: none"> ○ How did you know they were feeling that? <ul style="list-style-type: none"> ▪ They told you ▪ Someone else told you ▪ You guessed ▪ You could tell from what they did or said • You said that you felt XXXX. Do you think your brother/sister knew you were feeling that? <ul style="list-style-type: none"> ○ How do you think they knew? <ul style="list-style-type: none"> ▪ You told them ▪ Someone else told them ▪ They guessed ▪ They could tell from what you did or said • Did you talk about it? <ul style="list-style-type: none"> ○ Who did the talking? <ul style="list-style-type: none"> ▪ You
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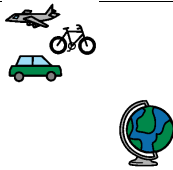







- Your brother/sister
 - Both of you
 - Someone else
- What did you say?
 - Explaining what was happening
 - About what you felt
 - About what you were going to do about it
- Did you actually *do* something about it?
 - Who did something about it?
 - You
 - Your brother/sister
 - Someone else
 - What did you/they do?

Alternative and augmentative communication board




Can you rephrase the question?	I'm going to start my answer again	I'd be worried about my brother or sister knowing I said that	I don't want to answer that question
How many more questions to go?	Can we have a break?	I want to finish the interview soon – can you ask me just the main questions?	I want to finish the interview now

Visual prompts


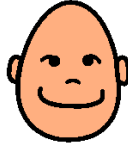


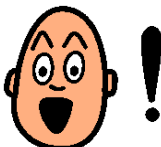
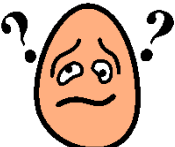

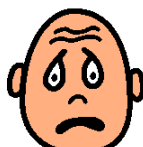
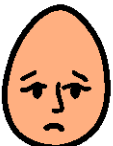
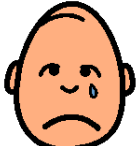

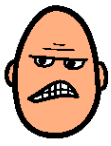
Important events

Changing where you live 	Travelling / holidays 
Being at school or finishing school  	Starting work  
Earning money 	New services or things to do  

Things that have made you feel like an adult


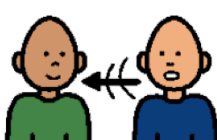


New relationships 	Having more of a say 
More responsibilities or things I need to do 	More independent or making more choices 
Meeting new people 	Having new ideas 

Feelings

Happy 	OK with it 	Excited 	Proud 
Surprised 	Confused 	Worried 	Scared 
Hurt or disappointed 	Sad 	Angry 	Jealous 

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What happened

Just thought about it	Talked about it	Did something about it	Didn't know what to do
			

Appendix 8. Analysis frameworks

Initial coding tree

Parent-codes	Sub-codes
Sibling relationship	Feelings Actions Similarities Differences Other
Young adult experiences	[To be inductively defined – important events, things that make you feel like an adult, conceptualisations of adulthood]
Disability	Medical/functional impact Social issues Complexity Care Other
Context	Intersectional categories (gender, race, ethnicity, religion, sexuality, class, socio-economic status) Geography and location Family make up/demographics Other
Relationality	Relational processes Knowing about each other Talking together Expectations of each other Actions for each other Unaware about each other Other Relational framings [To be inductively defined – siblings' feelings, attitudes and fixed perceptions about themselves and each other]

Final themes and sub-themes

Sibling relationship	Disability	Young adulthood
Functions of the relationship	Embodiment and enactment of disability	Social and economic engagement
<ul style="list-style-type: none"> • Enjoyment • Support • Conflict 	<ul style="list-style-type: none"> • Functional impact • Sibling issues • Social 'bits and pieces' • Care • Services 	<ul style="list-style-type: none"> • Education • Work • Disability services • Activities • Communities
Ways of enacting the relationship		Social and community relationships
<ul style="list-style-type: none"> • Talk • Activity • Perception • Feelings 		<ul style="list-style-type: none"> • Friends • Social life • Boy/girlfriends
Ways of understanding the relationship		Milestones
<ul style="list-style-type: none"> • Individuality • Comparison • Similarity • Difference • Normalising • Power 		<ul style="list-style-type: none"> • Graduations • Moving out of home • Driving • Travel
(horizontal)		Subjective experiences of adulthood
		<ul style="list-style-type: none"> • Independence • Responsibility • Choice • Developing identity
		Other
		<ul style="list-style-type: none"> • Health, wellbeing

← Context →

(Context cross cuts the sibling relationship, disability and young adulthood)

Family context – Generation – Birth order – Age gaps – Gender – Cultural background –
Socio-economic status – Geography – Resources

Appendix 9. Siblings with disabilities' young adult experiences of disability

<p>Social and economic engagement</p> <ul style="list-style-type: none"> • Impact of disability on education pathways – e.g. changing schools or choosing subjects to accommodate support needs. • Impact of disability on trajectories into employment – e.g. working in supported employment; finding it hard to get work; experiencing disability employment discrimination; or entering disability or advocacy fields. • Using disability services as a form of engagement. 	<p>Craig: “I actually ended up doing my Year 12 over two years, just because of those extra things I needed to deal with, with like physio and all those appointments”.</p> <p>Simone: “The school wasn’t going to bother [to help me find a future option other than a day program]... They were like, ‘Oh, well, we’re not going to help you then”.</p> <p>Ben: Through yes/no questions, Ben explained that he started gardening at his day program and that this is important because of ‘the friends he does it with’ and because he ‘likes the way the dirt feels’.</p>
<p>Social and community relationships</p> <ul style="list-style-type: none"> • Impact of disability on friendships – e.g. dealing with other people’s perceptions of disability when making friends; socialising through disability groups; planning for accessibility or support workers when socialising. • Influence of disability on community engagement – e.g. cannot wear hearing aids when playing in sport competitions. 	<p>Zoe: “I had to make new friends [when I changed schools], so for me that was a big thing because being me I didn’t find it very – well, it’s really hard for me. And I think that’s the difference, like people just look at you as, oh my god, she’s in a wheelchair so she can’t have a conversation. So every time I would walk past, they would stare at me and I suppose, that was really annoying. Now they’re not so bad, but that’s one hard thing”.</p> <p>Maria: “I am part of three social groups and when we go out on one of the social</p>

	<p>groups, sometimes we come home around about 7:30, 8:00... One is for people that are deaf and blind. One is for people with a learning disability and the other one is a learning disability [group] as well. So they come in and pick me up and drop me back home. So they pick, like, activities. So last weekend we went to the beach, we watched the jazz music”.</p> <p>Adam: “[My friends] are a little different... Like me... The [disability] mentoring program – I met them there”.</p> <p>Danielle: “When I play sport, I don’t wear hearing aids... I sometimes tell the umpire I’ve got hearing aids so they won’t penalise me if I hit the ball away having not heard the whistle... But I didn’t this game and... I don’t know whether the umpire said ‘Leave it, leave it, leave it!’ but anyway, I did an offence and I was sent off”.</p>
<p>Subjective experiences of adulthood</p> <ul style="list-style-type: none"> • Getting more of a say about services or using new disability services as forms of independence. • Developing independence in the context of disability and/or working on independent living skills. • Impact of inclusion and/or stigma on identity and belonging. 	<p>Ben: Through yes/no questions, Ben explained that he now gets ‘more of a say’ at his day program and about what his support workers do with him and that this makes him feel ‘good’ and ‘important’, but also sometimes ‘worried’.</p> <p>Brett: “[Now I] go to the toilet [by myself], be more independent... I come [to my day program] on the bike track [by myself]”.</p> <p>Macy: “[I’ve been] getting things out for</p>

the teachers here... getting all the resumes out for the people who haven't finished theirs".

Harry: "When I was younger I couldn't go out very much, because I had to have my mum or a carer with me, but coz I'm more social or more, I'm old enough and I'm more mature, I know what I'm doing with myself and that, I get to go out more places [now] and that".

Jeremy: "But everyone doesn't see me as a boy with a disability. They see me as Jeremy, a normal Year 12 boy who gets involved. Everyone talks to me and we had a Year 12 retreat – we got a chance to play soccer and table tennis and I was part of that and everyone was enjoying themselves, not really thinking about dis[ability]".

Simone: "I went back to the special school through bullying... bullied not by the people I was going to school with, by my aides and carers".

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