

Recognising reciprocity over the life course: adults with cerebral palsy and their non-disabled siblings

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A thesis submitted in fulfilment of the requirements for the degree of

Doctor of Philosophy

**Discipline of Speech Pathology
Faculty of Health Sciences
The University of Sydney
12 July 2010**

Declaration

I, Angela Dew, hereby declare that this submission is my own work and that it contains no material previously published or written by another person except where acknowledged in the text. Nor does it contain material which has been accepted for the award of another degree.

I, Angela Dew, understand that if I am awarded a higher degree for my thesis entitled *Recognising reciprocity over the life course: Adults with cerebral palsy and their non-disabled siblings* being lodged herewith for examination, the thesis will be lodged in the University Library and be available immediately for use. I agree that the University Librarian may supply a photocopy or microform of the thesis to an individual for research or study or to a library.

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Supervisor Statement

As supervisor of Angela Dew's doctoral work, I certify that I consider her thesis *Recognising reciprocity over the life course: Adults with cerebral palsy and their non-disabled siblings* to be suitable for examination.

Professor Gwynnyth Llewellyn



Faculty of Health Sciences

Date 12.7.2010

The University of Sydney

Dedication

I am dedicating this thesis to my parents, Nell and Ray Dew and my five sisters, Beth, Patti, Margaret, Veronica and Maree. Our father, Raymond Chanel Dew died, aged 94, on the 27th of September, 2007 just as I was embarking on this research journey. Two months prior to our father's death my sister Maree's husband, Peter Sarsfield died suddenly.

Death is a litmus test of how families cope under pressure. My family, like many of those who participated in this study, emerged from this experience stronger. The journey of nursing our father through the final months of his life, and supporting him to die peacefully at home with my mother and three of my sisters by his side, enriched and strengthened our family and our sibling bonds. Although I was not physically present throughout all of this period, being one of six means I always felt represented and I see this as one of the strengths of being a sibling. I am proud and feel lucky to be a part of such a large and loving family.

Lest We Forget.



The Dew girls, circa 1960

Acknowledgements

I would like to sincerely thank the 12 people with cerebral palsy and their 16 non-disabled siblings who participated in this research. The stories and insights they shared with me of their amazing, rich and indomitable lives have enabled me to understand just a little of what it means to be, or have a sibling with cerebral palsy.

My enduring thanks go to my supervisors, Professors Gwynnyth Llewellyn and Susan Balandin. Both Gwynnyth and Sue have been very supportive throughout the past 3 ½ years and indeed longer than that as I have worked with both of them over a number of years. Sue moved from Sydney to Norway during the course of my candidature and together we have tested the ability of technology to bridge geographic distance. Sue's in-depth knowledge of adults with cerebral palsy and the importance of communication to relationships have been invaluable. Gwynnyth's strategic and honest feedback has kept me from straying onto divergent paths. Her advice has always paid dividends and reflects her wealth of experience in both family/disability research and qualitative methodology. Gwynnyth and Sue have encouraged me to present my work in various stages of development at national and international conferences and have had faith in my ability to complete this, at times daunting, task. They have both been wonderful mentors in my late blooming academic career!

I have been through this PhD journey with a fantastic group of fellow PhD students: Bronwyn, Monique, Natalie, David, Leigha and Liora. We have met together regularly to exchange ideas and provide each other with support. This wonderfully collaborative group of peers has enhanced the experience of doing a PhD and thanks are due to Sue for bringing us together. I would also like to thank Dr

Nathan Wilson for being a “critical friend” and reading early drafts of my work, and Joan Rosenthal for editing the final draft.

Of course I could not have embarked on or completed this journey without the support of my family, Richard, Nick and Anna Tewson. Richard has been a wonderful support and mentor. On our weekend walks along the banks of the Nepean River, or to the lookout, he has shared the ups and downs of living a PhD and offered great feedback. He also proofread every page of the early drafts and added or deleted commas as necessary! Nick and Anna have been stoic and supportive as the house has been invaded by thesis related material and I have headed off to conferences and left them and Richard to fend for themselves. Nick has also given me technical help with scanning documents and formatting the layout. Anna has been a great emotional support and has cooked delicious dinners! I hope I have provided Nick and Anna with a role model to demonstrate that you are never too old to take on a challenge and work towards its conclusion. Hopefully I haven't put them off the idea of further study.

Finally, thanks to the Australian Research Council (ARC) which awarded me an Australian Post-graduate Award (Industry) (APAI) and to the specialist cerebral palsy service for their contribution towards this [the name of the organisation has been omitted to ensure the confidentiality of participants]. This award made it financially possible for me to undertake full-time study to complete the PhD. Thanks also to SPOT on DD which provided me with a small grant to extend my work outside of Sydney.

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Inclusion of Published Papers

Statement from co-authors confirming the authorship contribution of the PhD candidate to the published papers included in this thesis

Published Paper 1: Chapter 2, pages 12-15.


Dew, A., Llewellyn, G., & Balandin, S. (2004). Post-parental care: a new generation of sibling-carers. *Journal of Intellectual & Developmental Disability*, 29, 176-179.

As co-authors of the paper “Post-parental care: a new generation of sibling carers” we confirm that Angela Dew has made the following contributions to the paper:

- Literature search, sourcing and review
- Writing the paper and critical appraisal of content
- Corresponding author for communication with journal

Our contribution was in editing, commentary and discussion consistent with the co-author status.

Signed  Date 12.7.2010

Signed  Date 12.7.2010

Published Paper 2: Chapter 3, pages 22-45.


Dew, A., Balandin, S., & Llewellyn, G. (2008). The psychosocial impact on siblings of people with lifelong physical disability: A review of the literature. *Journal of Developmental and Physical Disabilities, 20*, 485-507.

As co-authors of the paper “The psychosocial impact on siblings of people with lifelong physical disability: A review of the literature” we confirm that Angela Dew has made the following contributions to the paper:

- Literature search, sourcing and review
- Writing the paper and critical appraisal of content
- Corresponding author for communication with journal

Our contribution was in editing, commentary and discussion consistent with the supervisory process.

Signed  Date 12.7.2010

Signed  Date 12.7.2010

Abstract

This study addresses the development of the relationship between individuals with moderate to severe cerebral palsy and their non-disabled siblings over their life course. There has as yet been no focus on the sibling relationships of adults with moderate to severe cerebral palsy. Those with moderate to severe cerebral palsy can require high levels of personal care and assistance with activities of daily living throughout their lives, due to their often significant physical and communication impairments. This coupled with the fact that they are living longer and outliving their parents, means that the support previously provided by parents may pass to siblings.

Previous research into the transition from parental care has focused on people with intellectual disability, with those with cerebral palsy as a sub-group. This approach overlooks the quite specific needs of individuals with cerebral palsy, which warrant separate attention. Previous research has also treated this transition as a singular event rather than looking at it within the context of the person's life course. Given that sibling relationships are the longest and most durable throughout a person's life, it makes sense to view the later life relationships between individuals with cerebral palsy and their non-disabled siblings in the context of their earlier life experiences.

The aim of this study was to explore the relationships between individuals with moderate to severe cerebral palsy aged 40 years and over and their non-disabled siblings in the context of the future: when parents can no longer provide care for their adult son or daughter with cerebral palsy.

To address this aim a qualitative research design was adopted, with symbolic interactionism as the theoretical underpinning. Two in-depth interviews were

conducted with each of 12 adults with cerebral palsy and 16 of their non-disabled siblings. The interviews took a life-course approach, asking participants to describe their childhood, emerging adulthood, and later life circumstances and sibling interactions. Constructivist grounded theory was used to analyse the data, identify the primary finding and develop a conceptual framework.

Analysis of the data highlighted the diversity of sibling relationships. Nonetheless, various pathways were identified. Living together with or being separated from their non-disabled siblings in childhood affected the sibling relationship and influenced either the development of warm relationships or a feeling of separation and distance. In young adulthood, participants with cerebral palsy who shared transition milestones with their non-disabled siblings and developed personal autonomy further strengthened their sibling bond. Subsequently, in middle and older age, facing parents' and their own ill health and mortality tended to bring siblings closer together.

Taking a life-course approach to the relationship between individuals with cerebral palsy and their non-disabled siblings led to the identification of the primary finding of this study that reciprocity can develop in the relationship between people with moderate to severe cerebral palsy and their non-disabled siblings. Reciprocity is recognised as operating as a generalised moral norm, with people motivated to reciprocate the help they receive from others based on obligation or altruism. Reciprocity may be either instrumental, through the exchange of practical aid and direct services, or symbolic, relating to the mutual trust, regard and respect which people develop towards those with whom they have a long-term relationship.

The existence of reciprocity in the sibling relationships of people with moderate to severe cerebral palsy and their non-disabled siblings is particularly

important in middle and later life when parents are no longer as actively involved in the life of their son or daughter with cerebral palsy. At this time sibling relationships may take on greater significance.

Four variables, contact, shared experiences, parental status and role, and support needs, formed the basis of a conceptual framework for understanding the development of instrumental and symbolic reciprocity between participants with cerebral palsy and their non-disabled siblings. The framework provides a useful way for people with cerebral palsy, their family members, and service providers to consider the roles which people with cerebral palsy and their non-disabled siblings might play in each other's lives. This study is an important beginning in identifying a nuanced relationship between individuals with cerebral palsy and their siblings in which reciprocity plays a significant and previously unrecognised part.

Glossary

Augmentative and alternative communication (AAC) is a term used to describe other ways to communicate used by people who find it hard to communicate by speech or writing. AAC includes many different methods from unaided systems such as signs and gestures; to aided systems including low tech picture charts and books to high tech special computers (International Society for Augmentative and Alternative Communication, 2010).

Clinical typology refers to a systematic classification of types that have characteristics or traits in common.

Developmental disability is a broad term which includes cerebral palsy, intellectual disability, autism, epilepsy and other neurological impairments. In Australia the term is used to refer to severe chronic disabilities attributable to intellectual and/or physical impairment which occur before age 6 years (Wen, 1997).

Dysarthria is a motor speech disorder caused by “disturbances in muscular control of the speech mechanism resulting from impairment of any of the basic motor processes involved in the execution of speech” (Darley et al. (1975, p. 2) cited in McNeil, 1997, p. 312).

Grounded theory is a qualitative research method which aims to develop, from observational data, a law, model or theory which explains the phenomenon being studied (Grbich, 1999).

Intellectual disability is a specific form of developmental disability. The key elements of which are: low general intellectual functioning as measured by Intelligence Quotient (IQ) test, difficulties in adaptive behaviour, and the conditions manifesting before age 18 (Wen, 1997).

Lifelong disabilities include cognitive and/or physical impairments which exist from birth or early childhood and last throughout a person's life (Wen, 1997).

Medical model refers to the traditional approach to the diagnosis and treatment of illness as practiced by physicians in the Western world. Within the medical model, disability is defined as an observable deviation from biomedical norms of structure or function that directly results from a disease, trauma, or other health condition (Bickenbach, Chatterji, Badley, & Ustun, 1999).

Reciprocity refers to the equal or comparable exchange of tangible aid, emotional affection, advice, or information between individuals in return for benefits received (Antonucci & Jackson, 1989, p. 84).

Social constructivism is the belief that individuals construct meaning of the complex world in which they live through their interactions with other people based on their shared social experiences and understandings (Crotty, 1989).

Symbolic interactionism is a theory of human conduct according to which the "mind" and "self" are social products which lead individuals to structure the external world by their perceptions and interpretations of what they conceive the world to be (Mead, 1934).

Chapter 1

Why Conduct This Study?

This thesis describes research in which I applied a symbolic interactionist theoretical framework with a grounded theory methodology to explore the relationship between older adults with cerebral palsy and their non-disabled siblings. Rosenbaum et al. (2007, p. 9) defined cerebral palsy as:

A group of permanent disorders of the development of movement and posture, causing activity limitations that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behavior; by epilepsy, and by secondary musculoskeletal problems.

As Rosenbaum et al. suggested, adults with cerebral palsy are not a homogeneous group. Nonetheless, many people with moderate and severe levels of cerebral palsy have significant physical and cognitive impairments and must rely upon others to assist them with their personal care, activities of daily living, mobility, and communication.

Furthermore, as older adults with cerebral palsy have rarely married or had children they lack a typical support hierarchy as described by Cantor (1979). Cantor developed an hierarchical compensatory model, with a descending order of formal and informal support based upon the primary relationship of the caregiver to the care-recipient. According to this model, a spouse and children are at the top of the hierarchy, followed by siblings and other family members. In the absence of a spouse or children, adults with cerebral palsy, particularly if the condition is moderate or

severe, often rely upon their parents to provide care and support, whether they live with their parents, in supported accommodation, or independently (Balandin & Morgan, 1997). With improvements in health care for people with cerebral palsy, many now outlive their parents (D. Strauss, Brooks, Rosenbloom, & Shavelle, 2008), and so they may turn to their non-disabled siblings to provide ongoing support.

Connidis (2001) noted that in typical families, the health crisis or death of a parent can precipitate a change in sibling relationships. Little is known, however, about the effect of parental decline on the relationship between adults with moderate to severe cerebral palsy and their non-disabled siblings. For example, is it likely that non-disabled siblings will provide support to their brother or sister with cerebral palsy? Does the individual with cerebral palsy want support from non-disabled siblings and if so, in what ways? This study is a step towards a greater understanding of the sibling relationship between people with moderate to severe cerebral palsy and their non-disabled siblings as all grow older and also the implications of getting older for these siblings' future relationships.

1.1. A family in transition

To orient the reader to the issue examined in this thesis, I start with the story of a family of three siblings who participated in this study.¹ Oliver is the youngest in a family of five and has cerebral palsy, Kitty is his eldest sister, and Arthur is the third youngest. The family's story highlights the dilemma faced by families when the main carer for the person with cerebral palsy is unable to continue in that role. Oliver, Kitty and Arthur agreed to participate in this study because they believed their experiences over the previous 18 months provided a salutary lesson to others who might find themselves in a similar situation. The issues faced by this family, and how

¹ All participants in this study have been given pseudonyms.

they worked together to resolve them, indicate the central place of the sibling relationship when a brother or sister with cerebral palsy is faced with the transition from parental care to sibling support.

Oliver is 42 years old and has severe cerebral palsy with dysarthric speech. He uses an electric wheelchair to get around and cannot attend to his personal care or perform other activities of daily living without assistance.

Until the age of 40 Oliver lived at home with his mother who provided full support. Eighteen months ago Oliver's mother was diagnosed with dementia and in the following 6 months Oliver and his siblings became increasingly aware that she was struggling to care for both herself and him. One day Oliver phoned his brother Arthur at work to say his mother was simply not coping. What followed was 12 months of intensive intervention by the family during which the four non-disabled siblings worked together as a team. They found nursing home accommodation for their mother and initially provided in-home support for Oliver while they organised respite, and then permanent care for him. While grieving for the loss of their mother, whose cognitive function had rapidly declined, this family re-negotiated their sibling relationships to provide for Oliver's physical and emotional needs. Throughout this time Oliver had to cope with significant changes in his life due to the loss of his mother's care, having other people including his siblings provide his physical care, and leaving his home and moving in with strangers. The experience of this family highlights a number of key issues which underlie the rationale and need for this study.

1.2. Identifying the issues

The first issue highlighted by this family's experience was a lack of planning for the future. Their mother was in her 70s when she started to decline cognitively, although it was inevitable that as she became older and frailer she would not be able to

continue caring for Oliver indefinitely. Nonetheless, the family had not made plans for or discussed who would care for Oliver when his mother could no longer do so. Perhaps this is not so surprising, as previous studies with older family carers of people with intellectual disability and their siblings have shown that a lack of future planning is common (Bigby, 1996; Heller & Kramer, 2009).

A second issue became clear in the way Kitty and Arthur spoke about the frustrations they experienced trying to navigate their way through the maze of government and non-government agencies to find help for their mother and Oliver. Their difficulties securing coordinated support suggest that services may be ill-equipped to provide immediate support at the required level. Heller and Factor (1994) identified this gap in transition services albeit in the United States as one reason why families might be reluctant to make long term plans as there was no assurance that having a plan would ensure a smooth transition from parental care.

The lack of services available to ease transition highlights the third issue, which is that non-disabled siblings like Kitty and Arthur might be required, at least in the short term, to provide personal care and other support tasks to their brother or sister with cerebral palsy. This is likely to place strain on non-disabled siblings' personal and professional lives as they seek to balance family and work commitments with this additional role. It is also awkward for all involved when, for the first time, siblings are required to assist their brother or sister with intimate tasks such as going to the toilet and bathing.

Related to the issue of who provides personal care to the person with cerebral palsy is the fourth issue, the impact on the person with cerebral palsy who faces a significant and possibly traumatic change in his or her life. In addition to having his siblings and complete strangers assist him to go to the toilet, bathe, dress and eat,

Oliver had to cope with the emotional distress of watching his mother deteriorate to the point where she no longer knew who he was. The emotional and social impacts on the person with a disability of losing a parent and lifetime carer have not been explored.

The fifth and final issue is the double support role likely to be required of middle-aged siblings with a brother or sister with a disability. At this stage of life, supporting older parents is common (Connidis, 2001). When there is also a brother or sister with a disability, the support role performed by siblings is likely to be different from the norm in both nature and intensity. For example, Arthur and Kitty found themselves negotiating with the aged care sector to find nursing home accommodation for their mother while at the same time liaising with the disability and health sectors to get respite care, allied health services and in-home support for Oliver. The four non-disabled siblings in this family were able to divide these tasks among them. When the non-disabled sibling is the only sibling, or the only sibling available or willing to undertake these tasks, the role is likely to be more intensive and stressful.

In middle-age many people face the normative stage of parent's health deteriorating, but those with a disability and their non-disabled siblings face additional challenges (Dew, et al., 2008; Meyer, 2009). Furthermore, as Priestley (2003) noted, the care and support required by an individual with a disability is likely to have pervaded all aspects of family life from childhood to adulthood. When ageing parents relinquish care of their adult "child" due to ill-health or death, the impact on the relationship between siblings should not be viewed as an isolated event. Rather, and because by their very nature sibling relationships are the longest and most durable of any (Cicirelli, 1995), what happens in the transition from parental care will be

determined, at least in part, by the siblings' previous relationships. Various researchers have suggested that, to support them through multiple transitions across their lives, siblings draw upon the warmth they build up through living together as children (Howe, Aquan-Assee, Bukowski, Lehoux, & Rinaldi, 2001; Stoneman, 2001), the shared experiences throughout their lives (Goetting, 1986), and the underlying affection they feel for each other (Sanders, 2004).

What is not known, however, is whether or how these typical attributes of siblingship apply to the relationship between middle-aged and older siblings when one sibling has cerebral palsy, or how these siblings negotiate their interactions in the absence of parental support. Given the likely significant physical support needs of a person with moderate to severe cerebral palsy coupled with increasing longevity, once parents are no longer able to provide support, the person with cerebral palsy is likely to require ongoing physical and emotional support. As was the case for Oliver, having non-disabled siblings to assist in the negotiation with services may be critical to ease the transition and ensure appropriate support (Bigby, 2000).

1.3. Aim of this study

This study evolved from an early focus on transition later in life to a subsequent, broader life-course view of sibling relationships. The specific aim was to:

- explore the relationships between people with severe cerebral palsy aged 40 years and over and their non-disabled siblings in the context of the future: when parents can no longer provide care for their son or daughter with cerebral palsy.

1.4. Scope of this study

This study positions the sibling tie as a central family relationship. Individual in-depth interviews were conducted with both individuals with cerebral palsy and at least one of their non-disabled siblings. Including the viewpoints of the people with a disability and their able-bodied siblings was central, as the dynamics of the sibling relationship from both perspectives had not been explored previously.

1.5. Personal impetus for this study

Having worked in both management and direct care positions with people with developmental disabilities and their families for many years, a lasting impression for me has been the importance of family support to people with lifelong disability.

During my professional life, I noticed that people with a disability whose family members were engaged and involved in their lives benefited in many ways. For example, family members provided advocacy and emotional support in addition to practical help. For years, “family” to me meant “parents”; I rarely considered the role of siblings. This was probably because I worked mainly with people who lived in institutions and subsequently moved into supported accommodation in the community. Research into the deinstitutionalisation of people with developmental disability, including the study I conducted for my Masters of Arts (Honours) suggested that family members can find it difficult emotionally and practically to maintain contact with a son, daughter, brother or sister who was institutionalised (Dew, 2005; Funnell, 2001; Mirfin-Veitch, Bray, & Ross, 2003). This may help to explain the limited contact I had with siblings, and indeed what appeared to be the sibling absence from the lives of people with developmental disability with whom I worked. Nonetheless, my eyes were opened to the importance of siblings in this

context when I started working with Professors Llewellyn and Balandin and became sensitized to the fears of older parent carers about who would care for their “child” with a disability when they were no longer able to do so. I was quickly converted to the need to explore the sibling relationship.

My personal experiences as a sibling, albeit not of a person with a lifelong disability, further piqued my interest in this topic. As the youngest of a family of six (all females) I recognise the concern we share as siblings for each others’ wellbeing and the interest we have in each other’s lives. Throughout the three and a half year journey of this study I have often reflected on my relationship with my sisters and I have wondered how this might have been different had one of us had a lifelong disability. Now aged in our 50s and 60s, my sisters and I are grappling with issues associated with our own ageing while at the same time supporting each other and our elderly mother through the death of our father. I have now had first hand experience of juggling the multiple responsibilities of teenage children, work and study, and fulfilling my share of support to my parents. Because three of my sisters and I live in a different country to our widowed mother and other two sisters, we have had to find ways to bridge the geographic divide and ensure that all of the support is not left to our sister who lives closest to our mother. I can only imagine the additional challenges involved in providing support to a sibling with a lifelong disability as well as elderly parents. So, at both a professional and a personal level, I embraced the opportunity to explore in-depth the relationship between siblings as parents’ grow older.

I have used the example of one family to identify some of the problems facing middle-aged and older people with moderate to severe cerebral palsy and their siblings when their parents are no longer able to provide care. In the following 10

chapters I record my research journey to understand the life events which influence the relationship that exists between these siblings.

1.6. Overview of the thesis

Chapter 2 provides a background to the study, including a pilot project conducted with non-disabled siblings of people with intellectual disability which informed this study, and a published paper (Dew et al., 2004) which raised the issue of non-disabled siblings taking on a caring role for their brother or sister with a disability after their parents' death. Chapter 2 also includes an overview of the current issues relevant to older people with cerebral palsy.

Chapter 3 consists of a review of the literature in three sections: (1) a published review on the psychosocial impact on siblings of people with a lifelong physical disability (Dew et al., 2008); (2) the contribution of life course theory to the exploration of sibling relationships and (3) an understanding of sibling development theory. Together the three perspectives informed the development and implementation of this study.

In Chapter 4, an overview of the methodological background, symbolic interactionism, is provided, along with an explanation of the specific method used, constructivist grounded theory.

Chapter 5 provides an application of these methods through the sibling interviews and includes a description of the interview participants and details of data collection.

Chapter 6 describes the process of analysis of the data using constructivist grounded theory. The chapter also provides a prelude to the subsequent three results chapters by describing their format. The results are presented according to life course stages.

Chapter 7 describes the importance of the early years of sibling relationships for participants using the stories from three sibling dyads: Richard and Ruth, Bruce and Ruth, and Helen and Isobel, and a sibling triad: Betty, Bob, and Derek.

Chapter 8 describes participants' journey from childhood to adulthood using the stories of sibling triad Mathew, Therese and Kitty, and dyads: Caroline and Margaret, Rebecca and Amelia, and Philip and Harry.

Chapter 9 describes participants' experiences later in life by focusing on the impact of parental death and sibling ill health through the stories of sibling dyads: Kristine and Natalie, and Louise and Jill, and sibling triads: Oliver, Kitty and Arthur, and Thomas, Stephanie and Marilyn.

Chapter 10 integrates the results from the sibling interviews with previous research to describe and explain the primary finding of this thesis: that over the life course reciprocity can develop in the relationship between people with moderate to severe cerebral palsy and their non-disabled siblings. The chapter concludes by presenting a conceptual framework which identifies the influences leading to reciprocity in these sibling relationships.

Chapter 11 provides an overview of the study and discusses its limitations and implications for practice, policy, education and research.

Chapter 2

Setting the Scene

2.1. Pilot study

The background to this study had its genesis 7 years ago when Professor Gwynnyth Llewellyn and colleagues (2003) conducted narrative life history interviews with 64 ageing parent carers (average age 69 years) of 64 adults with an intellectual disability (average age 38 years). Over half (58%) of the adults with intellectual disability “had an additional condition such as cerebral palsy, epilepsy, and other physical disabilities” (Llewellyn, et al., 2003, p. 3). One of the main findings of that study was that the parent carers were anxious about what the future held for their sons or daughters with intellectual disability.

Subsequently Dew, Llewellyn and Balandin (2004) published the following paper that discussed the role non-disabled siblings may play after their parents’ deaths as sibling-carers for their adult brother or sister with a disability. This paper highlighted the need for further study to explore the relationship between siblings over time, but particularly when one has a developmental disability.

2.2. “Post-Parental Care: a new generation of sibling-carers”

Dew, A., Llewellyn, G., & Balandin, S. (2004). Post-parental care: a new generation of sibling carers. *Journal of Intellectual & Developmental Disability*, 29, 176-179.

Following the publication of this paper, Professors Llewellyn and Balandin and I conducted a pilot project in 2005 in which we interviewed 11 non-disabled adult siblings of people with intellectual disability. Seven sisters and four brothers were interviewed. The pilot project identified that although non-disabled siblings were concerned about the nature of their future role in the life of their brother or sister with a developmental disability, they also felt a sense of responsibility to continue supporting their sibling in place of their parents when this became necessary (Dew, Llewellyn, & Balandin, 2005).

The initial study by Llewellyn and colleagues (2003), the paper highlighting the need for further study (Dew, et al., 2004), and the subsequent pilot study with non-disabled siblings of people with intellectual disability (Dew, Balandin, & Llewellyn, in preparation) pointed to the need for an in-depth study of the issue of sibling relationships from the viewpoint of both individuals with a disability and their non-disabled sibling/s. This study was designed to meet those requirements with a focus on middle-aged adults with cerebral palsy and their non-disabled siblings.

2.3. Why focus on individuals with cerebral palsy?

The current population of middle-aged people with moderate to severe cerebral palsy is, due to improved health care, the first generation² to outlive its parents (D. Strauss, et al., 2008). As such we have little understanding of what the future holds in terms of the support needs of these people later in life. We do know that people with moderate to severe cerebral palsy often have significant physical impairments requiring lifelong support (Murphy, Molnar, & Lankasky, 1995). It has also been

² Generation refers to a group of people who share the same historical time frame during their youth (Alwin & McCammon, 2004).

established that as these people age their health is likely to deteriorate further (Balandin & Morgan, 1997). Indeed, older people with cerebral palsy have reported increased pain and problems with mobility and communication and there is evidence that these health problems occur at an earlier age than those in the general community (Balandin & Morgan, 1997; Murphy, et al., 1995). The combination of deteriorating health and increasingly high support needs means they are at risk of placement into a nursing home at a much younger age than for the general population (Crawford, 1996; Murphy, et al., 1995; Overeynder & Turk, 1998).

Individuals with moderate to severe cerebral palsy typically experience communication difficulties that can make it difficult for them to articulate their preferences and desires in ways others can understand. These communication difficulties range from dysarthric speech which is slow and slurred to little or no functional speech and a need for augmentative and alternative communication systems (McNeil, 1997). Although approximately 40% of people with cerebral palsy are considered to have normal cognitive abilities (Kriger, 2006; Pellegrino, 1997), their inability to communicate clearly can mean they are not consulted about life choices including future care needs (Overeynder & Turk, 1998). The increasing use of augmentative and alternative communication systems (AAC), such as speech generating devices, has the potential to provide for those with complex communication needs an easily understood voice. However, AAC is not without its challenges (Rackensperger, Krezman, McNaughton, Williams, & D'Silva, 2005; Smith & Connolly, 2008), and among the older population of people with cerebral palsy the use of such devices is limited (Balandin & Morgan, 2001). One potential benefit of the sibling relationship, if indeed siblings without disability remain closely involved with their brother or sister with a disability, would be the non-disabled

sibling's ability to understand the communication of the person with cerebral palsy and thus advocate and ensure that his or her voice is heard.

Although the few studies of sibling relationships among people with lifelong disability have included people with cerebral palsy, they have been a sub-group within the larger group of people with developmental or intellectual disability. This approach overlooks the quite specific needs of individuals with cerebral palsy which warrant separate attention. The specific and separate needs of individuals with cerebral palsy are well documented (e.g., Balandin & Morgan, 1997; Crawford, 1996; Murphy, et al., 1995) and include motor disorders, communication impairments, and a requirement for significant support with personal care and activities of daily living. In recognition of these requirements, state-based services have been established in Australia which specifically cater to the needs of people with cerebral palsy.

2.4. The Australian context of service provision to people with cerebral palsy

Specific cerebral palsy organisations, which were set up typically by groups of parents in the various states in Australia to provide therapy and education to children with cerebral palsy, operated as non-profit, parent run organisations with a commitment to whole-of-life and lifelong care (CP Australia, 2009). Not surprisingly, the family members of individuals with cerebral palsy who are now middle-aged continue to expect ongoing support. This is in no small part due to the considerable expectation on the part of the organisations that, in return for the services provided to their children, parents would donate both their time and money to ensure the organisations' ongoing viability (The Spastic Centre NSW, 2005). Indeed, parents quite literally built and staffed the services.

An important branch of the earliest services was boarding schools for country children who were disadvantaged by the complete lack of services in regional and rural areas (McLeod, 1986). From the 1950s through to the 1980s, children from the country lived in purpose-built country children's hostels during the school term and returned to their family home for the holidays. This meant that non-disabled siblings saw their brother or sister with cerebral palsy for only a few months each year and so did not share many of the foundational experiences of growing up together (Drapeau, Simard, Beaudry, & Charbonneau, 2000; The Spastic Centre NSW, 2005). Furthermore, country mothers worked 6-8 weeks per year in the boarding hostel providing domestic duties and support to the children. This took mothers away from their non-disabled children at home and potentially further highlighted the differences between the siblings at home (non-disabled) and away (with a disability).

Children with cerebral palsy who lived in the city were collected by bus from all over the metropolitan area and transported to a central location to attend special schooling and receive therapy. Their mothers worked one day per week in the school, assisting with therapy and tuition. Again, being bussed off to the special school distinguished siblings with cerebral palsy from their non-disabled brothers and sisters.

The services provided by the organisations grew with the original clients and from the late 1960s workshops, day programs and hostels were added to cater for the increasing number of adult clients. Many of the now middle-aged people with cerebral palsy "graduated" from one service level to another maintaining contact with their cohort³ peers as they did so.

³ A cohort is a group of people who have shared some critical experience during the same interval of time (Alwin & McCammon, 2004).

Reflective of a change in the way services were to be delivered to people with lifelong disability in higher income countries, from the mid 1980s onwards there was a greater emphasis on decentralised, community-based services in Australian cities and regional centres. With this decentralisation came a shift away from the philosophy of the early days of providing pervasive, lifelong care to people with cerebral palsy. The history of specialist service provision in their early lives however, provides a contextual backdrop to relationships between people with cerebral palsy and their non-disabled siblings. For this reason, and because sibling relationships are lifelong, a life course perspective is fundamental to the understanding of sibling relationships at the chosen life stage, in the present study, middle adulthood for individuals with cerebral palsy and their non-disabled siblings.

Chapter 3

Review of the Literature

This chapter reviews the literature in three sections: (1) a published review article examining the psychosocial impact on siblings of people with a lifelong disability; (2) an overview of Elder's Life Course Paradigm and discussion of the application of this to the study of sibling relationships when one has a disability; and (3) a critique of the literature relating to sibling relationships across the life course. Within sections (3.2) and (3.3), life course and sibling literatures form the basis for discussion of disability-specific literature in these areas. Approaching the literature review in this way permits gaps to be identified in the knowledge of sibling relationships across the life course for people with moderate to severe cerebral palsy.

3.1. Sibling Relationships and Lifelong Disability

In the early stages of this study, I conducted a literature review of the empirical research into the psychosocial impact on siblings of people with a lifelong physical disability. This review was published in 2008 in the *Journal of Developmental and Physical Disability* and is presented below as an introduction to the literature review chapter.

3.1.1. "The psychosocial impact on siblings of people with lifelong physical disability: A review of the literature"

Dew, A., Balandin, S., & Llewellyn, G. (2008). The psychosocial impact on siblings of people with lifelong physical disability: A review of the literature. *Journal of Developmental and Physical Disabilities, 20*, 485-507.

The review paper identified that there were few published studies of the psychosocial impact on non-disabled adult siblings of having a brother or sister with cerebral palsy. It also highlighted that people with cerebral palsy were generally not included in research into relationships with non-disabled siblings. Furthermore, the review indicated that although it was likely that childhood sibling experiences influenced the relationship in later life between brothers and sisters when one had cerebral palsy, there was no empirical evidence to support this supposition. The review paper pointed to a number of conceptual categories identified in the literature which suggested ways of understanding the relationship between siblings when one has cerebral palsy. However, as yet the application of these conceptual schemas across the life course has not been examined in detail. A model is needed which has the capacity to allow interrogation and exploration of these concepts from the empirical data and, given the changing history of services for people with cerebral palsy outlined in Chapter 1, which allows application of life course as ‘trajectory’, ‘transition’ and ‘turning point’. In what follows the relevance of adopting a life course model such as the one proposed by Glen Elder (1994) is outlined.

3.2. Applying a Life Course Approach

According to German life-course theorists Heinz and Kruger (2001, p. 33) the term “life course” describes “a sequence of stages...and transitions in life which are culturally and institutionally framed from birth to death”. Of particular relevance to a life-course view, Cicirelli (1995) reminded us that the sibling relationship is the longest relationship that many people experience in their lives.

American sociologist Glen Elder (1994), considered a seminal figure in the development of life-course theory, asserts strongly that “the later years of ageing cannot be understood in depth without knowledge of the prior life course” (p. 5).

Elder developed a life-course paradigm that provides a useful framework for considering interdependencies, generation and cohort influences, and individual sibling choices.

3.2.1. Elder's life course paradigm

Elder's work originated in the 1960s when he analysed data from the landmark longitudinal "Oakland Growth Study" and "Berkeley Guidance Study" carried out by the University of California, Berkeley. Participants in the Oakland Growth study were born in 1920-1921, and those in the Berkeley Guidance Study were born in 1928-1929. Both groups grew up during the Great Depression of the 1930s and lived through World War II. Elder's interest was in identifying participants' career pathways to determine what impact growing up during these events had on subsequent life trajectories (Elder, 1974, 1998, 1999). Elder noted that despite adversity when growing up, the participants' stories detailed "how so many women and men successfully overcame disadvantage in their lives" (Elder, 1998, p. 9). He identified many intersecting variables which accounted for differing life course outcomes, bringing these together in the development of his life-course paradigm with an age-based concept of timing (Elder, 1994). Elder's paradigm is based around five principles summarised here from the description provided by Elder et al. (2004, pp. 11-14.):

- (1) The Principle of Life-Span Development: Human development and ageing are lifelong processes.
- (2) The Principle of Agency: Individuals construct their own life course through the choices and actions they take within the opportunities and constraints of history and social circumstance.

- (3) The Principle of Time and Place: The life course of individuals is embedded and shaped by the historical times and places they experience over their lifetime.
- (4) The Principle of Timing: The developmental antecedents and consequences of life transitions, events, and behavioural patterns vary according to their timing in a person's life.
- (5) The Principle of Linked Lives: Lives are lived interdependently and socio-historical influences are expressed through this network of shared relationships.

I have represented Elder's Life Course Paradigm in Figure 1.

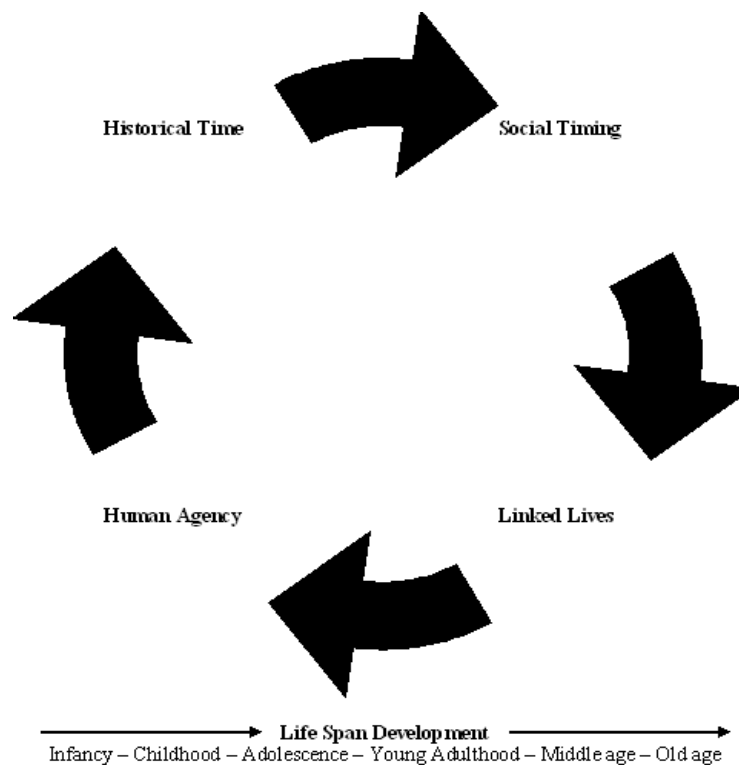


Figure 1 Elder's Life Course Paradigm

Elder et al. (2004) stated that applying life-course principles in research resulted in “the holistic understanding of lives over time and across changing social contexts” (p. 13). Life-course theorists including Elder use the terms *trajectories*, *transitions* and *turning points* to encapsulate the temporal nature of individuals’ lives (Elder, et al., 2004; Hagestad, 1986). Although trajectories, transitions and turning points are important concepts in the life-course literature they have specific meanings which are at times misrepresented. Due to the centrality of trajectories, transitions and turning points in this thesis it is important to understand the differences inherent in those terms in order to relate them to the lives of people with cerebral palsy and their siblings.

3.2.2. Trajectories, transitions and turning points

According to Elder and colleagues (Elder, et al., 2004), trajectories refer to the sequences of roles and experiences of an individual over the long term, during which specific events occur within definable duration and order. An example of a trajectory would be growing up in a certain area, leaving school and getting a job, marrying and having children, retiring, and participating in civic duties.

The concept of transitions, according to Elder et al. (2004), and based on psychological role theory (Burr, 1972), relates to the changes in state or role of an individual which give the transition its form and meaning within the context of a trajectory. Most transitions are age-graded and occur during predictable times in the life span.⁴ According to Clausen (1998), although transitions represent a re-ordering of priorities and activities, they do not result in a substantial change in direction. An

⁴ Life span refers to the length of time during which a person may be expected to live under normal circumstances.

example of a transition would be a young adult moving out of the parental home to establish a separate household and independent life.

In contrast, turning points, according to Elder and colleagues (2004), mark a substantial change in the direction of an individual's life. An example of a turning point would be a middle-aged person with cerebral palsy having to move out of the parental home and into supported accommodation after the death of the parent-carer.

Given the historic development of policy and changes in service provision to families with children with cerebral palsy who are now adults, I believe that Elder's paradigm offers a useful structure within which to examine the relationships of individuals with cerebral palsy and their siblings as, by definition, the sibling relationship "plays out" across the life course. Furthermore, adopting a life-course perspective is one way of ensuring that sibling relationships are placed within the context of temporality and socio-cultural influences. As will be seen in Chapters 4 and 5 the elements of Elder's model also reflect Kathy Charmaz's methodological recommendations on the constant comparison of data across people, time, places and resources allowing a consonance between the theoretical and methodological approaches described in this thesis.

Elder's paradigm formed the basis of much of the subsequent work on life course in various fields and in diverse areas of interest, from migration to health and nutrition (e.g., see Treas, 2008; Wethington, 2005). However, to the best of my knowledge, the paradigm has not been applied to the study of the lives of people with cerebral palsy. To gain insights to apply to a study of adult sibling relationships where one sibling has cerebral palsy it was necessary to draw on life-course research from related areas, of which ageing is one.

In his discourse on the importance of adopting a life-course perspective to the study of ageing, Settersten (2004) explained that doing so brought together (1) the interdependence of family members with reference to the cohort into which they were born, (2) the generation to which they belonged (made up of different cohorts within a family, and (3) the individual paths family members followed in relation to both their family and their wider social relationships.

These three concepts identified by Settersten (2004) are important in framing questions that address the aim of this study, to explore the relationship between adult siblings with and without cerebral palsy as they grow older. For example, what individual, familial and environmental factors influenced the relationship that developed between the individual with cerebral palsy and the sibling/s? In the absence of life-course studies of people with cerebral palsy, two published papers are discussed which applied Elder's paradigm to highlight some of the issues relevant to another marginalised group of people with a disability, specifically mental illness.

In a theoretical paper, Cook et al. (1997) discussed the cohort effects of historical changes on the way people with mental illness were viewed and treated in the USA. Cook et al. described:

younger cohorts [of people with mental illness] having more integrated cultural experiences and growing up with higher expectations about the kinds of lives they could hope to lead, and older cohorts having spent longer periods of time in institutional settings, receiving less education, and experiencing far less community integration (p. 428).

Cook and colleagues theorised that employing a life-course perspective facilitated a deeper understanding of how changes in socio-historical context led to differences in the lived experience of people with a mental illness and their families.

Influenced by the article of Cook et al. (1997), Stein and Wemmerus (2001) adopted a life-course approach to study how families of people with schizophrenia adapted to the life changes resulting from the diagnosis. Twenty-two participants, including adults with schizophrenia ($N = 6$), parents ($N = 12$) and non-disabled siblings ($N = 4$), were interviewed. These authors were particularly interested in role transitions within Elder's notion of social timing. Their study highlighted discontinuities in the life course due to the diagnosis of a mental illness which disrupted the "normal" life course of the person with the illness as well as the family members. This study highlighted how expectations for the person's life must be realigned due to the "social off-timeness" (p. 732) of life transitions with resulting stress for all family members.

Offering a different viewpoint to that expressed by Stein and Wemmerus, a British researcher in disability, Priestley (2000), identified a danger in concentrating on how the lives of people with a lifelong developmental disability differed from the "norm". According to Priestley, the focus on "normal" transitions ignored the broader social issues which influenced the timing of events in people's lives, and was likely to be counterproductive and ultimately of little value to the individuals and their families. Rather, Priestley, who advocated the social model approach to the study of impairment and disability, argued that by changing social and cultural practices, rather than focusing on ameliorating individual deficits, greater improvements in the lives of people with impairments would be achieved. Priestley (2003) argued that whereas the concept of life course could be thought of as incorporating both individual and social constructs, the adoption of a social approach allowed greater consideration of how societies and social institutions perpetuated the ideal of a "normal" life.

Priestley's work is important as he is one of the few researchers in the disability area to adopt a theoretical life-course approach. Nonetheless, in keeping with a symbolic interactionist stance, I would argue that the timing of life-course transitions and the importance attached to them are formed through the interaction of people within their cultural context, and so the desire to conform to socially prescribed transitions is strong. Indeed, in discussing the importance of socialisation between siblings, Kramer and Conger (2009) pointed out that due to their similar ages and the rivalry inherent in their relationships, siblings in particular were likely to compare their achievement of life transitions against one another. Furthermore, the attainment or lack of attainment of life course transitions such as moving out of the parental home and getting married might be particularly important in developing an independent "adult" relationship between siblings when one has moderate to severe cerebral palsy.

Nonetheless, some limitations must be acknowledged when employing Elder's paradigm to people with cerebral palsy, as issues of control or agency over life transitions can be problematic for people with moderate to severe cerebral palsy. For example, decisions such as moving out of the parental home may be made for people with cerebral palsy by others rather than by themselves. Also, Elder did not specifically consider the role of siblings.

Sanders (2004) wrote a text on sibling relationships in which he commented that the relationship which developed between siblings in childhood was likely to influence the adult sibling relationship. In particular, for siblings where one has a lifelong disability such as cerebral palsy, the relationship developed between siblings throughout their lives might be important in relation to the support provided in later life (Dew, et al., 2008). Nonetheless, in the absence of longitudinal studies of sibling

relationships making the link between childhood experiences and later life, interaction between siblings is at best based on conjecture. Rather than adopting a life-course approach, studies of the relationship between siblings can largely be divided into those which have considered the impact during childhood and those which have concentrated on adult sibling relationships.

In keeping with the life-course approach taken in this study, the remainder of this chapter focuses on studies conducted over many years on siblings: on the sibling relationship in childhood and adolescence, in young adulthood, and in middle and older age, to gain an understanding of the impact of each life stage on the development of sibling relationships for children more generally.

3.3. Understanding Sibling Relationships Across the Life Course

3.3.1. Childhood and adolescent sibling relationships

According to McHale and Crouter's (2005) summary of sibling relationships in childhood, the majority of children grow up in a household with at least one sibling and are likely to spend a considerable amount of time playing with, arguing with, learning from, and learning about their brother/s or sister/s. Sibling relationships in childhood tend to be both egalitarian, with siblings forming a child's first peer group (Sanders, 2004) and hierarchical, as older siblings act as role models for younger ones (Howe & Recchia, 2005; McHale & Crouter, 2005; Stoneman & Brody, 1993).

Indeed, as described by Goetting (1986, p. 703), "Sibling relationships are unique among close human relationships by virtue of [their] long duration and also because participants share a common genetic and social heritage, a common cultural milieu, and common early experiences within the family".

Sanders (2004) reviewed the historical development of sibling research for his text on sibling relationships. According to Sanders, in the 20th century there were three dominant approaches to understanding typical sibling relationships.

The psychoanalytical approach was prevalent in the early decades of the 20th century, led by Freud, Levy, and Adler (Bedford, 1989; Sanders, 2004). Based on personal experience and case studies of clients accessing their psychoanalytic practices, proponents of this approach focused on the development of rivalry and jealousy between siblings, particularly in the relationship with their mother. Although based on unrepresentative samples, the psychoanalytical approach influenced sibling research for some 20-30 years. Not surprisingly, therefore, studies of siblings in the disability field also focused on the jealousy a non-disabled sibling might feel towards the brother or sister with a disability who, due to additional care needs, monopolised their mothers' time and attention supposedly to the detriment of the non-disabled siblings (e.g., see Coleby, 1995; Roe, 1988). Over time the psychoanalysts' focus on siblings' rivalry for mother's attention was seen as a narrow approach and led to the development of the clinical typology approach.

Predominant from the 1960s to 1990s, the clinical typology approach was led by family therapists and by psychologists such as Walter Toman (Sanders, 2004). This approach was based on the experiences of conflicted sibling relationships revealed to clinicians by the clients accessing their practices (Bedford, 1989). According to this approach, relationships between siblings are determined by the variables of birth order, gender and age gap in relation to family size. These variables have been used to develop typologies of personality characteristics (e.g., Toman, 1959). For example, according to Toman's typology (cited in Sanders, 2004, p. 63), oldest brothers of brothers were leaders who liked to exercise power and control over

others, compared to youngest sisters of sisters who loved change, excitement and were impulsive and erratic. The reliance on observations of clinical patients to develop theoretical frameworks raised questions about rigour and scientific merit, to such an extent that Sanders (2004) referred to Toman's typology as reminiscent of a horoscope.

The clinical typology approach also did not accommodate possible differences in sibling relationships when one sibling has a lifelong disability. For example, birth order might not be a primary variable for those siblings, as a younger non-disabled sibling may developmentally "over take" the older sibling with a disability and therefore adopt a more dominant sibling role (e.g., see Dallis, Stevenson, & McGurk, 1993). In a book chapter introducing the research challenges of studying the sibling relationships of children with and without a disability, Stoneman and Brody (1993) referred to the assumption of dominant roles by younger siblings over their older brothers and sisters with an intellectual disability as "role crossover" (p. 7). Nonetheless, despite this shortcoming, the clinical typology approach had considerable influence on thinking and research on typical sibling relationships and also in relationships where one sibling had a disability. There was a similar focus among researchers in the disability field at that time to explain sibling interactions based on the impact of birth order and gender (e.g., see Breslau, 1982; Dallis, et al., 1993).

The early sibling research focused on the negative impact on the first-born child of having a brother or sister. The positive impact of sibling relationships was not mentioned until later, by writers such as Provence and Solnit (1983) (cited in Sanders, 2004, p. 59) who used a case study approach to study sibling relationships

and noted that “the sibling experience provides frequent and ongoing opportunities for children to develop a capacity for empathy”.

In the last 20 years more complex and sophisticated understandings of sibling relationships have been proposed by researchers such as Judy Dunn and colleagues (e.g., Dunn & Munn, 1986; Dunn & Plomin, 1991) drawn from the application of the increasing range of research methods to study sibling relationships along with theoretical perspectives enhancing the study of families more generally. Along with quantitative studies using standardised instruments, this new era of sibling research has included qualitative methods such as direct observation of sibling interactions (e.g., Dallis, et al., 1993; Stoneman, Brody, Davis, & Crapps, 1987, 1989), case studies (e.g., Flaton, 2006), questionnaires (e.g., Begun, 1989), interviews with parents and siblings (e.g., McHale & Gamble, 1989; Roe, 1988; Stoneman, Brody, Davis, Crapps, & Malone, 1991) and, most recently, analysis of postings on internet chat rooms (Barr & McLeod, 2010). This emerging research sophistication has led to an understanding that rather than sibling relationships being either “good” or “bad”, they are complex and varied. In her review of the research themes regarding siblings of children with a disability, Stoneman (2005) had already highlighted the progression in research from a focus on the detrimental effects of being a non-disabled brother or sister to the more recent inclusion of positive effects.

Historically, it was taken for granted in sibling research that brothers and sisters would grow up together in the family home (Sanders, 2004). However, according to Drapeau and colleagues (2000), recent changes in family composition due to higher divorce rates and the increased intervention of family welfare services result in some siblings becoming separated in childhood. Many children with cerebral palsy who were born during the 1950s to the 1980s in country areas in Australia were

sent away from their family homes to special-purpose boarding schools to access education and therapy. Therefore, in order to better understand the adult sibling relationship between people with cerebral palsy and their non-disabled siblings, it is particularly relevant to this study to consider the impact of siblings growing up together or being separated in childhood.

Growing up together

In introducing a recent special issue on siblings as agents of socialisation, Kramer and Conger (2009) proposed that growing up together in the family home contributed to the development of empathy and caring between siblings. These traits are important in understanding the quality of the relationship that develops between siblings. For example, in lamenting the lack of research on the quality of sibling relationships, Sanders (2004, p. 70) noted that “the intimacy and affection that a child shows towards his or her siblings are probably very important as indicators of sibling relationship quality as well as being an influence on the sibling relationship”. Moreover, Sanders stated that empirical evidence pointed to the presence or absence of warmth in the sibling relationship as the most important determinant of the quality of that relationship, more significant even than the presence or absence of rivalry or hostility. Nonetheless, in their empirical study described below, Howe et al. (2001) described warmth or affection, rivalry, and hostility as significant but not mutually exclusive aspects of sibling relationships. A child can feel affection towards a brother or sister while at the same time being the rival and sometimes feeling hostility towards the sibling.

An example of the importance of growing up together for the development of warmth between siblings can be found in a study by Howe et al. (2001). They studied emotional understanding and warmth among siblings ($N = 40$) with a mean age of

11.5 years using the Sibling Relationship Questionnaire (Furman & Buhrmester, 1985 cited in Howe, et al., 2001) and the Hypothetical Relationships Picture Task (adapted from Schneider, 1989, and Aquan-Assee, 1992 cited in Howe, et al., 2001). Howe et al. defined warm sibling relationships as those involving the sharing of confidences and emotional support. The authors attributed the development of warmth between siblings to a combination of shared family history and shared environment. They described trust and the sharing of confidences between siblings as important indicators of positive sibling relationships. Furthermore, they concluded that positive sibling relationships were built on feelings of reciprocity, reliance and emotional support, which can be of particular relevance to their relationships later in life.

In a subsequent study, Howe and Recchia (2005) used observations and a sibling relationship quality measure to study the associations between siblings' reciprocal (defined as play) and complementary (defined as teaching) interactions in 70 sibling dyads (first-born aged between 4 years 9 months and 9 years 9 months; and second-born aged between 2 years 9 months and 6 years 5 months). The authors reported that those siblings who engaged in both reciprocal and complementary interactions "co-construct shared meanings about their play through a history of friendly joint experiences" (p. 501). It is interesting to note the recognition of reciprocity in the interactions between siblings at such an early age. Indeed, according to Howe and Recchia, living together in the family home provides the environment in which siblings play with and learn from each other.

Stoneman (2001) reviewed the literature on the interpersonal relationships between children with a disability and their non-disabled siblings. Stoneman identified that, contrary to what might be expected, researchers consistently reported, across disability groups and countries, more positive and nurturing relationships

between siblings when one had a disability compared to control groups where neither sibling had a disability. Stoneman related this to the development of warm, positive sibling relationships between non-disabled siblings and their brother or sister with a disability.

If warmth is an important factor in establishing close sibling relationships and if sharing the family home is instrumental in developing warmth, it follows that separation of siblings in childhood might detrimentally affect the development of a warm sibling relationship. Children with a lifelong developmental disability were, and in many countries remain, vulnerable to out-of-home placement in childhood (Baker & Blacher, 2002; Blacher, 1993). For those who are now middle-aged, their parents were often advised by health professionals to remove the child with a disability from the family home in the best interests of their other children (e.g., Daly, 2009; Goldstein, 2009; Mirfin-Veitch, et al., 2003; Moyer, 2009). Seemingly little thought was given to the effect of this separation on the relationship between siblings with and without disability (Eisenberg, Baker, & Blacher, 1998). However, retrospective accounts such as those in Meyer's (2009) collection of 39 essays written by non-disabled siblings of people with disabilities (including Daly, Goldstein, and Moyer cited above) provide poignant reminders of the lifelong impact of growing up with, and separation from, a brother or sister with a disability. As mentioned previously, given that many children with cerebral palsy and their siblings experienced separation (either for short periods as noted earlier or over longer periods), it is useful to understand the effect of separation on siblings in childhood.

Separation in Childhood

In a study of children undergoing major transitions in their lives due to their placement in foster care or their parents' divorce, Drapeau et al. (2000) highlighted

the importance of siblings sharing an environment during their developmental years. The authors used questionnaires to examine sibling relationships during transitions of children to foster care placements ($N = 150$ family units) and those experiencing parental divorce ($N = 144$ family units), 618 children in total. They reported that separated siblings had less contact with and felt less warmth towards their siblings than those who remained together. They concluded that warmth between siblings was fostered through living together in childhood and that separation of siblings during critical transitions denied them a crucial part of their support system.

In developing a model to guide future research on sibling socialisation, Conger et al. (2009) reviewed the literature on the effects on the quality of sibling relationships of stressful life events and experiences, including parental marital conflict, parental divorce and remarriage, foster care placement, and having a brother or sister with a developmental disability. The authors warned that the experience of separation from the family, for whatever reason and however well intentioned, can have negative affects on a child and the relationship with parents and siblings. The model developed by Conger and colleagues highlighted the importance of the quality of early sibling relationships in predicting later sibling interactions. Importantly, in the context of this study, Conger et al. concluded that “Siblings who enjoy positive relationships are more likely to maintain prosocial interactions and provide support in the face of family stressors” (p. 53). Not all separations in childhood are permanent, and the experience of spending time away from the family home at boarding school is a not uncommon experience for children with and without disability.

Drawing on three case studies from her clinical practice as examples, psychotherapist Joy Schaverien (2004) used the term “boarding school survivors” (p. 684) for the adults to whom she provided psychotherapy, to describe the trauma of

being sent away to boarding school at a young age. Schaverien is based in the United Kingdom where attendance at boarding school was, and still is to a lesser extent, common especially among the “well to do”. Schaverien acknowledged that despite parents’ best intentions, separation from the family in young childhood resulted in a loss of intimacy, familial feeling and contact with home. She also highlighted the “secondary rupture that damages sibling relationships” (p. 694), especially when one sibling is sent to boarding school and others are not. Indeed, Schaverien noted that this can cause jealousy between siblings which can extend to lifelong animosity. Schaverien’s work must be treated with a degree of caution as, in common with early work by psychoanalysts and clinical typologists, Schaverien’s work was conducted with clients seeking professional help for psychological problems, who may therefore constitute a negatively predisposed sample.

In contrast to Schaverien’s work, and as a reminder that boarding school experiences are not always traumatic and detrimental, Australian authors Bramston and Patrick (2007) reported on the results of questionnaires administered to rural-based adolescent children ($N = 36$) with a mean age of 13.2 years who were making the transition from their rural homes to boarding school for their high school education. The authors reported that, although the move to boarding school was regarded as a life-changing transition, it was generally considered by the children as positive, with 60% of participants reporting that their initial feelings of homesickness were mild and passed quickly. Using focus groups with another group of adolescents ($N = 28$) who had previously made the move to boarding school, Bramston and Patrick (2007) reported that the children identified educational opportunities and the ability to make new friends as just two of the main benefits of moving from isolated

rural communities to city-based boarding schools. A lack of privacy, freedom, and boredom were the negative aspects reported.

Bramston and Patrick did not consider the issue of how sibling relationships are affected for these children and their brothers and sisters left at home. Another important difference between the studies of Schaverien (2004) and Bramston and Patrick (2007) is that in the former the participants attended boarding school from as young as 5 or 6 years of age whereas those in Bramston and Patrick's study were adolescents. According to Laursen and Bukowski (1997) and Schulenberg et al. (2004), adolescents are much more likely to adapt to being away from home and living communally with others of their own age, as during adolescence teenagers try to construct autonomous identities outside their families and peers often take on greater importance than siblings during that time.

Blacher and colleagues (e.g., Blacher, 1993, 1994; Blacher & Baker, 1994) have conducted research on the out-of-home placement of children with a disability. Drawing on the results of this earlier research, Eisenberg et al. (1998) conducted one of the few studies to consider the effect on non-disabled siblings of the placement into out-of-home care of their brother or sister with an intellectual disability. Using interviews, self-report questionnaires, and parental reports, Eisenberg et al. compared the sibling experiences of children and adolescents (age range 9-20) whose sibling with a disability was living at home ($N = 25$); whose brother or sister had been placed into out-of-home care ($N = 20$); and a control group whose siblings did not have a disability ($N = 28$). They reported that whereas there was little difference between the groups on measures of psychological adjustment, self-esteem, and family environment, the siblings who had a brother or sister with a disability in out-of-home placement were more likely to report less warmth and less conflict in their

relationship with the placed brother or sister. Despite this, the siblings of children who were in out-of-home placement supported their parents' decision to place their brother or sister out of home, and reported positive personal growth experiences and less family conflict as a result of the placement.

In common with other sibling studies, the findings of Eisenberg et al. demonstrated that separation during childhood lessened warmth between siblings when one had a disability, and pointed to a need for further study of the long-term impact on the sibling relationship. As far as I am aware there is no research specifically focused on the impact on children with cerebral palsy who were sent away from home to attend specialist boarding schools. However, it is reasonable to surmise that they may also experience a distancing from their non-disabled siblings who stayed at home.

Adolescence marks a significant transition in the life course, during which siblings may become emotionally if not geographically distant from each other. According to Goetting (1986) and White (2001), contact between siblings during adolescence often becomes more voluntary and less frequent, and sibling relationships shift from being involuntary to being voluntary. Goetting (1986) reviewed the research on the developmental tasks of being a sibling over the life course. She commented that during adolescence siblings may also act as confidants to each other, especially in discussions about sex and drug use, topics that they might not wish to discuss with their parents, and also older siblings may play a role in explaining younger siblings' behaviour to their parents.

In studying sibling relationships across the life course, White (2001) examined data from 9,000 individuals aged from 16-85 years, collected as part of a large national survey of families in the USA in 1987-1988 and 1992-1994. White

concluded that contact between siblings is likely to diminish in young adulthood but increases again as siblings experience similar transition milestones such as getting married and having children. Having a chronic lifelong disability such as cerebral palsy might mean that people do not achieve the same transition milestones as their non-disabled siblings. Following a life-course perspective, the transition to adulthood is the next stage in the developing relationship between siblings.

3.3.2. Transition to adulthood

In Australia, 18 is recognised as the legal adult age at which young people attain the right to vote in elections, drink alcohol, get married without parental consent, and sign contracts (Australian Human Rights Commission, 2010). However, 18 is an arbitrary age associated with leaving high school, and it is generally recognised that the transition to adulthood evolves over a number of years, with significant differences in the way individuals experience it.

There have emerged two schools of thought, which are not mutually exclusive, about how to identify when a person has achieved “adult” status. One school of thought focuses on the attainment of transition milestones such as leaving school and getting a full-time job, going on to further education, leaving the parental home to establish an independent residence, entering a romantic relationship, and having children. As Priestley (2003) warned, the danger with this approach is that it tends to discriminate against those who may never achieve some or any of these milestones. Priestley (2003, p. 113) wrote, “many people (often with learning difficulties or complex impairments) [are consigned to] a nether world of repeated, unresolved transitions in which true adult status is neither envisaged or attained”. In particular, due to the severity of their physical impairments, achieving some transition milestones may be difficult for people with chronic lifelong disabilities such as those

with moderate to severe cerebral palsy and this can “widen the gap” between non-disabled siblings who are leaving home, getting a job and getting married and their brother or sister with cerebral palsy who is not.

The other way of viewing the achievement of adult status is to consider the personal qualities (rather than the milestones) that are recognised as indicative of adulthood. These personal qualities may include accepting responsibilities for one’s actions and decisions, making independent decisions, becoming self-sufficient, and gaining financial independence (Arnett, 1998, 2000). Adopting this view of adulthood may be more inclusive of people with chronic lifelong disability, as it is possible, although sometimes difficult, to exercise agency while relying on others to carry out activities necessary to achieve life goals (Galambos, Darrah, & Magill-Evans, 2007). Both viewpoints are presented here with reference to the general and disability-specific literature. Due to the reliance of many people with moderate to severe cerebral palsy on formal services throughout their lives, the final part of this section examines the literature on the impact of moving from child to adult services for young adults with cerebral palsy.

Attaining transition milestones

Three studies drawn from the disability literature focus on the achievement of identified transition milestones as indicative of adult status. These studies assess whether, and how well, people with lifelong disabilities compared to their non-disabled peers achieve the following transition milestones: full-time employment or study, independent residential status, marriage and/or having children.

Wells et al. (2003) drew on longitudinal data from two large U.S. national surveys, the National Longitudinal Transition Study of Special Education Students, 1987-1991 ($N = 5,297$), and the National Educational Longitudinal Study of 1988 (N

= 12,490) to examine educational attainment, competitive employment, residential independence, and family formation (marriage and parenthood) for people with a disability aged between 18 and 26 years of age. Cerebral palsy is not specifically mentioned in the participant descriptions, but “speech impairment”, “orthopedic impairment” and “other physical disability” are all mentioned; thus people with cerebral palsy may have been included. The authors conducted latent class analysis of demographic variables including education, employment, marital status, parental status, and residential independence. They then used multinomial logistic regression to find specific factors associated with these variables. The authors reported that having a disability affected the socio-economic and personal outcomes of the person, as 40% of those who attended special education continued to live at home with parents and were not involved in education or employment after leaving school. Indeed, Wells et al. (2003, p. 826) stated:

Disability and type of disability profoundly impact youths’ early steps toward adulthood, and among young persons with disabilities, the effects of disability and the type of disability greatly overshadow those of race and ethnicity, family structure, and number of siblings.

However, the authors reported that those with mobility and sensory impairments were more likely to progress to some form of postsecondary education than those with an intellectual disability.

Van Naarden Braun et al. (2006) used a structured questionnaire with 635 young people, 21-25 year olds recruited from the U.S. Metropolitan Atlanta Developmental Disabilities Follow-up Study of Young Adults who had been identified at the age of 10 as having a childhood impairment, including a small group with cerebral palsy ($N = 18$). In studying the relationship between childhood

impairment and the attainment of normative adult social roles, the authors measured participation in competitive employment, participation in postsecondary education, and being a caregiver. Van Naarden Braun and colleagues reported that study participants were “significantly less likely than young adults without impairment to have acquired an adult social role” (p. 919). For example, of the 18 participants with cerebral palsy, 50% were employed, 11% were students, none was a caregiver, and 38.9% held none of those social roles. The authors stated that among young adults with cerebral palsy, hearing loss, vision impairment, epilepsy, and mild intellectual disability, there was considerable diversity in attaining normative adult social roles, in large part dependent upon the individual’s ability to independently perform activities of daily living (e.g., bathing, dressing, getting in and out of bed, getting around outside the home) or instrumental activities of daily living (e.g., meal preparation, shopping, paying bills, using the telephone, and doing laundry). The authors concluded that increasing independence in activities of daily living and instrumental activities of daily living was likely to enhance a person’s chances of acquiring at least one of the adult social roles identified in their study.

In a recent study, Janus (2009) used data from the U.S. National Education Longitudinal Study of 1988 to estimate the effect of disability on 9,345 young adults’ (aged 26) attainment of four adult transition milestones: full-time employment, living independently, marrying, and having children. Replicating the method of analysis used by Wells et al. (2003), Janus used latent class analysis to categorise respondents based on the adult transitions they had completed by the age of 26 and multinomial logistic regression analysis to ascertain the effect of type of disability on latent class membership. According to Janus, the presence of a visual, hearing, speech or “other” impairment significantly increased the likelihood that the person by the age of 26

would not be in full-time employment, have moved out of home, have married or had children. Therefore, Janus proposed a category which he termed “laggards” (p. 109) to describe this group who, he said, were “falling behind their peers in the transition to adulthood” (p. 115). In particular Janus identified living independently from parents by the age of 26 as a crucial indicator of transition to adulthood, a milestone which he linked with full-time employment, as economic independence is required to live independently. Janus also highlighted that living independently indicated self-sufficiency and “affords a private space that is necessary for developing intimate relationships and starting a family” (p. 116). Janus commented that having a job, living independently and having a relationship are therefore interlinked rather than discrete variables.

The similar results from these studies indicate that the transition from adolescence to adulthood for people with lifelong disability such as cerebral palsy is challenging, and that few are able to “successfully” achieve the milestones which were identified as indicative of transition to adult status. The study by van Naarden Braun et al. (2006) suggested that people who were more independent in living skills were more likely to achieve transition milestones than those who were dependent on caregivers for these tasks. These studies were all large, quantitative studies which focused on achievement (or lack of achievement) of transition milestones. As such, they did not seek to find out whether participants perceived themselves as adults or what qualities they considered to be important in defining themselves as adults. Also, since these studies provided a snapshot of milestone achievement at a particular point in time they did not capture the emerging and evolving aspects of becoming an adult over time. For people with significant physical impairments it may be the

achievement of adult qualities rather than transition milestones which is more important in marking the passage to adulthood.

Developing personal adult qualities

Acting as a bridge between adolescence and adulthood is a period which Arnett (1998, 2000) termed “emerging adulthood”, describing it as “the process of developing the capacities, skills, and qualities of character deemed by their culture as necessary for completing the transition to adulthood” (Arnett, 1998, p. 312). Building on his earlier work with late adolescent American college students (Arnett, 1994), Arnett (1998) used questionnaires and structured interviews with 140 young adults aged 21-28 years to ascertain their understanding of what it meant to become an adult. He reported that these young Americans identified: “accepting responsibility for one’s self, making independent decisions and, financial independence” (Arnett, 1998, p. 304) as the three most important characteristics of adulthood.

Based on data from his 1998 study, Arnett (2000) noted that on their way to acquiring these attributes, emerging adults typically experienced a period of frequent change and exploration, during which they were relatively free from the responsibilities and expectations of full adulthood. Therefore, during the period of emerging adulthood people were experimenting with different interpersonal, study and work relationships while at the same time exploring where they stood on various moral and philosophical issues. Arnett (2000) identified residential status and school attendance as two demographic aspects that reflected this period of exploration and instability. He described the period when emerging adults were attending higher education and living away from their parents’ homes in residential colleges as a period of semi-autonomy from parents. Nonetheless, Arnett (1998, 2000) concluded that it was the acquisition of the individual character qualities of self-sufficiency,

responsibility, and independent control over decisions and finances which was more important in conceiving of oneself as an adult than the achievement of specific events such as getting married, having children or establishing a career. The comments of Arnett's participants that they did not consider attainment of these milestones as necessarily indicative of adult status are interesting in the context of people with physical impairments associated with cerebral palsy who, as mentioned previously, may experience difficulty achieving some milestones.

In order to see whether Arnett's (1998, 2000) concept of emerging adulthood was applicable to people with a motor disability, Galambos et al. (2007) used questionnaires and interviews with 148 young Canadian adults aged 20-30 years, 54 of whom had cerebral palsy, 22 spina bifida, and a control group of 72 who had no motor disability. Galambos and colleagues hypothesised that due to their physical limitations, young adults with a motor disability might find it harder to become autonomous and independent, to be employed in productive activity, to establish a sense of identity, and to achieve intimacy, compared to the control group without a disability. Contributing to this was the reported delay in young adults with motor disabilities in achieving developmental milestones at age-appropriate times, parental overprotection which might create dependency, and lower expectations of independence. Supporting their hypothesis, Galambos et al. found that, compared to the control group, participants with motor disability achieved fewer role transitions, were given less autonomy by their fathers (but not their mothers), and felt that their parents treated them as younger than their chronological age. However, in keeping with Arnett's findings, the authors reported that psychosocial maturity was important for participants with motor disabilities and, in particular, a sense of responsibility and

independence were significantly aligned with the belief that they had achieved adult status.

Interestingly, Galambos and colleagues (2007) reported that participants with more severe physical impairments reported feeling older than their chronological years. The authors proposed a number of reasons for this. First, people who cannot keep up physically with peers and who rely on assistive devices and support may perceive themselves as older. Second, due to the severity of their disability, they might not have the same opportunities for interactions with their peers and may spend more time with older adults, including their parents. Third, because they have had to deal with physical challenges and people's perceptions of them based on their impairment, they may feel older and more mature than people with less severe impairments or no disability at all.

Offering a note of caution about accepting Arnett's (1998, 2000) distinct developmental category of emerging adulthood, Hendry and Kloep (2010) applied Arnett's concept in their study with young people who were not in any form of higher education and who lived in South Wales in the U.K. Hendry and Kloep conducted interviews with 38 young adults between the ages of 17 and 20 (representing the younger end of Arnett's emerging adult stage) who were in full- or part-time employment or were unemployed. Thirty two participants still lived with their parents, one was married, one had a child and one was pregnant.

Hendry and Kloep used a two-stage data analysis process. First, they used thematic analysis matched to Arnett's characteristics of emerging adulthood. Second, they identified emerging themes from the individual analysis of participants' narratives. Hendry and Kloep suggested that Arnett's identification of a distinct stage of emerging adulthood lacked universal applicability and applied only to young

people who were enrolled in higher education. According to Hendry and Kloep, their participants demonstrated a greater range of variation in the transition to adulthood than suggested by Arnett. For example, Hendry and Kloep reported that “many young people in our sample stated they were already settled, either in their job or in a relationship, and had gained independence from their parents at the very beginning of the emerging adult period” (p. 172). In particular, for their participants, leaving school and getting a full-time job was perceived as a major turning point in their achievement of adult status, regardless of whether they were still living with their parents or not. These authors therefore considered that the achievement of turning points was important but should not be tied to particular ages. Although Hendry and Kloep’s sample size was small, they identified that differences in the transition to adulthood were likely to be due to differences in socio-economic status, culture, and life experiences. There may also be differences for some people with cerebral palsy due to their significant physical impairments.

It would seem that both individual qualities as identified by Arnett (1998, 2000) and Galambos et al. (2007), and the achievement of recognised milestones as discussed by Wells et al. (2003), van Naarden Braun et al. (2006), Janus (2009) and Hendry and Kloep (2010) have a place in marking the transition from adolescence to young adulthood. However, reliance on the achievement of transition milestones alone may be problematic when considering transitions to adulthood for young people with a chronic lifelong disability such as cerebral palsy. It seems preferable to consider both personal qualities and transition milestone achievement in any consideration of adulthood.

Throughout their lives the majority of people with moderate to severe cerebral palsy are likely to receive services from specialist support organisations. Parents, and

later possibly non-disabled siblings, are likely to assist the person with cerebral palsy to navigate the service sector. It would be reasonable, therefore, to assume that specialist services would guide people with cerebral palsy and their family members through the transition from one service type to another, including the move from school to post-school activities and services. However, a number of studies indicate that this is not necessarily the case. Child and adult services are often quite separate, with little coordination between them.

Specialist support services and parents' roles in the transition to adulthood

Stevenson et al. (1997) used questionnaires with two groups (Group 1 aged between 15 and 18 years and Group 2 between 20 and 22 years) comprising 74 young people with cerebral palsy and their main carers, to investigate the young people's transition to adult health and social services in the United Kingdom. The authors reported little difference between the two groups on any of their measures. They did, however, report that participants' use of health and social services decreased and they engaged in fewer leisure activities after they left school, with the older age group the least socially active. The study identified that making the transition from child to adult services was potentially socially isolating for people with cerebral palsy, and that because of their reduced service use in young adulthood they might rely more, rather than less, on their parents.

To separate the effects of transition to adulthood from the effects of having a diagnosis of cerebral palsy, Magill-Evans et al. (2001) in Canada compared the views of two groups of 90 people with cerebral palsy (Group 1 aged 13-15 years, Group 2 aged 19-23 years) with those of 75 people without a physical disability and their family members. Using standardised questionnaires they gathered data from the

participants about family functioning, life satisfaction and perceived social support. The authors found no significant differences between either of the groups of people with cerebral palsy or the control group on many of the measures. However, there was a difference in expectations about the future, with the older group of participants with cerebral palsy and their family members reporting lower expectations than the younger group with cerebral palsy or the control group. The authors noted that this more pessimistic outlook was consistent with that found in an earlier study (Magill-Evans & Restall, 1991) which identified restricted lifestyles for young adults with cerebral palsy (average age 22 years). The 1991 study found that young adults with cerebral palsy were more likely to remain living with their parents and less likely to be employed than their age peers without cerebral palsy. Therefore, according to Magill-Evans et al. (2001), the pessimistic view of the older people with cerebral palsy and their parents might represent a more realistic appraisal of their opportunities and challenges to achieve transition milestones.

Antle et al. (2007) studied the health promotion efforts of parents on behalf of their adolescent child with a physical disability in Canada. They interviewed 15 families of children aged between 11-16 years who had a physical disability, including 7 with cerebral palsy. They reported that parents made extraordinary efforts to ensure the health and wellbeing of their son or daughter with cerebral palsy. Furthermore, parents strove to achieve a balance between their involvement in their son or daughter's life and the independence their son or daughter wanted, the parents acknowledging that independence was an important factor in assisting their son or daughter to make the transition to adulthood.

In a review article, Binks et al. (2007) identified 149 peer-reviewed publications addressing the transition from child-centred to adult-centred health care

services for people with cerebral palsy or spina bifida. From the reviewed publications the authors identified that barriers to transition came from (1) the young people themselves who were reluctant to transfer from the child-centred services which had provided them with care all their lives, (2) their parents who were reluctant to relinquish control over their “child’s” health care, and (3) service providers, with child-centred health care providers distrustful of adult-centred health providers’ knowledge about how to treat this population, and adult-centred health providers reporting they indeed felt ill-prepared and ill-trained to meet the needs of these groups. Binks and colleagues acknowledged that the complex health care needs of young adults with cerebral palsy and spina bifida presented unique challenges in the transition from one service model to another.

Binks et al. (2007) further identified five key elements as important in assisting people with cerebral palsy and spina bifida to make successful transitions from child to adult health care: (1) the timing of the transition, which ideally was determined by the person’s cognitive development, physical abilities, environment, and family support; (2) a long lead-time over a number of years in preparation for the transition; (3) a coordinated approach involving the person, the family and a multidisciplinary team; (4) implementation of transition clinics to ensure a smooth handover; and (5) interested adult-centred health care providers who looked beyond physical health to include issues such as independence, sexuality, and body image. These five elements might go some way to addressing the concerns about less service, greater dependence on parents, and a pessimistic outlook, identified in the studies of Stevenson et al. (1997) and Magill-Evans et al. (2001). However, Binks and colleagues found that the five elements were not consistently applied or evaluated in

the studies they reviewed. Rather, the five elements were based more on theory and clinical experience than in evidence-based research.

Roebroek et al. (2009) conducted a review of the literature on the issues related to functioning, quality of life and lifespan care for adolescents and young adults with childhood-onset physical disability including cerebral palsy. From the findings of the reviewed articles, Roebroek and colleagues concluded that young people with a physical disability required significant support to develop autonomous adult lives and that some “choose or are expected to adopt passive, childlike roles” (p. 676). According to the authors, compounding the problem of achieving autonomous adult lives was the “discontinuity of care” (p. 676) faced by people with a lifelong physical disability as they transition from child to adult services.

This perceived discontinuity of care was also noted in two studies by Darrah and colleagues. On the basis of semi-structured interviews with 49 adolescents (aged 13-15 years) and 39 young adults (19-23 years) and their family members, Darrah et al. (2002) reported widespread dissatisfaction with both the bureaucratic structures and attitudes of Canadian service providers. In a follow-up study, Darrah et al. (2010) interviewed 76 young Canadian adults between 20-30 years of age, of whom 54 had cerebral palsy (the other 22 had spina bifida) about their experiences of educational, employment, transportation and assured income service programs in relation to their transition to adulthood. The authors (2010, p. 224) reported a “paradox of services”, by which they meant that although services had been established to enhance the independence of people during their transition to adulthood they in fact often impeded independence and community participation by creating dependencies and limited choices. The authors concluded that “successful transition to adulthood for people

with motor disabilities is dependent on the best fit between their functional abilities and the environmental supports available to them” (p. 228).

In sum, the studies discussed in this section have identified the difficulties which many young adults with cerebral palsy experience in making the transition from child to adult services. In particular the reviews by Binks et al. (2007) and Roebroek et al. (2009) and the study by Darrah et al. (2010) highlighted the discontinuities between the more comprehensive and coordinated childhood services and the less structured adult services which appeared to require more individual effort to access. As indicated by Stevenson et al. (1997), because of difficulties in finding and accessing adult services young people making the transition to adulthood may rely more on their parents at a time when other young adults are taking greater control over their lives. The studies by Stevenson et al. (1997) and Antle et al. (2007) identified the key role of parents in encouraging and supporting their young adult child with cerebral palsy to develop independence in adulthood. Lastly, all the studies highlighted that more work needs to be done to identify the barriers and opportunities for independence at the time of transition from childhood to adulthood for young people with cerebral palsy.

None of these studies included the viewpoint of non-disabled siblings about the transition of their brother or sister with cerebral palsy, or of themselves, to adulthood, nor were any carried out in Australia, where the context, particularly the service context, may have some essential differences. Non-disabled siblings may be achieving transition milestones and acquiring the personal qualities of adulthood while their brother or sister with cerebral palsy is struggling with making this transition. Indeed, as indicated by Priestley (2000), not all siblings will achieve transition milestones, and so Arnett’s (1998, 2000) approach of considering the

development of personal qualities might be more useful in identifying the extent to which young adults with cerebral palsy have a sense of control over their lives and are able to experience self-sufficiency.

People with moderate to severe cerebral palsy are living longer and are more likely, along with their non-disabled siblings, to survive to middle age and outlive their parents. At that time people with cerebral palsy may need the support of their non-disabled siblings to assist them with some of the tasks previously performed by their parents. The next section reviews the literature on middle and later life sibling relationships.

3.3.3. Middle and later life sibling relationships

In adulthood, sibling relationships become increasingly voluntary. Despite, or perhaps because of this increasingly voluntary nature of sibling relationships in adulthood, Goetting (1986) reported that adult siblings provided each other with social and emotional support throughout their adult lives. Drawing on her substantial work in the areas of ageing, family relationships, and siblings (Connidis, 1992, 1994), Connidis' (2001) book on family ties and ageing highlighted that sibling relationships provide a sense of continuity across the life course, which may be especially important if and when other relationships end (e.g., due to divorce or death). According to Connidis, this continuity is developed through siblings sharing a common background in terms of cultural and social experiences, and is related to shared class and race. Siblings who lived together throughout childhood also developed family "sentiments", which are indicative of the affection and love they feel for each other and their parents.

Connidis (2001) also identified that differences between siblings can be based on variables such as gender, birth order, age differences, personality, and geographic

proximity. In the context of this study, I would add lifelong disability. In the following section I review the literature about the effects of these variables, including lifelong disability, on families with and without an adult member with a disability.

Gender

In the literature on siblings' involvement in caregiving for elderly parents, gender is the variable most often discussed, with sisters credited as taking on a greater caregiving role than brothers (e.g., Connidis, 1994, 2001; Goetting, 1986; White, 2001). Similarly, the literature on sibling relationships where one has a disability suggests that sisters are more likely than brothers to take on a caregiving role for their brother or sister with a disability (e.g., Bigby, 2000; Grossman, 1972; Harland & Cuskelly, 2000; Hodapp, Urbano, & Burke, 2010; Orsmond & Seltzer, 2000).

The most frequently cited study on this topic in the disability field is by Orsmond and Seltzer (2000), who investigated the impact of gender on the support offered by sisters and brothers of adults with an intellectual disability. The authors surveyed a sub-sample of adult siblings ($N = 245$: 167 sisters and 78 brothers, average age 39 years) of people with an intellectual disability nominated by their ageing mothers who took part in a longitudinal study in the U.S. of ageing parent-carers ($N = 461$).

The survey asked siblings about their instrumental involvement (caregiving and companionship) and affective involvement (positive affect and emotion) with their disabled brother or sister. According to Orsmond and Seltzer, sisters reported feeling more positive towards, and providing more support to their sibling with an intellectual disability, regardless of the sibling's gender. On the other hand, brothers' feelings and involvement varied according to the gender of their disabled sibling. Brothers of disabled brothers had the most positive feelings towards, the least

negative feelings about, and expressed the least concern regarding future care for their brother. This contrasted with brothers of disabled sisters, who demonstrated the least positive feelings, more negative feelings, and the most concern about the future.

Orsmond and Seltzer suggested a same-sex principle operating in such a way that gender in sibling dyads ought to be one factor to consider in determining which siblings might provide support to their disabled brother or sister later in life.

In a recently published study, Hodapp et al. (2010) gained responses from 1,160 participants including 910 adult sisters and 250 brothers of people with a disability to a U.S. national, web-based 163-question survey about their health, contact with, and perceived benefits from their relationship with their disabled sibling. The age range of participants was 18-85 years with a mean age of 36.72 years. Just under half of the participants had a brother or sister with an intellectual disability ($N = 549$), and 147 had a sibling with cerebral palsy. Hodapp and colleagues reported that, consistent with Orsmond and Seltzer's (2000) findings, female non-disabled siblings had more contact with, and regarded their relationship as closer to their sibling with a disability than did brothers. Hodapp et al. also reported that, compared to the general American female population, more sisters of people with a disability did not marry or married and had children later than their peers. The same was not found for brothers with a sibling with a disability. The authors proposed that these differences might be due to sisters taking "a more cautious stance toward major life decisions" (p. 60), given their anticipated future role in the life of their brother or sister with a disability compared to the general population and compared to their non-disabled brothers.

Consistent with Connidis' claims (1992, 1994, 2001), Orsmond and Seltzer's research with adult siblings where one is disabled demonstrates greater closeness in middle and old age, and particularly as parents' health deteriorates. Orsmond and

Seltzer (2000) and Hodapp et al. (2010) also identified that sisters and brothers would be involved in supporting their disabled brother (although not necessarily sister) after their parents died or could no longer continue their caring role. The majority of Orsmond and Seltzer's sample had a sibling with a mild/moderate (76%) rather than severe/profound (22%) intellectual disability. Type and severity of disability may be important variables in considering sibling involvement in other populations, such as people with moderate to severe cerebral palsy.

Type and severity of disability

Three studies highlighted sibling issues associated with the type and severity of disability, although none related to people with cerebral palsy. Orsmond and Seltzer (2007) used questionnaires to examine the instrumental and affective involvement of adult siblings (mean age 38 years) in the lives of their brothers or sisters with Autism Spectrum Disorder ($N = 77$) or Down syndrome ($N = 77$). Orsmond and Seltzer reported less contact, lower levels of positive affect, and more pessimism about the future for siblings of people with autism spectrum disorder compared to those with a sibling with Down syndrome. The authors suggested that the particular features of autism spectrum disorder, including behavioural and communication difficulties, could affect the quality of the sibling relationship, which in turn might affect the support provided by non-disabled siblings to their brother or sister in later life. Many people with cerebral palsy also have communication impairments, which may affect their relationships with their non-disabled siblings. However, the communication difficulties of people with cerebral palsy's are usually related to motor disorders and are thus quite different from those experienced by people with autism. Nonetheless, difficulty in communicating with a brother or sister can create challenges in the relationship.

Hodapp and Urbano (2007) reported the results of a large-scale web-based study of the differences between adult siblings of people with Down syndrome ($N = 284$) and autism ($N = 176$) using The Adult Sibling Questionnaire to measure contact, warmth, closeness, and positiveness of the sibling relationship. They also assessed the non-disabled siblings' overall levels of depression, perceived health, and the rewards they felt from being a sibling. Hodapp and Urbano reported similar findings to those of Orsmond and Seltzer (2007): non-disabled siblings of people with Down syndrome demonstrated more warmth and closeness in their relationship with their brother or sister than those with a sibling with autism. Siblings of people with Down syndrome also reported more contact with their brother or sister and better health, including less depression. Consistent with the conclusions drawn by Orsmond and Seltzer (2007), Hodapp and Urbano hypothesised that the differences might be due to the specific characteristics of the disability. Hodapp and Urbano (p. 1018) described the "Down syndrome advantage", with lower levels of behavioural problems than people with autism. Hodapp and Urbano pointed out that this is the first generation of people with Down syndrome to live to older age and to outlive their parents. The warmth, closeness and positive feelings of non-disabled siblings towards their brother or sister with Down syndrome may play an important part in their possible future role in the life of their brother or sister after their parents' death.

It is not possible to draw conclusions about the sibling relationships of people with cerebral palsy on the basis of studies of people with Down syndrome and autism spectrum disorder. However, these studies sensitise the researcher to think about specific issues related to different types of disability.

In one of the only studies to consider the sibling relationships of people with sensory impairments, Harland and Cuskelly (2000) conducted interviews in Australia

with six siblings of people with multiple disabilities including severe to profound levels of vision and hearing impairment aged between 24 and 34 years. The authors reported that these siblings said they were willing to act as advocates for and to provide emotional support to their brother or sister with a disability but most did not envisage taking on a care-giving role for them. Given the relatively young age of the participants and the small sample size it is difficult to attribute differences in the stated involvement of non-disabled siblings to the nature of their brother or sister's disability. Indeed, the study highlighted the study participants' similarities, rather than differences, to the literature on siblings of people with an intellectual disability.

The findings from Harland and Cuskelly (2000), Orsmond and Seltzer (2007), and Hodapp and Urbano (2007) are helpful in understanding the relationships of adult siblings in this first generation where adults with disability live into middle adulthood and beyond. Nonetheless, due to the lack of specific research with people with cerebral palsy and their non-disabled siblings, it is not known yet whether similar findings would come from studying this group. As indicated previously, the high physical support requirements of people with moderate to severe cerebral palsy are likely to mean that they have different relationships with their non-disabled siblings compared to people with Down syndrome, autism spectrum disorder, or a sensory impairment. Geographic proximity and family size are likely to be important variables, regardless of disability type.

Geographic proximity and family size

Zetlin (1986) conducted one of the first published studies of the relationship between adults with intellectual disability and their non-disabled siblings. Over an 18-month period, Zetlin conducted participant observations with 35 adults with a mild intellectual disability aged between 23 and 60 years (mean age 35.4 years) who were

living in the community. Zetlin identified five variations of sibling relationships based on three major relationship variables: warmth, frequency of contact, and degree of involvement. Zetlin reported that siblings who had the most frequent contact and extensive involvement in each other's lives had the warmest relationships. Geographic proximity facilitated sibling involvement and this contributed to the quality of their relationship.

Similar to the findings of Zetlin's (1986) research, Orsmond and Seltzer (2007), in their study described earlier, reported that closer geographic proximity between non-disabled siblings and their disabled brothers or sisters resulted in greater instrumental and affective involvement in their lives.

As an example of the impact of geographic proximity and family size on contact between adult siblings without disability and their ageing parents in later life, Dutch researchers van Gaalen et al. (2008) analysed data from a large-scale survey on the nature and strength of family ties (the Netherlands Kinship Panel Study). Van Gaalen and colleagues surveyed 2,554 parents about the frequency of their contact with 4,601 of their adult children. They also collected "network characteristics" about the siblings, such as size, gender composition, spacing, step-children, geographic dispersion, and cohesion. The authors found that individual siblings from larger families interacted less frequently with their parents, as they shared the role of supporting their parents amongst the group. They also noted the impact lower fertility rates and hence smaller family size would have on future family support, as fewer siblings would be available to "share the load" of providing support to their ageing parents.

Additionally, van Gaalen et al. (2008) highlighted a greater likelihood of emotional closeness between siblings and between siblings and their parents,

regardless of geographic proximity, due to technological advances such as relatively inexpensive long distance telephone calls, emails and text messages which enable family members to keep in touch despite the distance. Nonetheless, as van Gaalen and colleagues pointed out, for siblings to provide ageing parents with personal care and practical support they required frequent face-to-face contact with their parents.

Technological changes and the importance of face-to-face contact also impact on the support of older people with cerebral palsy. Exploring participants' experiences of loneliness, Ballin and Balandin (2007) interviewed seven older adults with cerebral palsy, three of whom used AAC, and Cooper et al. (2009) interviewed six younger adults aged 24-30 years who all used AAC. The authors reported that, due to their complex communication needs, participants experienced difficulty trying to use communication technologies such as telephones, mobile phones and the Internet to keep in touch with family members and friends. Thus some people with cerebral palsy might find it harder to keep in touch with geographically distant non-disabled siblings than those who have access to and can use these technologies with or without assistance.

In sum, single-variable research suggests factors that may contribute to the development of sibling relationships. Another approach in the sibling literature encompasses the impact of life-course trajectories on sibling relationships in later life. Due to the longevity and complexity of sibling relationships, it is likely with the added complexity of childhood disability that more than one theoretical perspective will be needed to explain later life relationships in siblings when one has a disability.

Combining theoretical perspectives to study later life sibling relationships

Avioli (1989) reviewed the literature on social support functions of siblings in later life to propose a theoretical model to explain the dynamics influencing exchanges between siblings. She concluded that siblings are a valuable but underutilised source of support to their brothers and sisters in older age. According to Avioli, siblings seek to achieve both balanced reciprocity and personal autonomy in their relationships with each other. However, reflecting the complexity of sibling relationships, Avioli identified that the support offered by siblings to each other is mediated by geographic proximity, social network structure, health and functional status, developmental stage, gender composition and ethnicity. She concluded that there was no easy formula for predicting social support between adult siblings.

Drawing on Connidis' previous work on adult siblings (Connidis, 1994, 2001; Connidis & Davies, 1992), Walker et al. (2005) combined different theoretical perspectives to study the impact of parental ill health and death on typical sibling relationships. These authors combined four theoretical perspectives to develop a framework for understanding critical individual transition points on sibling relationships. The four perspectives were: (1) the life course perspective and, in particular, Elder's (1994) life course paradigm described earlier, (2) the feminist perspective in which the authors identified the central role females played in what they called "kin keeping" (p. 170), (3), the social constructionist framework which provided a backdrop to the negotiations that occurred among siblings around who did what and when, and (4) the concept of ambivalence which "links individual action with the contradictions created by social structures" (p. 171).

The theoretical framework of Walker et al. (2005) was useful in identifying which siblings did what, and how that was negotiated and accepted by all siblings. Such a theoretical framework can be used to obtain a more cohesive understanding of sibling relationships when elderly parents require support.

In a book chapter discussing the adult sibling relationships of people with intellectual disability, Seltzer and Krauss (1993) proposed three theoretical perspectives from the study of typical sibling relationships which could productively be applied to study the adult sibling relationships of people with an intellectual disability. The three perspectives, different from those used by Walker et al. (2005), are: (1) lifespan development, including an understanding of Goetting's (1986) developmental tasks of siblingship, (2) attachment theory, including the importance of early family ties to later life relationships, and (3) exchange theory, with an understanding of generalised, balanced and negative reciprocity in sibling relationships. Seltzer and Krauss' proposal of applying exchange theory to the study of sibling relationships where one has a developmental disability is the first such mention in the literature and, to the best of my knowledge, the idea of reciprocity in these sibling relationships has not been pursued in subsequent research.

Overall, researchers in the field of disability have been slow to address the impact on adult sibling relationships of ageing parent-carers relinquishing their caring role, an important life transition for both the ageing parents and their non-disabled and disabled adult children. Yet, as identified by Seltzer et al. (2005), and due to the increased longevity of people with lifelong disability, researchers are increasingly interested in the impact of this life transition. For example, over the past 20 years, Seltzer and colleagues and Heller and colleagues have conducted research into the effects on ageing parent-carers of supporting an adult son or daughter who has an

intellectual disability (Heller, 1998; Heller & Factor, 1994; Heller, Miller, & Factor, 1997; e.g., G. Seltzer, Begun, Seltzer, & Krauss, 1991; M. Seltzer & Krauss, 1994; M. Seltzer, Krauss, Hong, & Orsmond, 2001). Despite the differences described earlier between people with cerebral palsy and those with intellectual disability or mental illness, the lack of research specifically addressing the issue of transition later in life for adults with cerebral palsy means that it is important to this study to consider the findings of the research with non-disabled siblings of people with mental illness and those with intellectual disability.

Transitions for adults with a mental illness and the role of their non-disabled siblings

Horwitz and colleagues (Horwitz, 1993, 1994; Horwitz, Reinhard, & Howell-White, 1996; Horwitz, Tessler, Fisher, & Gamache, 1992) conducted a series of studies to examine the factors which predisposed adult siblings of people with mental illness to become involved in their brother's or sister's care. The first study reported on by Horwitz et al. (1992) involved face-to-face and telephone interviews with 109 non-disabled siblings (mean age 35 years) with a brother or sister with severe mental illness (62% had schizophrenia). The authors reported that non-disabled sibling involvement was dependent on the quality of the relationship with the disabled brother or sister as, due to the more voluntary nature of the sibling tie, they felt fewer obligations to provide care compared to their parents.

A subsequent study reported by Horwitz (1993, 1994) was based on telephone interviews with 108 non-disabled adult siblings aged from 21 to 69 years (mean 40 years) of 85 seriously mentally ill people (80% had a diagnosis of schizophrenia and 15% bipolar disorder). Horwitz reported that many non-disabled siblings already provided support to their brother or sister and nearly all indicated a willingness to do

so in the future as part of a transition of care from parents to siblings. Horwitz (1994, p. 287) described “small acts” of reciprocity to the brother or sister by the person with mental illness as important in creating reciprocal bonds with the non-disabled siblings.

To determine the importance of reciprocity between people with mental illness and their non-disabled siblings, Horwitz et al. (1996) interviewed 66 people with a mental illness, and at least one of their parents or non-disabled siblings, about the amount of social support they received from or provided to each other. Horwitz and colleagues reported that reciprocity operated in a generalised way between people with mental illness and their parents and siblings. That is, the people with a mental illness did not reciprocate the support they received with equivalent exchanges. Instead they provided largely symbolic forms of support such as gifts, affection, and involvement in family activities, actions which were nonetheless perceived by their family members as reciprocal acts. Horwitz and colleagues concluded that recognising reciprocity in the relationship between people with a disability and their non-disabled siblings might predispose the sibling to continue or provide more support to the disabled brother or sister in the future. It is not known whether having a motor disorder such as cerebral palsy impacts on reciprocity between siblings in the same way as having a mental illness.

In the following two studies Seltzer and colleagues have compared the involvement of non-disabled siblings of people with a mental illness to those with an intellectual disability. Drawing participants from two ongoing longitudinal studies in the U.S., Greenberg et al. (1999) used postal questionnaires with 119 siblings of people with intellectual disability (mean age 42.9 years) and 61 siblings of people with mental illness (mean age 41.8 years) to determine which factors were associated

with sibling involvement in the life of their brother or sister with a disability. Greenberg and colleagues reported that two thirds of non-disabled siblings of adults with an intellectual disability expected to take over primary caregiving for their disabled brother or sister, compared with only one third of those with a sibling with a mental illness. Non-disabled siblings' involvement with their disabled brother or sister was enhanced by a greater feeling of closeness to their parents and other siblings, and limited by their other family responsibilities. These feelings of closeness may be related to the lifelong nature of intellectual disability in contrast to acquired mental illness, and it may be surmised therefore that the feelings of non-disabled siblings of people with cerebral palsy might be more similar to those of people with intellectual disability than those with a sibling with a mental illness.

Taylor et al. (2008) drew their participants from a prospective longitudinal study that followed participants from age 18 to 64 years. Using questionnaires and standardised instruments, Taylor and colleagues compared against the norm ($N = 791$, average age 64.03 years) the sibling involvement of 268 siblings of adults with a mild intellectual disability (average age 63.93 years) and 83 adult siblings of people with a mental illness (average age 63.87 years). The authors reported that, compared to the normative group, siblings of people with an intellectual disability were more likely to live closer to their brother or sister, but they appeared less emotionally close to them. Taylor and colleagues suggested this was evidence of an obligatory relationship characterised by high levels of proximity and interaction but low levels of emotional attachment. Conversely, siblings of people with a mental illness compared to the norm had less contact with their disabled brother or sister and felt more dissimilar to them.

The research by Seltzer and colleagues described earlier highlighted that the relationships between people with a mental illness and their non-disabled siblings was likely to differ in many respects from that between people with chronic lifelong disability such as cerebral palsy or intellectual disability. As described by Cook et al. (1997), Greenberg et al. (1999) and Stein and Wemmerus (2001), mental health problems often do not present until adolescence or young adulthood, when siblings have an already established relationship. The changes in their brother or sister's behaviour and the loss of their "normal life" (Stein & Wemmerus, 2001, p. 732) due to their mental illness might be especially distressing and confronting for their adult non-disabled siblings.

Nonetheless, there are also similarities between the circumstances of people with a mental illness and those with an intellectual disability. For example, Horwitz (1994), Cook et al. (1997) and Stein and Wemmerus (2001) identified that many people with a severe mental illness were unmarried, their parents were likely to be their primary carers, and they might have few friends; therefore their siblings might be their only long-term source of informal support. According to Heller (1998) and Bigby (2000), this description also applies to many people with an intellectual disability. Furthermore, work by Balandin and colleagues (Balandin & Morgan, 1997; Ballin & Balandin, 2007; Cooper, et al., 2009) indicates that many adults with moderate to severe cerebral palsy likewise do not marry, rely on their parents for support, and have few friends.

The focus of the body of work on older adults with a disability has largely been on planning for transition from parent-care to alternative accommodation for people with intellectual disability (e.g., Bigby, 2000; Heller, 1998; M. Seltzer, Greenberg, Krauss, Gordon, & Judge, 1997). The role of non-disabled siblings has

been discussed within this context, although in contrast to the intent in the current study, the viewpoint of the adult disabled person has not been included.

Transitions for adults with intellectual disability and the role of their non-disabled siblings

Heller and Factor (1994), Heller, Caldwell and Factor (2007), and Heller and Arnold (2010) reviewed the literature on future planning among families of adults with intellectual disability, given the increasingly pressing issue of older parent-carers. Conducting reviews of the literature on the topic 16 years apart, Heller and colleagues showed that little had changed: few families made formal plans for their disabled son or daughter's future in relation to residential services, legal or financial planning. Rather, older parents relied upon a sibling to take over caring for the brother or sister, often without discussing this expectation with the non-disabled sibling. Heller and Factor (1994) suggested that lack of planning for an inevitable transition was likely to result in crises.

Extending Heller's earlier work, Heller and Kramer (2009) conducted an on-line survey with adult siblings of people with a developmental disability ($N = 139$), 75% of whose brothers and sisters had an intellectual disability. The purpose was to ascertain the involvement of non-disabled siblings in future planning for their disabled brother or sister. Consistent with their previous work, Heller and Kramer (2009) reported that few families had made plans for the future care of the person with disability, and that those who had made plans rarely involved the non-disabled sibling in the process. Nonetheless, the non-disabled sibling participants expressed a willingness to be involved, with those siblings currently providing informal support to their disabled brother or sister more likely to say they would be involved in providing them with future support. Consistent with the findings of Zetlin (1986), Orsmond and

Seltzer (2000, 2007) and Hodapp et al. (2010) described earlier, Heller and Kramer commented that sisters who lived closest to their disabled brother or sister were more likely to provide them with support than brothers or than siblings of either sex who lived further away.

This work by Heller and colleagues highlighting a lack of future planning on the part of parents for their adult son or daughter with an intellectual disability has been further explored in Australia by Bigby (Bigby, 1996, 1997, 2000). Bigby has written extensively about the issue of transition from parental care for older people with intellectual disability. Bigby (1996, 1997, 2000) examined future planning for people with intellectual disability aged 55 years and older ($N = 62$) who had lived with their parents until middle age. Bigby interviewed 51 of the 62 older people and a primary informant for each person, including siblings ($N = 30$). She (1996, 2000) was interested in how older people with intellectual disability made the mid-life transition from parental care and what sources of support they drew upon to assist them during and after the transition. Bigby reported that for the majority of the participants with intellectual disability, transition was a gradual process aided by family members, often non-disabled siblings, who supported both the ageing parent-carer and the person with disability to make the transition.

In contrast to the studies reported by Heller and colleagues, and possibly reflecting cultural differences between the U.S. and Australia, the majority (69%) of the parents of participants in Bigby's study had made "key person" succession plans, nominating the person who would oversee the transition along with details for the transition. Bigby found that in most cases these plans were successfully activated after parents were no longer the primary caregivers. However, she (1997, p. 15) reported that "in the longer term very few siblings continued to substitute for their

parents fully although the majority assumed part of their parent's previous role; oversight of well-being". It is possible, therefore, that siblings tried in the period immediately following their parents' death to fulfil their wishes but found it increasingly hard to do this over time. In subsequent work, Bigby (2007) identified the need for transition plans to be flexible to allow for the changing circumstances, needs, and wants of the person with a disability. Although Bigby's work has made a considerable contribution to understanding of later life transitions it focused on people with intellectual disability, whose experiences might be dissimilar to those of people with moderate to severe cerebral palsy, who typically have significant physical and communication support needs. The support needs of people with cerebral palsy can also mean that they require specialist care in environments modified to accommodate the equipment necessary to aid their mobility and safety, such as hoists, ramps, and accessible bathrooms.

Seltzer et al. (2001) has conducted one of the few studies to consider the viewpoint of non-disabled siblings to their disabled adult brother or sister's planned residential transition from the family home to supported accommodation. As part of a large longitudinal study with mothers, contact between non-disabled siblings whose brother or sister with intellectual disability had moved out of home ($N = 26$) was compared with contact between siblings when the adult with intellectual disability remained living with the parents ($N = 26$). Non-disabled siblings completed a range of measures of sibling involvement. For siblings whose brother or sister made a planned move out of the parental home, data were collected before and after their sibling's move. Seltzer and colleagues reported that non-disabled siblings of disabled brothers or sisters living in the parental home reported feeling emotionally closer to their disabled sibling than those whose disabled sibling had moved out of home.

However, those whose disabled brother or sister had moved out of home reported an increase in the activities they shared with their disabled sibling and felt less worried about the future care for their disabled brother or sister. Nonetheless, the study of Seltzer et al. did not include the viewpoint of the sibling with intellectual disability about the role of the non-disabled sibling in their life.

The literature reviewed in this chapter provides beginning evidence that growing up together, sharing transitions, and developing adult qualities, along with gender, geographical proximity, and the severity of disability, are variables that influence why some non-disabled siblings adopt a supportive role in later life whereas others do not. Nonetheless, there are a number of gaps in the literature which highlight the need for the current study:

- The psychosocial impact of having a brother or sister with a disability on non-disabled *adult* siblings has been largely unexplored;
- The perspective of the middle-aged to older person with a disability has not generally been included in the literature. Therefore, we do not know what they desire in later life from their non-disabled siblings or what their expectations, needs and wants are;
- The current empirical evidence fails to provide a link between sibling relationships in childhood and those in adulthood;
- Life course models such as Elder's, which provide a context for understanding how trajectories, transitions and turning points impact on relationships, have not been applied to the study of the relationship between people with a disability and their non-disabled siblings;
- The failure to adopt a life course perspective means there is a lack of understanding of the factors which predispose siblings with and without a

disability to provide support to each other throughout their lives and the nature of that support in particular later in life when their parents are no longer alive.

In addressing its aim, the current study sets out to redress these gaps in knowledge and to do so specifically with older adults with cerebral palsy, from their perspectives and the perspectives of their non-disabled sibling or siblings. Stanley (1994) identified that the incidence of cerebral palsy, which is the most common physical disability among children, was rising due to higher rates of survival among prematurely born, low birth weight infants. Despite this, there has been little focus on the increased physical care needs of people with cerebral palsy as they get older. Providing increasingly high levels of support to an adult son or daughter with severe cerebral palsy is likely to result in additional physical and emotional stress for older parent-carers, and in turn, for non-disabled siblings. It is important, therefore, to understand the relationship between siblings when one has moderate to severe cerebral palsy, particularly in the context of post-parental care.

This study has its underpinnings in symbolic interactionism and utilises applied grounded theory methods to address the gap in understanding adult sibling relationships when one sibling has cerebral palsy. The rationale for adopting grounded theory methods is discussed in the next chapter.

Chapter 4

Epistemology, Theoretical Perspective, and Methodology

The epistemological underpinning of this research was social constructivism, chosen due to my philosophical beliefs, based on my background training in sociology and my life experiences, about how people understand the social world in which they live. Within the tradition of social constructivism, I used symbolic interactionism as the theoretical perspective, and grounded theory as the methodology.

4.1. Epistemological Issues

A social constructivist epistemology, or understanding, based on a combined realist and relativist ontology, or conceptualisation, informed this study. According to Crotty, (1998) implicit in social constructivism is the belief that individuals construct meaning of the complex world in which they live through their interactions with other people based on their shared social experiences and understandings.

According to the principles of social constructivism, objects do not have inherent meaning but rather people attach meanings to objects through the value and purpose they ascribe to them. In this way meaning is constructed through the interaction of object and subject (Crotty, 1998). Constructing meaning involves an active process of interpretation and choice on the part of an individual in order to develop an understanding of reality. As meanings may be constructed differently by individuals, there is no one absolute reality but rather multiple realities. Nonetheless, individuals learn about the world in which they live from others and from previous

experience, and are therefore influenced in constructing meaning by their pre-existing understanding of the world in which they live (Crotty, 1998).

Social constructivism developed as an alternative epistemological viewpoint to positivism. Positivist thinking, with a base in the natural sciences, emphasises objectivity, generality, replication, and testing of hypotheses and theories (Charmaz, 2006). I agree with Denzin and Lincoln (1994) that positivist techniques are not intended or suited to interpreting meanings inherent in individual behaviour and beliefs. For the purpose of this study, I wished to explore participants' understandings of their sibling relationships and how their familial and social contexts influenced that understanding. Therefore I adopted a social constructivist approach, which included bringing to the research a number of assumptions. These are:

- Siblings within a family will interpret their relationship differently. Therefore, individuality of experience needs to be acknowledged and embraced.
- Historic and contextual factors embed the experiences of siblings with and without cerebral palsy in their pre-existing social worlds. It is important, therefore, to interpret individual experiences in the context of historic, social and cultural patterns and influences.
- The process of participating in research can provide people with an opportunity to reflect upon and explore the meaning they attach to their sibling relationships. People with communication difficulties, including many individuals with moderate to severe cerebral palsy, might not be familiar with being asked about their experiences and relationships. Therefore, time, patience and sensitivity are required when interviewing participants, particularly those with complex communication needs.

- Through sharing participants' intimate life histories and experiences, I will gain some understanding of what being an individual with cerebral palsy, or having a sibling with cerebral palsy, might be like. However, my understanding is only partial and is constructed from interviewing those who live with this experience.

4.2. Symbolic Interactionism

Consistent with a social constructivist epistemology, symbolic interactionism is the underlying theoretical perspective chosen for this study. Symbolic interactionism is a theory of human conduct according to which the "mind" and "self" are social products which lead individuals to structure the external world by their perceptions and interpretations of what they conceive the world to be (Mead, 1934).

George Herbert Mead, an American social psychologist based at the University of Chicago in the early decades of the 20th century, is considered the "father" of symbolic interactionism. His student Herbert Blumer further developed Mead's work and in 1937 coined the term "symbolic interactionism". According to Blumer (1969), symbolic interactionism has three main premises: (1) human beings know things by their meanings, (2) meanings are created through social interaction, and (3) meanings change through interaction.

Furthermore, symbolic interactionism has three central concepts: the self, the world, and action.

- (1). People construct a sense of *self* through their interaction with others. The self is characterised as having two components, a "Me" component which can be reflected on and talked about (i.e., the self as an object), and an "I" component which is the reflector (i.e., the self as the subject). The Me component is developed throughout people's lives as they do, think, act, and interact in

multiple social contexts. Meanwhile, the I component of the self receives, accumulates and interprets social environmental cues and forms a view of how others view the Me. For example, in the context of the current study this means that an adult with cerebral palsy will develop a sense of Me through her multiple roles as daughter, sister, employee, and so on. The sense of I will be influenced by how others see her: as a person with a lifelong physical disability, as a service user, a group home resident, a person with dysarthric speech, and so on. Reconciling the components of Me and I is part of socially constructing a sense of self.

- (2). The social *world* consists of “objects” which people recognise and come to know. These objects may be physical, social or abstract (Blumer, 1969). According to symbolic interactionism, objects have no inherent meaning. Rather, their meaning is derived from the way others in the social world act toward these objects. Different meanings attributed to objects are learned through socialisation within the subcultures of family, school, work, leisure groups and so on. These shared meanings provide predictability, as we expect others to respond to objects in similar ways to ourselves. An example relevant to the current study would be that objects such as an electric wheelchair, a speech generating device, or a hearing aid, which might enable a person with moderate to severe cerebral palsy to interact with the world, will be recognised by others as devices to assist the person to be mobile or to communicate.
- (3). Society operates through people *interacting* with each other through symbolic and non-symbolic interaction in order to construct meanings (Blumer, 1969). Symbols are made up of language, behaviour, and cultural norms and values, and emerge from human interaction. Shared meanings become attached to

verbal and non-verbal language symbols, and individuals learn through interaction and communication to interpret the meanings of actions and to take many things for granted (Blumer, 1969). However, people with complex communication needs, including many with moderate to severe cerebral palsy, lack clear verbal communication and have obvious disability, which can disadvantage their interactions with others. Augmentative and alternative communication devices such as speech generating devices and alphabet boards are designed to assist individuals to overcome such difficulties, provided others are prepared to engage with them.

Due to its roots in social psychology and sociology, symbolic interactionism has been applied to studying the lives of people with a disability. A well-known example is that of one of the Chicago school proponents of symbolic interactionism, Erving Goffman (1971), who studied the effect of stigma on people with a mental illness living in asylums in the USA. According to Thomas (1999), Goffman's work now seems dated in portraying people with mental illness as helpless victims of discrimination. Nonetheless, as Becker (2003) noted, Goffman's work shone a spotlight on what was happening in institutions at the time and was instrumental in bringing about their closure.

More recently, a student of grounded theory, Kathy Charmaz (1990), studied the concept of self from the perspective of people with a chronic illness. Charmaz contributed to the understanding of symbolic interactionism as useful in the disability field by advocating a social constructivist perspective which included the multiple realities and complexities of participants' lives (Creswell, 2007).

I became familiar with symbolic interactionism from my undergraduate study and Masters research (Dew, 2005) and was confident that this theoretical perspective

would be the most appropriate to conduct this study into the relationships between adult siblings where one had cerebral palsy. Within the symbolic interactionism tradition there are a number of qualitative research methodologies which I could have adopted to conduct this study.

Creswell (2007) identified five main qualitative research approaches: (1) narrative, (2) phenomenology, (3) ethnography, (4) case studies, and (5) grounded theory. Each of these approaches comes with its own literature, history, and preferred methods for implementing the approach. According to McVilly et al. (2008), deciding upon which approach best suits the needs of a particular study involves consideration of epistemological and ontological perspectives, along with the personal preference of the researcher in relation to the topic under investigation.

As the aim of this research was to explore the relationships between middle-aged and older people with severe cerebral palsy and their non-disabled siblings, I considered both narrative and grounded theory as possible research methods. I believed that individual interviews with participants would elicit stories about their sibling experiences and hence a narrative approach could be appropriate. However, as identified in the literature review in Chapter 3, no studies had incorporated the views of siblings both with and without cerebral palsy about their relationship in later life. As a new area of study and following Grbich (1999), I decided that grounded theory was the most useful approach to take when little was known about the area under investigation. Grounded theory is also appropriate when concepts have not yet been fully identified, as was the case in this study. It seemed likely that, although this study would have a relatively small sample size, there would be the potential to offer insights into the adult sibling relationship when one has cerebral palsy. For these reasons, I chose grounded theory rather than narrative.

4.3. Grounded Theory

According to Denzin and Lincoln (1994), grounded theory arose during the 1960s in what is known as the “modernist phase” of qualitative research as a new Chicago method of symbolic interactionism developed by Glaser and Strauss (1967). In the creation of a method by which qualitative data could be codified while at the same time acknowledging the underlying philosophy of symbolic interactionism, Glaser’s quantitative training and Strauss’ Chicago school viewpoint were melded to develop grounded theory. In the course of their studies of dying patients in hospitals, Glaser and Strauss “developed systematic methodological strategies that social scientists could adopt for studying many other topics” (Charmaz, 2006, p. 4).

The premise of Glaser and Strauss’ work was that theory could be developed which was grounded in the data, rather than using data to test hypotheses from existing theories as was common in the prevailing quantitative, positivist research methodology used in sociological studies. The aim of the grounded theory method was to develop, from observational data, a law, model or theory which explained the phenomenon being studied (Grbich, 1999; A. Strauss & Corbin, 1998).

Grounded theory uses a number of interactive, concurrent steps of data-gathering, inductive reasoning, hypothesis formation, purposeful data-gathering and logical deductive reasoning to generate explanations of complex behaviour. Bryman (2001) and Grbich (1999) identified four central “tools” applied by grounded theorists as follows:

(1). Theoretical sampling – the process of data collection for generating theory whereby the researcher jointly collects, codes and analyses her data and decides what data to collect next and where to find them, to develop theory as this emerges.

- (2). Coding – the key process in grounded theory that involves breaking the data down into component parts which are then given names. Coding begins soon after the collection of initial data and the emerging codes are grounded in theory with different types or level of theory recognised.
- (3). Theoretical saturation – which relates to two phases in grounded theory: the coding of the data, where the researcher reaches a stage where there is no further point in reviewing data to see how well these fit with concepts; and the collection of data, where the researcher reaches a stage where new data are no longer illuminating the concept that has been developed.
- (4). Constant comparison – a process of maintaining a close connection between data and conceptualisation so that the theoretical elaboration of that concept can begin to emerge. The researcher needs to be sensitive to contrasts between concepts that are emerging.

Following the widespread acceptance of grounded theory as a qualitative research method, Glaser and Strauss pursued different paths in their application and explanation of grounded theory, particularly in relation to data coding (D. Walker & Myrick, 2006). According to Walker and Myrick (2006) and Charmaz (2006), Glaser's criticism of Strauss and his new research partner Corbin (A. Strauss & Corbin, 1998), was that rather than allowing for the emergence of theory through comparative methods, Strauss and Corbin's technical procedures for coding data "force data and analysis into preconceived categories and, thus, contradict fundamental tenets of grounded theory" (Charmaz, 2006, p. 8). Conversely, Strauss and Corbin argued that their approach provided students of grounded theory and other researchers with some guidelines for "doing" grounded theory (A. Strauss & Corbin, 1998).

While Glaser and Strauss (1967) and Strauss and Corbin (1998) are the founders and dominant proponents of grounded theory, albeit from diverging viewpoints, the at times acrimonious debate between them has polarised grounded theorists. From this debate a new approach to grounded theory emerged, using constructivist principles which provide a less structured and more interpretive approach. This approach, led by Kathy Charmaz (1990, 2000, 2006) was the one adopted in this study.

There were a number of reasons why I decided to use Charmaz's constructivist grounded theory approach in this study. Charmaz's approach represented a contemporary application of grounded theory which differed from Strauss and Corbin's more prescriptive data analysis methods that I had used in my Masters' research. I was impressed by the way in which Charmaz's data analysis methods enabled her to describe the continuities and discontinuities in the lives of the participants with chronic illness who she interviewed. I felt that Charmaz's approach would enable me to maintain the cohesion of the sibling dyads and triads while also identifying individual nuances. I believed, as suggested by Creswell (2007), that Charmaz's approach to grounded theory represented an interpretive approach to data collection and analysis, an approach that would suit the current research.

4.3.1. Constructivist Grounded Theory

According to Creswell (2007, p. 65), Charmaz adopted more flexible guidelines than the traditional grounded theorists by exploring "the experience within embedded, hidden networks, situations, and relationships, and making visible hierarchies of power, communication, and opportunity". Charmaz (2006, p. 126) claimed that "interpretive theory calls for the imaginative understanding of the studied phenomenon", further asserting that "this type of theory assumes emergent, multiple

realities; indeterminacy; facts and values as linked; truth as provisional; and social life as processual”.

Charmaz promoted her approach as relevant to understanding and explaining diversity among research participants and the complexity inherent in their multiple realities of a common situation or experience. That approach to grounded theory appeared appropriate for this study, as multiple sibling perspectives both within and across families were to be gathered. Even within a family, it was possible that siblings would not view their relationship in the same way. Therefore, complex data representing multiple realities were likely to be collected, requiring flexible and interpretive analysis.

Charmaz described her approach in this way “Grounded theory guidelines describe the steps of the research process and provide a path through it. Researchers can adopt and adapt them to conduct diverse studies... we can use basic grounded theory guidelines with twenty-first century methodological assumptions and approaches” (Charmaz, 2006, p. 9). In comparing Glaser and Strauss and Strauss and Corbin’s traditional grounded theory approach with Charmaz’s constructivist grounded theory approach, I identified three main differences relevant to the current study.

First, Charmaz (2006) acknowledged the importance of researchers being sensitive to the way in which their background assumptions and disciplinary perspectives inform their choice of research topic, methodology and conceptualisation of the problem to be studied. Charmaz maintained that researchers “*construct* our grounded theories through our past and present involvements and interactions with people, perspectives, and research practices” (Charmaz, 2006, p. 10). Therefore, according to Charmaz, acknowledgment of prior knowledge and interest in the area

being researched opens “points of departure for developing, rather than limiting, our ideas” (Charmaz, 2006, p. 17). Nonetheless, Charmaz stressed that the research findings are developed through data analysis and conceptualisation and that “sensitizing concepts and disciplinary perspectives provide a place to *start*, not to *end*” (Charmaz, 2006, p. 17). Charmaz’s statements on the usefulness of sensitising concepts contrasts with the view of Strauss and Corbin (1998) who proposed that by sticking closely to the data researchers can set their own views to one side in the interpretive process. Charmaz argued that this is both impossible and undesirable. To even contemplate undertaking the current study I had incorporated my professional experience working with family members and conducting research with siblings of people with a developmental disability along with my personal experience as a sibling as a point of departure.

Second, Charmaz took a more flexible and less prescriptive approach to data coding than that proposed by Strauss and Corbin. Charmaz referred to the two initial levels of coding as open and focused coding. Using Charmaz’s approach, open coding proceeds in the same way as the traditional grounded theory method described previously. Charmaz’s use of focused coding incorporates elements of axial coding as defined in the approach taken by Strauss and Corbin (1998). Indeed, Charmaz has acknowledged that Strauss and Corbin’s axial coding approach is useful for researchers who prefer to apply a pre-set framework to their data analysis. However, Charmaz viewed Strauss and Corbin’s axial coding approach as cumbersome and overly technical, instead advocating an approach of focused coding which, she asserted, is more flexible and accommodates greater ambiguity in the data analysis stage. Charmaz’s focused coding approach provided me with the flexibility I required to analyse the data as individual experiences and as experiences from a sibling group.

Charmaz's final stage of coding is based upon Glaser's (1992) theoretical coding, which operates at a conceptual level to integrate the focused codes into an original theory about the topic studied.

Third, Strauss and Corbin (1998) referred to memos and diagrams as essential but adjunctive procedures to data coding and analysis. Charmaz elevated memo-writing and diagramming as central to the ongoing process of data analysis. "Memos catch your thoughts, capture the comparisons and connections you make, and crystallize questions and directions for you to pursue" (Charmaz, 2006, p. 72). I made extensive use of both memos and diagrams throughout my data collection and analysis, and found both to be useful central tools to record, challenge and focus my thinking.

Charmaz (2006) identified the following process in describing the fluid and iterative processes involved in the social constructivist form of grounded theory. First, a research problem is identified and research questions posed. Both sensitising concepts and the disciplinary perspective of the researcher influence these questions. The researcher then collects data and conducts initial coding while at the same time creating initial memos outlining preliminary categories. Further data collection follows, along with focused coding and advanced memos which aim to refine emerging conceptual categories. At this stage, theoretical sampling may be conducted to seek specific new data identified as important, so further data collection and initial coding may be necessary. The following stages involve adopting certain categories as theoretical concepts and writing theoretical memos as a way of further refining these concepts. Throughout the process earlier data are re-examined in the light of new data and emerging categories. Memos are then sorted and diagrams of concepts drawn which help to integrate the memos, resulting in the writing of a first draft.

Even at this stage, further theoretical sampling might be required, with resulting data collection and focused coding. The process described above, rather than being prescriptive, is indicative of the steps taken in constructing a grounded theory.

In sum, symbolic interactionism is described as the theoretical underpinning of this study, with a qualitative research method chosen as most appropriate to explore the issue of sibling relationships. Grounded theory, following Charmaz (2006), was the method chosen to guide the research design, including data collection and analysis. Within the grounded theory method, the social constructivist method of Charmaz (2006) was adopted as offering greater opportunity for flexibility and sensitivity to data from multiple individuals about a common experience than the traditional grounded theory approaches.

In-depth interviews were used to collect data from participants. The following chapter describes the data collection process.

Chapter 5

Speaking to Siblings

Individual in-depth interviews were conducted with people with cerebral palsy and their non-disabled brothers and sisters.

5.1. Ethical Issues

Ethics approval was obtained from the University of Sydney Human Ethics Committee (Reference no. 06-2006/9056 – Appendix 1) and from the Ethics Committees of both the non-government organisations from which participants were recruited. All three committees also required annual reports on the conduct of the research prior to renewal of the approval for the following 12 months.

In addition to the usual ethical concerns covered in the Participant Information Sheets and Consent Forms (copies of which are attached in Appendix 2) regarding voluntary participation and the right of the participant to withdraw from the study at any time, there were three ethical issues specific to the conduct of interviews with adult siblings recruited to participate in this study.

5.1.1. Confidentiality between siblings

A decision was made to interview siblings with and without cerebral palsy individually. This decision was based on a desire for siblings to feel they could speak freely without being constrained by the presence of their brother or sister.

Additionally, some people with cerebral palsy have communication difficulties which have resulted in other people, including their siblings, speaking for them. In this study, I wanted the individual with cerebral palsy to have the opportunity to speak for

themselves. Interviewing siblings separately meant that I needed to maintain confidentiality in interviews with different family members. I needed to explore issues raised by one participant with other family members without breaking the confidence of each participant. This required skilful phrasing in the interviews to ensure that questioning related to issues of a general rather than a specific nature. I also needed to assure all participants that the information they provided would not be disclosed to their siblings.

5.1.2. Protecting anonymity

The community of adults with moderate to severe cerebral palsy in Australia is relatively small. There was the potential for oral and written presentations about this research to inadvertently expose the identity of participants (Holloway & Wheeler, 2002). This matter was dealt with in two ways. First, a pseudonym was allocated to each participant immediately following recruitment and used in all subsequent references to that person. Second, reporting on personal background information about participants was kept to a minimum (Berg, 1989). For example, the state where the participant lived, the participant's occupation, and other details which could potentially identify the person are not reported.

5.1.3. Emotional subject matter

Participants were asked to speak about their relationships with their siblings. Speaking about close personal relationships can be an emotional experience. From the pilot interviews, I had witnessed the emotions which this subject matter could bring to the surface. I prepared for the possibility of emotional responses from participants by planning the following strategies: turning off the digital recorder and suspending the interview until the participant recovered and wished to proceed; and

having on hand the name and contact details of suitably qualified counsellors which I would offer to the participant if needed.

5.2. Recruitment and Sampling

The criteria for inclusion in this study were:

- 1) being a person with cerebral palsy who was 40 years or older;
- 2) having the ability to give informed consent to participate;
- 3) having a method of communication which would enable the person to participate in an in-depth interview (e.g. speech; augmentative and alternative communication such as a speech generating device or alphabet board);
- 4) having at least one non-disabled sibling who also consented to participate.

Participants for the in-depth interviews were recruited to the study with the assistance of two non-government organisations providing services to people with cerebral palsy in Australia. These organisations sent a cover letter along with a copy of the information sheet, the consent form and a stamped, addressed envelope to all people with cerebral palsy aged 40 years and over who were registered with them. The organisations were not able to identify from their data bases who had siblings and who did not. Therefore, people with cerebral palsy who received the information needed to consider participation on the basis of having at least one non-disabled sibling who they could also recruit to participate. Besides the mail out, one organisation posted an article about the research in its on-line and hard-copy newsletter and provided details about the research on its website.

My supervisors' and my own personal networks were also utilised to recruit two participants. One potential participant was known to one of my supervisors and asked by her if she would consider participating in the study. After indicating her interest, that potential participant was sent the information sheet and consent form.

The other potential participant was known to a colleague who informed him about the study. This potential participant also agreed to receive an information sheet and consent form.

Once potential participants returned their completed consent forms I made contact with them by telephone or email to arrange a suitable interview time and venue. For five individuals with cerebral palsy, interview arrangements were made via a staff person or family member as they were unable to speak to me personally via telephone.

Participation in this research was open to as many consenting non-disabled siblings of the people with cerebral palsy as they invited to participate. Of the 12 participants with cerebral palsy, four had two non-disabled siblings who volunteered to participate.

5.3. Participants

In the time available for the doctoral research 28 participants were recruited: 12 people with cerebral palsy and 16 of their non-disabled siblings.

5.3.1. Individuals with cerebral palsy

Of the 12 individuals with cerebral palsy who agreed to participate, six were female and six were male. They ranged in age from 42 to 65 years with a mean age of 55 years. Individuals with cerebral palsy described themselves as having moderate to severe cerebral palsy with varying abilities to perform their own personal care, to undertake activities of daily living, and/or described their restrictions with mobility and communication. Nine individuals with cerebral palsy had dysarthric speech with varying levels of intelligibility, one used a speech generating device, and two used

sign language and gestures to communicate. Three participants with cerebral palsy were married, with two married to each other. None had children.

At the time of the interviews, four people with cerebral palsy were living in group homes, which I have defined as three or more unrelated people living together in a house supported by paid staff; three lived in rented homes, defined as a property rented from the government through a subsidised housing scheme with support from paid staff for specific tasks; two lived in their privately owned homes with paid support for specific tasks; two lived in their parental home with both parents providing them with support; and one lived in a hostel, defined as a large residence with 15 or more unrelated people living together with paid staff support.

Three individuals with cerebral palsy were the eldest in their family, four were the youngest and the remaining five were middle children. The number of participants' siblings ranged from one to five siblings. Four participants with cerebral palsy who had more than one sibling mentioned they had invited other non-disabled siblings but they had declined the offer to participate. In column 11 of Table 1, these non-participating siblings are listed as "invited but declined". Another five participants with cerebral palsy who had more than one sibling did not indicate that they had invited other non-participating non-disabled siblings to take part in the study. In column 11 of Table 1, these non-participating siblings are listed as "not invited". Five participants with cerebral palsy had both parents still alive, four had one parent alive (four mothers and one father) and three had both parents deceased.

5.3.2. Their non-disabled brothers and/or sisters

The 16 non-disabled siblings who agreed to participate ranged in age from 30 to 70 years with a mean age of 49 years. Twelve non-disabled siblings were female and four were male. Five non-disabled siblings were the eldest in the family, five were

the youngest and six were middle children. The geographic proximity of participating sibling pairs to each other ranged from a 2-minute drive to living in another country. Eight sibling pairs lived within a 1-hour drive of each other. Three of the non-disabled siblings had never married, two were divorced, and of the remaining 11 who were married, two had no children. Table 1 provides background information for all the participants, using pseudonyms. More detailed information about participants is provided in the results chapters.

Table 1 Participants

Person with Cerebral Palsy	Age	Communication	Accommodation	No. of siblings	Place in family	Non-disabled sibling	Age	Place in family	Geographic distance between siblings	Non-participating siblings	Parents
Louise	65	Dysarthric speech	Hostel	2	Second	Jill	65	Youngest	5 hr drive	1 sister; not invited	Father living
Bruce	62	Dysarthric speech	Own home	3	Youngest	Charlotte	70	Eldest	2 min drive	1 brother, 1 sister; not invited	Both deceased
Richard	62	Sign language	Rented house	3	Third	Ruth	69	Second	10 min drive	2 brothers; not invited	Mother living
Kristine	55	Dysarthric speech	Group home	1	Eldest	Natalie	36	Youngest	30 min drive		Both deceased
Betty	53	Sign language	Rented house	4	Youngest	Bob Derek	62 58	Eldest Fourth	3 hour drive	2 brothers; invited but declined	Both deceased
Caroline	52	Dysarthric speech	Rented house	5	Second	Margaret	50	Third	30 min drive	3 brothers, 1 sister; not invited	Both living
Rebecca	47	Dysarthric speech	Parental home	1	Youngest	Amelia	52	Eldest	12 hr drive		Both living
Helen	45	Dysarthric speech	Own home	2	Eldest	Isobel	38	Youngest	Different country	1 sister; invited but declined	Mother living
Philip	45	Dysarthric speech	Group home	5	Eldest	Harry	33	Middle	8 hr drive	4 siblings; not invited	Both living
Mathew	43	Speech Generating device	Group home	2	Second	Therese Kirsty	46 39	Eldest Youngest	30 min drive 10 hr drive		Both living
Thomas	43	Dysarthric speech	Parental home	3	Eldest	Stephanie Marilyn	37 30	Third Youngest	2 hr drive 10 min drive	1 brother; invited but declined	Both living
Oliver	42	Dysarthric speech	Group home	4	Youngest	Kitty Arthur	52 47	Eldest Third	10 min drive 10 min drive	1 brother; 1 sister; invited but declined	Mother living

5.4. The interviews

Initial and follow-up interviews were individually conducted with each person with cerebral palsy and the non-disabled sibling or siblings. Nine individuals with cerebral palsy and 10 non-disabled siblings were interviewed face-to-face for both their initial and follow-up interviews. Due to geographic distance, one individual with cerebral palsy and three non-disabled siblings were interviewed by telephone for both interviews, and two individuals with cerebral palsy and three non-disabled siblings had one face-to-face and one telephone interview. Face-to-face interviews were conducted in the participant's home, work, or day program venue, depending on the participant's preference.

The initial interviews were conducted with all participants from March 2007 and continued over the following 18 months. This was essential to the design of the study, as grounded theory requires that emerging theoretical categories influence the ongoing collection of data (Charmaz, 1990). In this instance, beginning analysis led into questioning in later interviews. Follow-up interviews commenced in March 2008 and continued until the beginning of 2009.

The initial interview lasted on average 1 hour for the individuals with cerebral palsy and 2 hours for their non-disabled siblings. Similarly, follow-up interviews lasted on average 45 minutes with the individuals with cerebral palsy and 1 hour with their non-disabled siblings. The difference in time was due to the volume and complexity of information given. The individuals with cerebral palsy tended to give shorter answers than their non-disabled siblings who tended to elaborate with more detail. I was also sensitive to the individuals with cerebral palsy becoming fatigued after about an hour of interviewing.

Before the commencement of each interview I spent time establishing rapport with all participants through an explanation of the study and my background. This was an important part of participants' both getting to know me and my bona fides for conducting the research and feeling comfortable talking to me about often sensitive subjects relating to their sibling relationship (Glesne & Peshkin, 1992; Grbich, 1999).

5.4.1. Interview guides

Drawing on the pilot project with non-disabled siblings conducted prior to this study, and the international literature in the area, interview "guides" were developed for use with participants to ensure that similar topics were canvassed with each participant at both the initial and follow-up interviews (see Appendix 3).

The guides were deliberately constructed taking into account Charmaz's (1990, p. 1167) suggestion that "framing, pacing, and managing the interview questions all affect the type and quality of material the researcher obtains". Charmaz described five steps to framing and ordering interview questions: (1) gathering initial factual information about the participant, (2) informational questions which may establish a chronology and the key people in the participant's story, (3) reflective questions which may serve as transition questions to get participants to talk more about themselves, (4) feeling questions which develop the narrative of the participant's story, and (5) ending questions which are designed to bring the interview to a positive conclusion.

Incorporating these five steps as described by Charmaz (1990), the initial interviews in this study followed a broad life-course perspective by asking participants to describe their family, talk about their relationship with their sibling/s and reflect on any changes that might have occurred in that relationship during the transition to adulthood. Participants were also asked to describe their view of the

future for themselves/their sibling with cerebral palsy, and the possible impact of this on their lives. Follow-up interviews were conducted with all participants to clarify information, discuss my initial interpretation of the individual interview, and explore the emerging theme of life-course transition points in the sibling relationship. In line with grounded theory techniques, the guides served as aide memoires only such that I explored in each subsequent participant's interview ideas developed from items raised in interviews with previous participants. In this way an exploration of the developing themes occurred in subsequent interviews.

5.5. Data collection procedures and data checking

The interviews were audio-taped with participants' permission. Immediately after each interview I wrote a memo note about the participant or interview content or process that could not be captured on the audio recording. An example of a memo is included in Appendix 5.

As part of the member checking process to establish trustworthiness (Bryman, 2001), after each interview I developed a summary of the key points of that interview which I sent, along with a full transcript of the interview, to each non-disabled sibling participant and to participants with cerebral palsy who indicated that they would like to receive it. Two participants made minor corrections to names and dates. Overall, participants expressed satisfaction with the record of their interview. Summaries and transcripts were not sent to all participants with cerebral palsy, as not all were able to access written material without assistance due either to difficulty in holding and turning pages or to limited literacy skills. Those individuals with cerebral palsy who indicated that they did not wish to receive written feedback were provided with a verbal summary of the initial interview prior to the follow-up interview. Again, participants expressed satisfaction with the summary. All participants were interested

to know how their experiences were similar to or differed from other participants. The follow-up interviews provided participants with an opportunity to discuss and reflect on these issues. In these discussions, many participants demonstrated significant insight into how their life experiences were indicative of disability-specific and broader social issues. The opportunity to discuss with participants my emerging interpretations of the data at this stage in the research process was invaluable as the discussions honed, extended and challenged my thinking.

As an additional step in ensuring rigour in the research process, the transcripts and summaries from the interviews were read by and discussed with my supervisors. This process allowed me to further develop my interpretation of the data as data collection proceeded and to clarify additional areas for investigation in subsequent interviews.

The following chapter describes the data analysis process and provides a prelude to the results chapters.

Chapter 6

Data Analysis and Prelude to Results

6.1. Data Analysis

6.1.1. Initial coding using NVivo

The initial line-by-line coding of the interviews was conducted using QSR NVivo™ (Richards, 2005). This is a software program designed to assist with data management and analysis in qualitative research. As interviews were completed, the de-identified transcriptions were saved in Word documents and imported into the NVivo Version 7 software program. Within the “Sources” file in NVivo two folders were created, one for participants with cerebral palsy and one for their non-disabled siblings. In the relevant folder a “participant case book” was established which contained all the information about or from each participant including the raw data (transcripts), attributes and memos.

Attributes

Attributes were assigned to each “participant case” and could then be cross-referenced across cases by variables. Linking participants by relationship was also possible in NVivo, and this function was used to link participants by family group. Attributes and relationships were useful data management facilities within NVivo. The “case” attributes established for participants were gender, age, disability, communication status, parental status, living environment, number of siblings, and place in the family. For example, using the case attribute function I could instruct NVivo to provide me with information on all females aged over 50 who had only one sibling. This was an

easy way of checking for variables that might have particular relevance in certain situations. Appendix 4 provides a printout of the attributes assigned in NVivo and the data in Table 1 on page 118 were compiled using the attribute function.

Memos

A further useful function of NVivo was the ability to link memos to each “case”. A series of memos were created for each participant which were linked at the case level, and later at the node level as discussed below. A case-level memo was created after each interview. Each memo contained a reflection on the interview and additional information about the individual or the interview environment. For example, I commented in memos about the nature and extent of the physical and communication impairment of each participant with cerebral palsy. I also recorded in the memo my initial thoughts about topics to be covered in the follow-up interview with that sibling or with other siblings. After the follow-up interviews were completed, I recorded in the memos thoughts about emerging categories. An important component in ensuring rigour and checking for authenticity in the research findings, the memos provided an audit trail of my developing analysis (Bowen, 2009). An example of a memo for one participant is included in Appendix 5.

Initial codes

According to Charmaz (2006), initial codes should closely mirror the data and should be written as gerunds⁵ with active code names (examples of gerunds used in this study can be found in the node/code column of Table 2 on page 124). Gerunds should be simple, precise and short. Charmaz wrote that initial codes “are provisional, comparative, and grounded in the data” (p. 48). She advocated working quickly when

⁵ A gerund is a noun formed from a verb, denoting an action (Hanks, 1979)

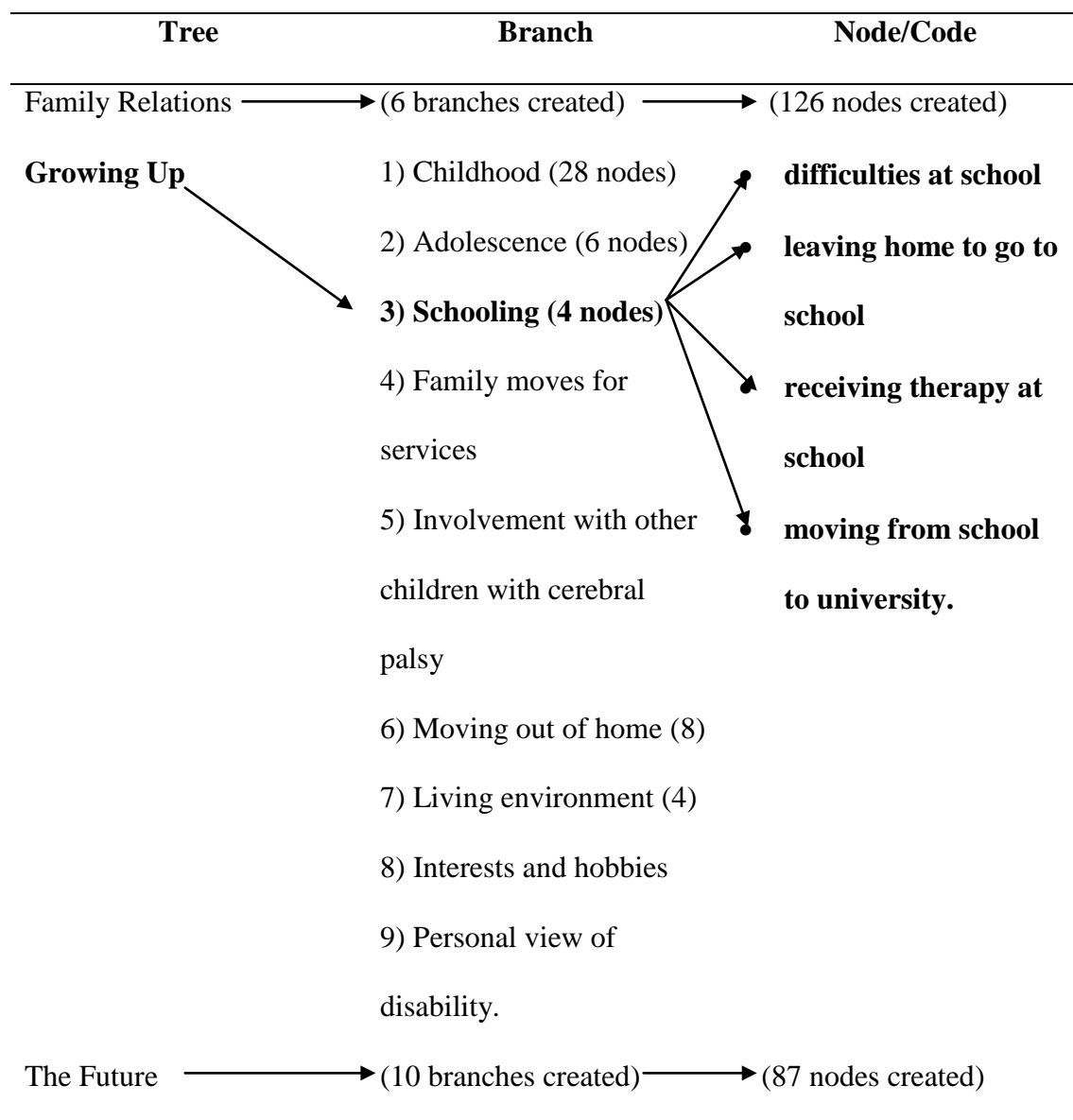
conducting initial coding, in order to spark fresh ideas. Using a qualitative research data management program such as NVivo assisted with rapid coding as “highlight”, “drag” and “drop” techniques were quick and easy to use.

Initial coding in NVivo occurred through the allocation of codes or, in NVivo parlance, “nodes” stored in hierarchies known as “trees”. A tree or overarching heading was used to organize the large number of nodes. Under each tree, an intermediary level of heading called a “branch” was used to organise the data according to broad categories. Each branch contained numerous active nodes. Within each participant’s transcript a word, sentence, or paragraph was highlighted and allocated a node name which best represented that piece of data. Pieces of data were then “dragged and dropped” into the same node or a new node was created on the branch. A single piece of data might be coded at multiple nodes. Nodes could be merged if there was more than one node for the same concept. NVivo provides the facility to view the coding of a document by employing a function called a “coding stripe” – a colour-coded system showing which pieces of data are coded at a specific node. A list of the initial nodes is provided in Appendix 6.

Based on the interview guides and the life course perspective adopted in this study, three trees emerged as providing a useful data analysis coding structure: (1) family relationships, (2) growing up, and (3) the future. Within each of these trees, branches were created to reflect the broad categories of the emerging analysis. For example, nine branches were formed in the Growing Up tree: (1) childhood, (2) adolescence, (3) schooling, (4) family moves for services, (5) involvement with other children with cerebral palsy, (6) moving out of home, (7) living environment, (8) interests and hobbies, and, (9) personal view of disability. An examination of the data yielded multiple nodes within each branch. For example, four nodes were

understandable only within the Schooling branch: (1) difficulties at school, (2) leaving home to go to school, (3) receiving therapy at school, and (4) moving from school to university. Coding the data in this way meant that it was possible to view this particular set of nodes only in relation to the Schooling branch and this provided some assurance that the data within these categories was authentic and excluded all other categorical analysis. In line with Charmaz's (2006) constructivist grounded theory, these nodes are active and descriptive (gerunds). Table 2 shows diagrammatically the tree, branch and node levels of coding with the Growing up tree, Schooling branch and associated four nodes in bold type.

Table 2 NVivo initial coding structure



The following interview extract demonstrates how a piece of data was initially coded as “Difficulties at school” in the Schooling branch, Growing Up tree.

Table 3 Example of initial coding - Bruce

Quote from initial interview with Bruce	Initial code for this piece of data
“Because the teachers didn’t know what was wrong with me they used to let me play.”	Difficulties at school (Schooling branch) (Growing Up tree)

At this stage of the coding process I used constant comparison (defined on page 111) to compare data within the one interview transcript and across interview transcripts both of one sibling and of different siblings in order to identify similarities and differences. The following extract from the initial interview with Bruce’s sister Charlotte demonstrates similarities in the issues raised by siblings and the way in which they were coded.

Table 4 Example of initial coding - Charlotte

Quote from initial interview with Charlotte	Initial code for this piece of data
“He went [to school] for a few years but I don’t think that really, you know he says he was badly treated...I think the kids used to poke fun at him.”	Difficulties at school (Schooling branch) (Growing Up tree)

The number of initial codes created was too great to be workable in the analytic process. Therefore, in line with Charmaz’s (2006) method, I followed the initial coding with focused coding. At this point I moved away from using NVivo as a coding tool. I found the restrictions of looking at the data on a computer screen hindered my ability to see nuances and complexity within a transcript and also across transcripts. Working with the printed transcripts helped me to see the inter-relationships and emerging sequences in the data.

6.1.2. Focused coding

According to Charmaz (2006, p. 57) focused coding involves “using the most significant and/or frequent earlier codes to sift through large amounts of data.

Focused coding requires decisions about which initial codes make the most analytic sense to categorize your data incisively and completely”. At this stage in the process I

moved away from simply describing a topic by attaching an initial code to developing more abstract conceptual categories in an attempt to distil the properties of the topic being studied (Charmaz, 1990). Through applying focused coding I prioritised the most significant codes to develop three categories which encapsulated the life course perspective considered fundamental to exploring the research aim of this research project:

Category 1: Growing Up

Category 2: Becoming an Adult

Category 3: Getting Older

While these three categories loosely aligned with the three trees used to organise the initial coding structure: Family Relations, Growing Up, The Future, the level of abstraction obtained during the focused coding process meant that branches and nodes were realigned to form the three categories listed above. Table 5 demonstrates how this realignment occurred from codes in the Growing Up tree and associated branches to the categories of Growing Up and Becoming an Adult.

Table 5 Realignment of coding structure to form categories

Initial Coding Tree	Initial Coding Branch	Focused Coding Category
Growing Up	Childhood	Growing Up
Growing Up	Adolescence	Becoming an Adult
Growing Up	Schooling	Growing Up
Growing Up	Family move for services	Growing Up
Growing Up	Involvement with other children with a disability	Growing Up
Growing Up	Moving out of home	Becoming an Adult
Growing Up	Living environment	Growing Up
Growing Up	Interests and Hobbies	Not considered significant
Growing Up	Personal view of disability	Growing Up Becoming an Adult

A list of the focused codes informing each of the three categories can be found in Appendix 7. At this point in the analysis, Charmaz (1990, p. 1164) warned against “premature commitment to categories” as indicating that the “researcher has not fully explored the issues, events and meanings within the research problem or setting and has not gained... ‘intimate familiarity’ with it”. Although I was confident from my data analysis that the categories identified at this stage described the experience of siblings, I did not feel that they “incisively and completely” (Charmaz, 2006, p. 57) explained how, why, and for what purpose the sibling relationship continued in later life. Charmaz (1990) identified two analytic processes which assist researchers to take their data analysis to the next level: (1) further constant comparison of data with data, category with category, and concept with concept; and (2) continued questioning. Together these processes enabled me to identify emerging patterns which related to the past and present experiences of being a person with cerebral palsy or a non-disabled sibling. Furthermore, I identified factors which accounted for the similarities and differences in participants’ experiences. Six pathways emerged which related to the three categories identified earlier. Table 6 lists the pathways associated with each category.

Table 6 Development of categories and pathways

Category	Pathways
Growing Up	Coming from the country Coming from the city
Becoming an Adult	Exercising agency Relying on others
Getting Older	Influence of parental status Recognising the effects of growing old together

For example, the data highlighted that there were differences between participants who grew up in the city compared to those who grew up in country areas. At this stage in the data analysis I began to suspect that living environment in childhood may be significant in the later life relationship between siblings. The following extract from the follow-up interview with Bruce demonstrates the impact of being separated from his non-disabled siblings in childhood when his siblings went to boarding school.

Table 7 Example of focused coding - Bruce

Quote from follow-up interview with Bruce	Pathway and Category
“We never got to know each other very well because he [brother] was at the boarding school and I wasn’t...I’ve seen more of [sister] in the last 10 years than I saw when she was at school.”	Coming from the country (Growing Up)

As advocated by Charmaz (2000), throughout the coding process I had been using memo-writing and diagramming to flesh out categories as they emerged. At this stage I used these tools as a way of delving deeper into the data. Further exploration of the data using these methods revealed 12 themes which better explained the variation of participants’ experiences across the six pathways, presented in Table 8.

Table 8 Category, pathway and themes

Category	Pathway	Themes
Growing Up	Coming from the country	<ul style="list-style-type: none"> • Moving out of home for services • Growing up without specialist services • Moving the family for services
	Coming from the city	<ul style="list-style-type: none"> • Tapping into specialist services
Becoming an Adult	Exercising agency	<ul style="list-style-type: none"> • Pushing the boundaries • Forging an independent path
	Relying on others	<ul style="list-style-type: none"> • Depending on specialist services • Leaving decision making to parents
Getting Older	Influence of parental status	<ul style="list-style-type: none"> • Holding on • Letting go
	Influence of sibling ageing and ill health	<ul style="list-style-type: none"> • Taking on more responsibility • Recognising the effects of growing old together

The following excerpt from the initial interview with Helen demonstrates the development of the theme “Moving the family for services” from the pathway “Coming from the Country” and the category “Growing Up”.

Table 9 Example of development of themes – Helen

Quote from initial interview with Helen	Theme, Pathway, Category
“My folks were told that we should [move] to [place] if I wanted to have an education and so the whole family moved to [city] when I was three.”	Moving the family for services (Coming from the country) (Growing Up)

Built on the three conceptual categories identified in the analysis and in keeping with the life course perspective of this study, the results are presented in the next three chapters under the headings:

- (1) Growing up – the importance of the early years of sibling relationships, during which individuals with cerebral palsy and their non-disabled siblings can develop an emotional and cognitive closeness. This chapter explores the different pathways of participants who came from the country compared to those who came from the city.
- (2) Becoming an adult – individuals with cerebral palsy and their non-disabled siblings becoming independent adults through adopting adult roles of work, forming relationships, and moving out of home. This chapter explores the different pathways of participants who exercised agency compared to those who relied on others to make decisions for them.
- (3) Getting older – individuals with cerebral palsy and their non-disabled siblings facing the ill health and death of parents. Via the different pathways of participants, this chapter explores the issues related to parental status and sibling ageing and ill health on sibling relationships in the “post-parental” era.

6.1.3. Ensuring rigour in data analysis and authenticity of findings

Three strategies were used to ensure that the data analysis in this study was rigorous and the findings authentic. The first strategy was the data analysis process which combined open and focussed coding, memoing, and diagramming. Together these tools provided a checking mechanism whereby a theme could be explored from various angles using the different approaches recommended within the constructivist grounded theory method (Charmaz, 2006). The analysis process involved moving back and forth between coding, memoing and diagramming in order to test out the relevance and importance of themes.

The second strategy used to ensure rigour was the opportunity for participants to provide feedback throughout the study. Feedback from participants was received via telephone conversations, email communication, and in-person at follow-up interviews. As mentioned previously, apart from minor changes to names and dates, participants verified the accuracy of the transcripts and summaries of their interviews. Also at the beginning of each follow-up interview, participants were given a verbal account of the emerging analysis and were asked to reflect on whether and how the emerging themes related to their experience of being or having a sibling with cerebral palsy. In the latter stages of the study, an overview of the primary finding of reciprocity and how this related to the various pathways was sent to four participants who had previously indicated their willingness to comment on the findings of the study. Two of the four participants responded that they were able to identify their experiences within the analysis. The other two participants did not provide any feedback. In the original research plan (see Participant Information Sheet in Appendix 2), the intention was to conduct a focus group at the conclusion of the individual interviews during which participants would have an opportunity to hear about and comment on the findings of the study. This focus group was not held as it was decided that, given the geographic distribution of participants, it would be difficult to convene a group which would provide equitable access to all. Additionally, it was felt that discussion within a focus group forum had the potential to compromise the confidentiality of information and anonymity of individual participants.

The third strategy used to ensure the rigour of this study was the discussion of emerging analysis with my supervisors. As mentioned previously, my supervisors provided “fresh eyes” to the data analysis, suggested different perspectives and

challenged my assumptions and interpretations. Discussions with my supervisors occurred at each stage of the data analysis process and were conducted face-to-face, via email, and through SKYPE. I made notes of each discussion and these records of supervision form part of the analysis audit trail.

The combination of these strategies established rigour in the data analysis process and contributed to the authenticity of the findings.

6.2. Prelude to the Results

Each results chapter starts with a brief description of the importance of the life stage, followed by a number of stories from participants to illustrate this life stage, and concludes with a discussion with reference to the literature.

6.2.1. Challenges of interviewing people with cerebral palsy

The aim of this thesis was to explore the relationship *between* individuals with moderate to severe cerebral palsy and their non-disabled siblings. The study aimed to present with equal weight the viewpoints of the participants with and without a disability. In reality, conducting in-depth interviews with some people with moderate to severe cerebral palsy can be challenging due to their complex communication needs. In this study, four participants with cerebral palsy, Richard, Betty, Mathew, and Kristine, presented particular communication challenges.

Richard and Betty, who are married to each other, have no verbal communication and significant hearing impairments. With their agreement, a support worker was present during both their initial and follow-up interviews and this person assisted Betty and Richard to understand my questions by translating them into sign language, and me to understand their responses by interpreting their signs and body language. Besides the assistance of the support worker, I used written questions with

Betty to which she responded with brief written answers. Also, at the suggestion of the support worker I sent a written copy of the interview guides to Betty and Richard prior to their interviews. The support worker went through this with them and made some written comments which were given to me at the interviews. Despite these strategies, communication with Betty and Richard was slow and difficult and our interactions lacked the degree of depth and reflection which typically characterises qualitative in-depth interviews. In their stories presented in Chapter 7 the views of their non-disabled siblings, Ruth, Bob and Derek are somewhat more dominant.

Mathew also has no verbal communication but he indicates “yes” and “no” clearly using facial expressions and body language. Mathew has a speech generating device (SGD) onto which he types his message letter by letter using a pointer attached to a helmet. Due to the involuntary movements associated with his cerebral palsy, Mathew makes many errors in typing in his message and corrects these as he goes. Therefore, communicating is a slow, laborious process. However, he is a competent communicator and can get his message across clearly, albeit using single words and short phrases rather than sentences. Communicating with Mathew involved asking him many clarifying questions based on his short written responses, to which he would indicate “yes” or “no”. Communicating using his SGD is also very tiring and by the end of a 1-hour interview Mathew’s error rate increased and he answered with more single words. In the presentation of Mathew’s story in Chapter 8 his voice tends to be somewhat subsumed by the voices of his two sisters, Therese and Kirsty, with their more expanded quotes. This is not because Mathew was not clear about his viewpoint but rather that his responses were, as described, short.

I found Kristine’s speech very difficult to understand. Her sister Natalie warned me at our first interview that I would need assistance to understand Kristine’s

speech. However, at the first interview with Kristine she did not want to have a staff member present and we proceeded alone. As Natalie indicated, I struggled to understand much of what Kristine said. By constantly checking my understanding of what Kristine was saying with her I managed to piece together her story, albeit with many gaps. To better understand her story I asked her to nominate a staff member who could sit in on our follow-up interview and this person assisted by clarifying Kristine's responses. Kristine's story, presented in Chapter 9, represents a piecing together of her story as she told it to me over the two interviews.

The challenges I encountered interviewing these four participants with cerebral palsy are indicative of why people with complex communication needs may be excluded from research. Nonetheless, I am firmly of the belief that these participants' stories of their lives are essential. They were able to share with me, and highlight the difficulties they encountered in their everyday interactions with others, including their non-disabled siblings. It is true, however, that it was hard to capture the depth with the participants with cerebral palsy with severe communication difficulties that was much easier to achieve with the non-disabled participants. The remaining eight participants with cerebral palsy, although all having dysarthric speech, were able to communicate their views more fully within the interview setting. Therefore, their voices come through more strongly and there is more balance between the depth of their views and that of their non-disabled siblings.

6.2.2. Presentation of the results

Results chapters 7, 8, and 9 follow a similar format, bringing together analysis of data of the participants with cerebral palsy and their non-disabled siblings' viewpoints. In each results chapter, the quotes from participants are *italicised*. I have sometimes added joining or explanatory words in square brackets [...]. This is particularly done

with quotes from participants with cerebral palsy, to make the quotes flow and easier to read. These represent a bringing together of the question-and-answer nature of an interview with a person with a communication impairment. Throughout the interviews I checked that I was making the correct interpretations of what they were saying. Square brackets [...] are also used to replace the proper names of places, people or organisations which might disclose the identity of the sibling. For example, I write [sibling's husband] instead of his name.

Chapter 7

Growing up

Using the stories of participants in three sibling dyads and one sibling triad, this chapter describes the importance of childhood in the development of sibling relationships. Figure 2 provides a diagrammatic overview of the concepts discussed in this chapter and, via the dotted lines, how they lead on to the next chapter.

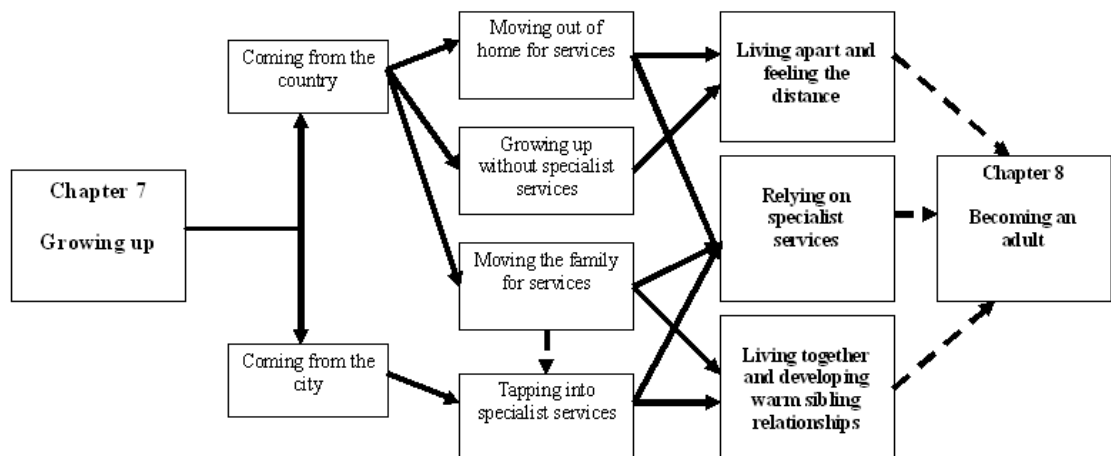


Figure 2 Growing up

The category “Growing Up” can be understood according to two divergent pathways, “Coming from the country” or “Coming from the city”. How these pathways impacted on the relationship which developed between siblings is explored using four themes, “Moving out of home for services”, “Growing up without specialist services”, “Moving the family for services”, and “Tapping into specialist services”. Appendix 7

contains the list of focused codes which informed the development of the themes, pathways and categories discussed in this chapter.

The childhood sibling literature identifies the benefits of children growing up together in their family home. Howe et al. (2001) discussed the importance of children learning how to negotiate positive and negative emotions through their earliest interactions with their brothers and sisters. According to Howe and colleagues, the opportunity to fight with siblings and to come to a resolution in childhood disputes is important in learning how to negotiate adult relationships. Sanders (2004), Stoneman (2001, 2005), and McHale and Crouter (2005) have identified the importance of variables such as the number of siblings, their place in the family and age distance, and their gender as influential on the interaction between siblings in childhood and later in life. Furthermore, Stoneman (2001), Howe et al. (2001), and Kramer and Conger (2009) proposed that growing up together in the family home contributes to the development of trust, warmth, empathy, and caring between siblings. These authors and others including Sanders (2004), suggest that ideally, all children would grow up in a family home with their parent/s and siblings. However, for some children with cerebral palsy born prior to 1970 in Australia, as was the case for some participants in this study, this did not occur.

Drawing on their body of work around the issue of out-of-home placement (e.g., Blacher & Baker, 1994; Blacher, Baker, & Feinfield, 1999), Baker and Blacher (2002) described children with lifelong disabilities as vulnerable to being placed out-of-home, depending on the complexity of their physical and emotional support needs. Eisenberg et al. (1998), Drapeau et al. (2000), Schaverien (2004) and Conger et al. (2009) have warned that separating siblings during childhood can result in less warmth, along with feelings of loss associated with separation. The placement of

children with a disability in out-of-home care is no longer government policy in Australia (Department of Ageing Disability and Home Care, 2004) and the majority of disabled children were always cared for in their family homes, with only a small proportion being placed into institutional or other care (Blacher, 1994). For example, Llewellyn et al. (2003) estimated that 82% of people with a severe or profound disability in Australia lived with an informal carer, usually a parent. In the USA, Greenberg et al. (1993) estimated that 85% of people with an intellectual disability lived with their parents.

Until the early 1970s, the birth of a baby with problems and the search for a diagnosis propelled the family along a certain pathway involving doctors, therapists and specialist service providers. According to participants in this study, engagement with specialist services from a very young age influenced many aspects of their lives, including the sibling relationship.

Reflecting the accessibility of specialist services for children with cerebral palsy at the time, one of the main factors influencing their life course was where the family lived. Families who lived in a capital city could access specialist services; those who lived in country areas could not, as there were no local specialist services.

According to participants, if the family lived in the country there were three options available: (1) to send the child with cerebral palsy to a specialist boarding school in the city to receive education and therapy, illustrated in this chapter by the story of Betty and her brothers Bob and Derek; (2) to keep the child at home with no access to specialist services, illustrated by the story of Bruce and his sister Charlotte; and (3) to move the family to a capital city where services were available, demonstrated by the story of Helen and her sister Isobel. Each of these choices had advantages and disadvantages for the child with cerebral palsy and the non-disabled

siblings. The experience of being born and brought up in a capital city with easy access to specialist services is illustrated by the story of Richard and his sister Ruth.

7.1. Coming from the country

7.1.1. Moving out of home for specialist services

Betty, Bob and Derek

Betty, who is 53, has cerebral palsy and is profoundly deaf as a result of Rhesus incompatibility. Her birth in the 1950s, prior to the treatment of Rhesus incompatibility with Rh-immune globulin during pregnancy, situates Betty's impairments within their historical context. Betty cannot speak; she communicates by lip reading, signing, written responses, and spelling words out using an alphabet board. Because of her complex communication needs, Betty's brothers' accounts are more prominent in the telling of this family's story. Both Betty's parents are dead. Betty is the only daughter and youngest in the family with four brothers.

Bob (65), now retired, is the eldest in the family and is married with adult children and grandchildren. Twelve years older than Betty, Bob was in his first year of high school when she was born. Derek (58), also retired, is the second youngest in the family and has adult children and grandchildren. Derek also had complications due to Rhesus incompatibility when he was born and had blood transfusions after birth. Bob, Derek and another brother live in a city 3 hours drive away from Betty; the fourth brother still lives in the regional town where they grew up.

At the time of Betty's birth the family lived in a regional town 6 hours by car from the closest capital city. Because Rhesus complications had arisen for the second and third sons in the family, their mother went to a large teaching hospital in the

capital city to give birth to Betty. Bob recounted what he remembered of Betty's birth and subsequent diagnosis:

Mum always wanted a girl of course so they were very cautious about everything so she went to [hospital in capital city] and they were prepared for Rh problems but nothing actually appeared to eventuate until a couple of days after she was born when she turned blue and then they knew they had a problem. But they didn't know how serious it was until... it probably took a couple of years I think for them to figure out that she was disabled. She wasn't walking and she couldn't speak and all those sorts of things.

According to Bob and Derek, when Betty was about 4 years old their parents were advised to send her to the capital city to live in the specialist boarding school for children with cerebral palsy where she would receive therapy and an education.

Betty's older brother Bob reflected on how he thought Betty's move away from home might have affected her:

That would have been a real drag for her I guess, leaving all the family behind. She was very young, very young to be away from Mum. Because she was just one of the family when she was at home [and] nobody saw her as being disabled, she was just a young kid.

Derek commented:

We sort of got used to the fact that she [Betty] was living, apart from the holidays in [city], at the hostel with all the other cerebral palsied kids and that wasn't so bad because the services were provided in one place, including schooling etc.

At the boarding school Betty learnt to finger spell and that opened up a way of communicating with her family. Bob said: "*I don't know how we communicated*

originally but I know we had a lot of fun so there didn't seem to be any problem. She got the message what was going on. She was a pretty bright young lady." Being closer in age to Betty, Derek had a clearer memory of how they communicated with each other:

Just by hand signals and [later] she learnt to lip read too. Lip reading was the main thing and just hand signals. So we could communicate by using little signs or when she had learnt to read, as long as you write it clearly, she can read it or pick up the main words and know what you're on about.

A requirement of receiving services from the specialist cerebral palsy service provider was that the country-based mothers had to work at the boarding school for 6 to 8 weeks a year helping out with domestic tasks and therapy. Bob and Derek remembered without resentment their mother being absent from home for blocks of time while she provided assistance at the specialist boarding school. Bob recalled:

I suppose the mothers spent, each mother who had a spastic child spent eight weeks down there to be with them, to assist, and also to create the right environment. They went through all the physiotherapy and all the rest of the stuff they did. I don't know that it [mother being away] was discussed [with us], it was just accepted, it was just part of what happened. I mean it was the "Victorian" era of raising kids so you were brought up tough, plenty of discipline and all that sort of stuff. That was just part of life. We are all independent types I guess so we didn't really feel anything strange about Mum being away...we just sort of carried on with life...we'd go off to school and Dad would cook dinner or whatever. We all took turns at doing something...it was just part of what happened.

Derek had similar recollections:

We learnt to look after ourselves pretty much. There was no resentment there at all. It was just the way it was, you know we just lived with it. Dad was always there and Mum was mostly there. There were only short periods of time when she was away which was probably good for us because we learnt to look after ourselves.

Bob recalled that “*Betty was the only spastic kid in [country town] I think.*” Despite this, and although they lived a 6 hour drive away from the capital city and the specialist service city headquarters, their parents maintained close contact with the service as they had to provide “voluntary work” both on site and in their home town by fund raising. Derek recalled the advantages for him and his brothers of their parents’ involvement in fund-raising activities:

Dad was the president of the [specialist service for people with cerebral palsy] down there [country town] so he was fairly involved with all the fundraising and he was pretty well known. I suppose the upside of it was that I got to meet most of the Miss Australias⁶ when they came to town...they all came to the house for BBQs and we all, all the boys hung out!

The move to boarding school at a young age was the beginning of a life time of reliance on specialist support services for Betty. Leaving home as a preschooler, Betty never returned to live permanently in her family home. Instead, she progressed through the special school to supported employment and accommodation. Bob encapsulated this progression for Betty:

[Betty] didn’t really come back to [home town] to live at all. She was at [the specialist boarding school] and she went from that environment to the training area where they go through all the physiotherapy, to the living

⁶ From 1954 to 2000 the “Miss Australia” contest was the main fundraising event for specialist cerebral palsy services in each of the states. An integral part of the beauty contest was the commitment by the contestants to raise funds for the specialist cerebral palsy service (CP Australia, 2009).

accommodation where they have their own separate accommodation, to the hostel where married couples live.

And Betty recalled: “[I lived in the specialist boarding school] *for 16 years* [and then at the specialist cerebral palsy hostel] *for [about] 12 years*. [I moved into the community about] *18 years ago.*”

Betty now lives with her husband, Richard in a house in the community in the capital city. With both their parents dead, oldest brother Bob has taken on the responsibility of maintaining contact with Betty through her service providers. Bob and Derek reported that they have direct contact with Betty two or three times a year and in a prepared response to the question about contact with her brothers, Betty wrote:

I see them [brothers], get letters or cards about four times a year. [I'd] like to see them more. [I] don't see them as much [now, but] brothers are busy. I understand and it's OK.

In a country as geographically large and sparsely populated as Australia, attending boarding school is not uncommon for children who live in rural and regional areas. Attendance at a boarding school in a larger centre or capital city was the main educational option for children from country areas in the 1940s and 1950s, prior to the growth of many regional centres and the introduction of other distance-based schooling methods such as the “School of the Air” for those living in more remote areas. Nonetheless, as described by Bramston and Patrick (2007), the majority of Australian country children went to boarding school as teenagers entering high school rather than as 4 year olds, as was the case for many disabled children with cerebral palsy.

In contrast to the child with cerebral palsy leaving home to attend a specialist boarding school for children with cerebral palsy, for one country family in this study it was the non-disabled children who attended boarding school while their brother, Bruce who had cerebral palsy remained at home with their mother without access to specialist services.

7.1.2. Growing up without specialist services

Bruce and Charlotte

Bruce (62) has cerebral palsy, a hearing impairment, and dysarthric speech. Like Betty, Bruce's disability resulted from Rhesus incompatibility. Bruce's father died when he was three years old and Bruce lived with his mother until her death, 13 years before the initial interview. After her death, Bruce continued to live in the family home in a regional town where he has lived for the past 60 years. Over the years Bruce has had a number of jobs in open employment, including working in a factory and running his own gardening business. Bruce is the youngest in a family of four.

Charlotte (70) is the eldest in the family and is married with adult children and grandchildren. Charlotte lives a 5-minute drive away from Bruce, and their other two siblings live some hours' drive away. Charlotte was 8 years old at the time of Bruce's birth and recalled the circumstances around his diagnosis. She said:

The doctor said "Look he's not going to survive". He said to Mum more or less "Just abandon him" because it was a Rh negative thing and they were just finding out, I think they'd done a couple of transfusions in [the capital city] but of course in the country there was nothing.

After their father's death, their mother moved with the children to a regional town where she had friends who could provide her with support. Charlotte explained:

Dad was killed very suddenly... [Mum] came to [regional town] with the four of us and she had a real struggle because she had no money and Bruce the way he was. She got the widow's pension and that was all. But the neighbours were very, very good and I can remember them giving us warm clothes for winter.

In the 1940s and 1950s, when Bruce was a child, there were no services for children with cerebral palsy available in the town where they lived. Bruce was the only participant with cerebral palsy in this study who received no specialist support services during his childhood. Charlotte remembered how her mother found creative solutions to compensate for the lack of formal therapy:

I think he [Bruce] was about nine before he even started to walk. He used to get around on his bottom and Mum used to put leather patches on the seat of his pants. I can remember her tying his feet to those little tricycles and she'd wheel him backwards and forwards to make him use his legs and get his muscles going. She just did it off her own bat – she was a marvellous lady.

Charlotte recalled the circumstances, impact, and her feelings about going off to boarding school:

[A family friend] took over and sent us off to [boarding] schools, us three elder ones. We only came home for holidays and it was very, very strict... in the long run it did us all good I think but at the time it was very tough and it must have been really, really tough on Mum for the three of us to go away together. We all went together but the boys and girls were separated and we didn't have any contact with one another during the school term.

Meanwhile, Bruce remained living with his mother. He remarked on the impact of this separation on his relationship with his siblings:

We never got to know each other very well...because [they] were at boarding school and I wasn't. I didn't see [them] very much. I've seen more of [other sister] in the last 10 years than I saw when she was at school.

While his non-disabled siblings went to boarding school, Bruce attended the local public school. He had unhappy memories of his time there and believes his illiteracy is the result of the poor education he received. Bruce said:

The teachers didn't know what was wrong with me. They used to let me play. I told the teacher off one day. I said "Teach me something please". And she sent me up to the headmaster to get the cane and I got the six. If they'd taught me to read when I was younger I would have been very good.

Charlotte added: *"He went to school for a few years but you know he says he was badly treated. I don't know a lot about that to be quite honest. But I think the kids used to poke fun at him."* Despite his limited education, Bruce said he was pleased that he had not been sent to boarding school like his non-disabled siblings. When asked if he regretted being unable to attend boarding school too Bruce responded emphatically: *"NO! I would have been more handicapped than I am now."* Bruce said he felt this way because he thought he had learned much by staying at home with his mother:

My Mum brought me up you know and Mum did a good job as you can see! She taught me well. She even taught me to knit and sew. My mother taught me lots of things like cooking and housework and how to dress yourself properly and things like that. She always said to me "Do your best, don't pay notice to the other fellow, do your best".

Similarly, Charlotte attributed Bruce's independence to the foresight of their mother in teaching Bruce independent living skills:

He lived with Mum all his life until she died and she taught him to cook, to wash, clean, all the things that you need to do to live on your own. And he does it all very, very well, even his ironing. When Mum died I said “Bring your ironing down and I’ll do your ironing” [but] he’s coping quite well.

Throughout their adult lives, Bruce and Charlotte have lived 5 minutes away from each other. Both of them value their relationship. Bruce described his relationship with Charlotte in the following way: *“Lovely relationship we’ve got. She doesn’t tell me what to do. [Other sister not interviewed] tells me what to do but Charlotte doesn’t.”* Charlotte in turn said: *“I mean if you wanted him to do something he’d be here. If you didn’t have a car or something and wanted to go somewhere and rang him up, he’d be here to take you.”*

Although their sibling relationship was disrupted during their childhood Bruce and Charlotte are now close, geographically and emotionally, with an underlying sense of “family”, and their geographic proximity makes it easy for them to keep in touch with and help each other out.

The story of Helen and her sister Isobel provides a view of what may happen when parents make the decision to move the family to a capital city in order to access specialist services for their child with cerebral palsy.

7.1.3. Moving the family for specialist services

Helen and Isobel

Helen (45) has cerebral palsy, post-graduate qualifications, and is employed full time in a professional job. Helen has dysarthric speech and uses an electric scooter to get around. Helen’s mother (74) is still alive, but her father died 5 years before the initial interview. Helen, who lives in a different country to her mother and sister Isobel, is the eldest of three sisters.

Isobel (38), the youngest in the family, is single, and manages a small business. Their other sister, who is 18 months younger than Helen, is married with two children and declined an invitation to participate in the study. Helen's and Isobel's story illustrates the impact on sibling relationships when families move from one area to another in pursuit of services for their child with cerebral palsy. Their story is also a reminder that siblings' memories and reactions to childhood events may differ.

Helen explained her understanding of the circumstances surrounding her diagnosis of cerebral palsy: "*I was born very traumatically I understand, and when I was 8 months old my grandmother came to visit and noticed something was wrong so that's when I was diagnosed.*" At the time of her diagnosis, Helen's parents were living in an area with few services for children with a disability and they were advised to move to a capital city in order to access services for Helen. Retelling her parents' account of this time Helen said: "*When I was three they [parents] took me down to [city] to have some testing done and my folks were told that we should [move] to [the city] if I wanted to have an education.*" Looking back, Helen reflected on the wider implications of this move:

Well I mean my father took a pay cut by half, he couldn't get a permanent job as a [profession] because he didn't have [a necessary skill]...so the extended family basically fed us with meat and that type of thing.

Nonetheless, as apparently intended by her parents, Helen believed that the move to the city was advantageous, providing her with access to therapy and education. Helen said:

Well there was a purpose-built school for cerebral palsied kids which I think had been started in the mid-50s or even early 60s because it was relatively

new and as usual it had been started by parents. And [the school had] very good therapy: Bobath⁷, physio, speech, OT, the lot [and] there was a bus service, so the school buses picked all the kids up.

By the time Helen was 10 years old this purpose-built school was no longer meeting her academic requirements. Again, indicative of the prevailing service arrangements at the time, and despite her intelligence, Helen could not access a regular school so her parents made the decision to move the family again. Helen recalled:

We actually moved up to [another city] to another school because by that time [special school] was not providing me with any academic stimulation and I actually started bunking school because I was bored stiff...my parents picked it up and went against all the perceived wisdom and moved because they tried to get me into regular schools and no one would take me because I would scare all the other children.

Looking back, Helen has a view on the impact of these moves on her siblings and in particular her sister who was not interviewed:

“[The family] basically moved for me which sounds really selfish... [Sister who was not interviewed] I think still resents that disruption. I think that it had a major impact in her whole life...it was really tough [for her] moving and making new friends. I think it caused a huge issue which, I mean you don't really see that when you're in the middle of it, but looking back at it, I mean Isobel when you talk to her, she's pretty level headed but [sister not interviewed] still sees the fact that she had a disabled sibling as the reason for all her problems.

⁷ The Bobath approach was developed in the United Kingdom in the 1940s as a way of assisting children with cerebral palsy to extend their range of movement. According to the website for the Bobath Centre, UK, “The main aim of the treatment is to encourage and increase the child's ability to move and function in as normal a way as possible” (The Bobath Centre).

As Helen suggested, Isobel reported being unconcerned by the family moves:

Obviously we moved places to make it happen [for Helen]...I didn't mind it, I quite liked it. I think [other sister not interviewed] maybe had more of an issue...I never held it against them [parents], it wasn't an issue.

The difference in the way her non-disabled sisters reacted to having a sister with cerebral palsy was, Helen believed, in part due to the closeness in age between her and her non-interviewed sister, but mainly due to their different personalities. In reflecting on this Helen said: *"I also think it's personality-wise...I think that it wouldn't have mattered what I'd been... [sister not interviewed] and I used to fight like cat and dog."* Helen thought that not attending the same school contributed to the problems between her and her sister. As Helen said: *"Well I think the big issue was that I was always at a different school which actually I think disrupted that relationship that we could have had. So we were always separate in terms of friendships."*

Helen recalled finding particularly irksome her younger sister's attempts to take on a caring role for her:

[Sister not interviewed] actually took on the role of the caring sister which I always ignored. It used to drive me up the wall. When we were out she would be the one that got me a plate of food etc. and I think in a sense she [sister not interviewed] was assuming the role of the older sister or [pause] trying to.

Youngest sister Isobel agreed with Helen's assessment of her relationship with their other sister and commented:

You'll get a completely different view of [Helen's] disability if you speak to [sister not interviewed]. [Other sister] always harboured the fact that she missed out in the family because Helen got the attention.

In contrast to the relationship between Helen and her non-interviewed sister, and perhaps due to the larger gap in their ages, Helen reported that from childhood she and Isobel had a close, warm relationship:

She [Isobel] was always the younger sister and I remember when she was born, it was the highlight of my life because I used to help Mummy look after her and it was a very big thing in my life as a 5 year old. I adore her.

And Isobel said:

I'm the baby in the family, the spoilt one and they both [Helen and sister not interviewed] looked after me. I was Helen's toy from what I understand. Listening to Helen I was her little baby. So I mean I'm close to both of them but definitely closer to Helen than to [sister not interviewed], which often puts you in the middle between them so I refuse to take sides any more.

From her viewpoint, Isobel commented that some aspects of family life were largely unaffected by Helen's cerebral palsy:

I think because I was so much younger I've never known any different...maybe I was just oblivious to things, they often say I'm like my father...things just wash over me. It [Helen's cerebral palsy] never stopped us doing things. We still did all the holidays, we still did all the hiking, Dad just carried her if we needed to...it was never a hindrance in fact growing up. As a youngster I don't remember actually ever having a difference or noticing or being aware of a change.

Both Helen and Isobel credited Helen's acceptance in the communities in which they lived to their parents' attitude. Isobel said:

I think they [parents] just believed "Well, so there are a few problems. We'll just eliminate as much as we can and make sure it works properly." I don't

think they ever thought of doing it any other way. I think my folks were phenomenal. I don't think it happens like that in every family. People either mollycoddle too much one way, whereas Mum and Dad just made sure she was like any other child.

Helen expressed a similar view:

Compared to my peers, they are all now totally dependent on other people because of basically their upbringing. They were mollycoddled and I think that's where my parents fought against the system and they were always told that they weren't accepting that they had a disabled kid. And yet they kept saying "Well, she's going to have to live in the real world." So they did me that huge service.

Nonetheless, Isobel recalled some instances of discrimination against Helen when they were out in the community:

I was aware of the fact that she was disabled when we'd go out and try and do things or buy things from a shop and people would talk to me instead of to her. And that was a big realisation and it would irritate the hell out of me. But we'd make a game of it because I'd totally ignore the people and they'd have to eventually talk to her.

It is clear from these excerpts from the interviews that Isobel does not consider Helen as defined by her disability. Isobel explained her perception of "who Helen is" in the following way:

I suppose if anything I thought more of her as "the boss" than as the disabled person. She was always "the brain". She was never the disabled sister; she was the brain in the family. Growing up with her, she was the brainy big sister who got "A"s for everything. That was my impression, not that she was

disabled and doing well, she was just “the brain”. I never thought of her as handicapped which is maybe wrong because it must have been bloody hard but I just always assumed that she could do it.

Despite living in different countries Helen and Isobel continue to share a close relationship which is maintained by regular contact using telephone and email and by taking holidays together. From Helen’s perspective, her relationship with the sister who was not interviewed remains difficult and although they keep in touch there is not the same degree of warmth. Helen explained:

I love both my sisters but it’s just very unfortunate that [sister who was not interviewed] has mega, mega issues...which focused on me for while...[but] I think it’s far deeper than just having a disabled sibling but I don’t think that helped. And Isobel struggles to cope with the whole issue as well. I think she just wants a happy family.

Helen’s and Isobel’s accounts of their lives growing up highlight how moving the family to access specialist services for the child with cerebral palsy can affect the relationship between siblings. As demonstrated by Helen’s and Isobel’s stories, siblings interpret differently family moves to access specialist services; they may be perceived as placing the needs of the child with a disability above the needs of the non-disabled brothers or sisters, or, in the case of Isobel, simply as a part of family life. The implications and results of these moves can therefore be more problematic for some siblings than for others.

Richard was born in a capital city and so had ready access to specialist services.

7.2. Coming from the city

7.2.1. Tapping into specialist services

Richard and Ruth

Like his wife Betty, Richard (62) has cerebral palsy and is profoundly deaf as a result of Rhesus incompatibility. Richard communicates using noises, his own brand of sign language, and reading/writing. Richard walks without help. He has an older stepbrother and stepsister (Ruth, who was interviewed) and a younger full brother who also has cerebral palsy and lives in a group home. Their widowed mother is in her late 80s and she and Ruth live together.

Ruth (69) is the second child and only daughter in the family. Ruth is divorced, with two adult children. Ruth and her older brother are the children of their mother's first marriage. Both Ruth's younger brothers are from her mother's second marriage. Ruth's oldest brother went to live with their father when their parents divorced and subsequently had little to do with his mother, Ruth, and stepbrothers, as Ruth explained:

[Older brother not interviewed] *lived in [place] with his father so we didn't see each other for a long time and he doesn't have much to do with the boys*

[Richard and other brother with cerebral palsy] *at all.*

Even with the assistance of his support worker, Richard's communication methods were slow and his answers consisted of single or few words. As a result of the challenges of communicating with Richard, Ruth's voice is more dominant in telling their story. Ruth was seven years old when Richard was born and she explained what she understood of Richard's diagnosis with cerebral palsy at that time:

We didn't know that there was anything wrong with Richard at first; for a little bit because he was deaf and...it was a bit hard to tell when they're babies [but] Mum was a carrier of Rh Negative.

The childhood medical and therapy support which was available to Richard and his brother because they lived in a capital city was indicative of the medical model of service delivery prevalent at the time for treating children with a disability. Ruth explained:

Mum came under Professor [name] because she had the two boys. We used to have to go in and the student doctors used to see us in their classroom and, not check us out, but Professor [name] would talk about the growing up things. Mum [also] had to take Richard to the deaf school near [university]. They didn't want him to learn sign language because they wanted him to speak because he has got a voice. But it didn't help him really. He does try to speak but it's very [hard to understand].

Growing up in the 1950s, Richard and his brother were among the first clients at the newly established specialist cerebral palsy service in the city where they lived. Ruth recalled the role their parents played in establishing the service:

The [specialist cerebral palsy service] opened at [place] first and then they built up there [current site]. And at both places the fathers had to work on the building sites, and they got people from their own work to come too on days when they needed a lot of men to do work. They didn't have to employ cleaners or cooks... [parents] were totally involved but then they didn't have to pay anything either [for the service].

Once the building was completed, the boys attended the school and received therapy. Ruth said: *"You had physiotherapy there and great teachers. It was quite good*

really. Mum had to do therapy with [other brother, not interviewed] his legs and he had irons he had to wear of a night time.” Another benefit of living in the capital city was the social interaction with other families of children with cerebral palsy. Ruth noted: *“Most of Mum’s friends were people who had spastic children because they had special dinners and balls and things.”* As the oldest child and only daughter living in the family home Ruth recalled her involvement in looking after her brothers:

I didn’t do as much with [brother not interviewed] as I did with Richard.

Richard used to like to escape. He’d get under the gate and you couldn’t call him back so I had to run after him. It wasn’t that he wouldn’t come back.

He’d come back with you no problem there. He’d just walk back with you if you held his hand. I’m sure Richard doesn’t think he’s deaf at all. He thinks he knows everything, he’s very funny, he has this great sense of humour. I used to take him, Richard to the movies on Saturday afternoons because I liked to go and I could go if I took Richard. He was good. I think the main thing was we got on with life and did what we had to do and we enjoyed life.

However, Ruth remembered a particular occasion when she encountered a negative community reaction while out with Richard:

I took Richard over to the beach one time and there were some people there and Richard wanted to pat their dog and they said “Get that mad boy away from me”. I think as they [brothers] got older, people sort of backed away too.

As a result of experiencing this type of reaction in the community, Ruth reported that the family tended to keep to themselves:

When we moved into this house no one [next door neighbours] came near us. [They thought we might ask for their help] but we’ve always been

independent, never asked people for help, always tried to do everything ourselves.

When her parents went out to social events, teenage Ruth was required to stay at home to look after her brothers. Ruth recalled: *“I’d stay home and look after the boys...I resented it a little bit but Mum and Dad wouldn’t let me go out until I was 15.”*

Also during her teenage years Ruth encountered the stigma associated with being the sister of brothers with significant disabilities. One incident in particular illustrated this: *“I was going [out] with someone and he sort of backed away. He had asked me to marry him and then he sort of backed away. It was the worry of me having spastic children. It’s very hurtful.”* Despite the loss of this boyfriend, Ruth married at 19. With the benefit of hindsight, Ruth remarked: *“I was sort of really wanting to get married to get away because there was always so much to do. There was always the boys to see to and various other things to look after.”*

Throughout their childhood, Richard and his brother lived at home and attended the specialist school and then went on to work in the sheltered workshop attached to the service. In his mid-20s Richard moved out of his parent’s home and into the specialist service hostel. In the 1980s he met and married Betty who also lived and worked at the specialist service. Due to the bond they had established in childhood and their close geographic proximity in adulthood, Richard and Ruth had developed a warm sibling relationship which has endured throughout their lives. Indicative of this relationship, Richard expressed his regard for Ruth, and how he valued the help she gave him, along with their mother, at significant times in his life. For example, Richard said Ruth organised his *“Party 60 years”* and he expressed the hope that she would also organise his *“65 year party”*.

7.3. Discussion

The experiences of the four sibling groups presented in this chapter demonstrate the diversity inherent in sibling relationships. Nonetheless, these participants' stories illustrate common threads which are representative of the experiences of the other participants in this study whose stories are told in the following two results chapters.

From the retrospective accounts of participants, three themes describe the experiences of those who either grew up as a person with cerebral palsy or as one of the non-disabled siblings. The first theme relates to the reliance on specialist services, the second to the development of a warm sibling relationship through living together in the family home, and the third to the effects of separating siblings in childhood. These themes are discussed here, with reference to the literature.

7.3.1. Relying on specialist services

The historical time and social timing components of Elder's life course paradigm (Elder, 1994; Elder, et al., 2004) are significant when considering the life experiences and pathways of the participants in this study who were born in the decades between 1940 and 1970. At that time, the basis of services delivered to people with a disability was a medical model which promised all-of-life care (The Spastic Centre NSW, 2005). All participants with cerebral palsy in this study except Bruce accessed specialist cerebral palsy services in their childhood.

The older participants with cerebral palsy were born at the time when specialist cerebral palsy services were being established, and their parents were an integral part of building and operating the services provided to their children. Indeed, parental involvement was a prerequisite for service use (The Spastic Centre NSW, 2005).

The specialist services provided to children with cerebral palsy at the time included therapy (physiotherapy, occupational therapy and speech therapy), and once they reached school-age, education. Helen commented on the importance of receiving physiotherapy from an early age; she bemoaned the fact that after academically outgrowing the specialist school for children with cerebral palsy she went to another school which provided no physiotherapy. Helen attributed her mobility problems in later life, at least in part, to this lack of physiotherapy from adolescence onwards. Richard, who lived in the city, and Betty, who moved from the country to live in the specialist boarding school for children with cerebral palsy, both received physio- and speech therapy throughout their childhoods. As both of them have significant hearing impairments and no speech, learning to lip read, sign, and read and write was crucial to their ability to communicate with others including their non-disabled siblings. Betty's brother Derek spoke about the difference it made to his ability to communicate with Betty once she and he learned how to finger spell and use sign language.

The experience of Bruce, on the other hand, provides an example of the detrimental affects of lacking access to any specialist services in childhood. Bruce is experiencing increasing mobility problems which he attributes, at least in part, to over-exerting himself physically when growing up, especially by working as a manual labourer. Despite attending the local state-run school, Bruce did not learn to read and write. His illiteracy is a source of regret to him and presents him with difficulties in living alone.

The establishment of specialist cerebral palsy services in capital cities and a lack of services in regional and rural areas provided an historical link to the subsequent living environment of a child with cerebral palsy. As demonstrated by the

experiences of Betty, Bruce and Helen, the parents of a child with moderate to severe cerebral palsy born outside of a capital city in the 1940s to 1970s had to decide how best to meet the special needs of their child. As children, and due to the era in which they were born, participants had very little say in the decisions made by their parents on their behalf. As stated in the introduction to this chapter, three choices were identified by participants: send the child with cerebral palsy to a capital city to access specialist services, do without specialist services, or move the whole family. The living environment chosen for children with cerebral palsy affected their opportunity to build a relationship with their non-disabled siblings.

7.3.2. Living together and developing warm sibling relationships

Seven participants with cerebral palsy in this study, Richard, Helen, Mathew, Caroline, Oliver, Rebecca and Thomas, lived together with their non-disabled siblings in the family home during childhood. Goetting (1986), Howe et al. (2001), Stoneman (2001), Sanders (2004), and Kramer and Conger (2009) have pointed to the importance of siblings growing up together for the development of empathy, warmth and closeness, as demonstrated in this chapter by Helen and her sister Isobel and Richard and his sister Ruth.

As identified by Goetting (1986), participants who lived together while growing up developed a common frame of reference based on their shared history and experiences. Moreover, according to Howe and Recchia (2005), older siblings teach younger siblings skills and how to negotiate social relationships by providing opportunities to practise solving social interaction issues and problems. Howe and Recchia credited reciprocal interactions between siblings in childhood as the “building blocks of relationships” (p. 497), as they provided children with

opportunities for learning more about themselves and how to interact successfully with others.

Stoneman and Brody (1993) discussed the difficulties for children with physical and sensory impairments of engaging in robust physical play with their non-disabled brothers and sisters. Nonetheless, the stories of Helen and Isobel, and Richard and Ruth, illustrate how sharing the family home in childhood and spending time playing together growing up meant that participants with cerebral palsy and their non-disabled siblings developed a history of shared experiences. For at least some participants, these shared childhood experiences resulted in close and intimate relationships to carry forward into adulthood. For example, as a much older sister, Ruth recalled taking Richard to the beach and to the movies. Helen joked that Isobel told stories of her being the bossy older sister during their childhood games; something Helen denies. Isobel spoke about fun family times bush-walking while her father carried Helen through difficult terrain.

Nonetheless, sharing the family home is not a guarantee that siblings will develop warm relationships with each other. Breslau (1982), McHale and Crouter (2005), and Stoneman (2001, 2005), have all discussed the importance of sibling variables such as gender, age spacing and place in the family, number of siblings, severity of disability, differential parenting, and personality for the relationship which develops between siblings who live together.

Helen identified personality as a significant factor in the differential relationships that developed between her and her two sisters. For example, despite all three sisters growing up together in the family home, Helen and her youngest sister Isobel reported a warm and loving relationship with each other, whereas between Helen and the middle sister there was distance and sometimes animosity. Helen

thought the difficulties experienced in her relationship with her sister who was not interviewed were due to their different personalities as well as to their closeness in age. Indeed, according to Breslau (1982) close age spacing between sisters may increase the likelihood of depression and anxiety for the non-disabled sister.

McHale and Gamble (1989), Stoneman and Brody (1993), and Stoneman (2001) have discussed the potential detrimental effects on sibling relationships of differential parenting. Helen commented that the family moved several times in order to access the most appropriate services for her, and she reported that her sister who was not interviewed resented this as she found it harder to make new friends than either Helen or Isobel. Helen believed that her sister therefore felt that their parents considered Helen's needs above hers, and this may have played a part in the difficulties in the sisters' relationship. Isobel, on the other hand, was unconcerned about this differential treatment and instead focused on the positive way in which their parents included Helen in all the family's activities.

For Ruth, gender and age differences were factors in her relationship with her younger brothers, both of whom had cerebral palsy. As the only daughter and older child by seven years, Ruth was expected by her parents to play a significant role in caring for her brothers throughout childhood. McHale and Gamble (1989), Stoneman and colleagues (Stoneman & Brody, 1993; Stoneman, Brody, Davis, & Crapps, 1988; Stoneman, et al., 1991), and Barr and McLeod (2010) reported that non-disabled children were more likely to take on childcare activities for their brother or sister with a disability compared to their peers, and there was a greater expectation that sisters rather than brothers would be involved in these activities. Ruth reported feeling some resentment about having to do so much for her brothers, and indicated that getting married at 19 was a way of escaping these duties. Nonetheless, Ruth also reported a

close relationship with Richard, continual contact with him throughout their lives, and a willingness to provide him with support as they both get older. Living geographically close to Richard and his wife Betty facilitates the contact Ruth is able to have with them and, as well as social and emotional support, she provides instrumental help such as cleaning out cupboards and organising Richard's birthday parties.

The experiences of Helen and Isobel, and Richard and Ruth, illustrate that living together in childhood is important in the development of early sibling relationships which are the cornerstone of later relationships. Through sharing the family home, these siblings built up a store of shared experiences and learned to like and trust each other. These attributes have carried through into their adult sibling relationships. Nonetheless, although she was not interviewed in this study, the reported difficulties in the relationship between Helen and her second sister indicate that living together in childhood is not always a guarantee for happy and harmonious sibling relationships in later life.

7.3.3. Living apart and feeling the distance

Four participants with cerebral palsy, Betty, Louise, Philip and Kristine, moved out of their family home in childhood to attend a boarding school for children with cerebral palsy. Bruce's sister, Charlotte, and their other two non-disabled siblings also went to boarding school. The experiences of the children who went to boarding school are represented in this chapter by the story of Betty and her brothers, Bob and Derek, and by the story of Bruce and his sister, Charlotte.

For families living in rural and regional areas of Australia, access to specialist boarding schools for the child with cerebral palsy was unavailable until the 1950s when these boarding schools were established in capital cities (CP Australia, 2009).

According to historical accounts of parents at the time, the establishment of the country children's boarding schools was viewed as a progressive move and welcomed by many families as providing a much needed alternative to unsupported care at home (McLeod, 1986). Indeed, none of the participants with cerebral palsy who went to live in a specialist boarding school, or their non-disabled brothers or sisters, spoke about their move negatively as an "institutionalisation". Rather, participants reported that their parents had sought therapy and education for their child with cerebral palsy in order to enhance the child's quality of life.

The view expressed by participants that specialist boarding school was not an institution was largely due to the philosophy of the service organisation. Set up and run by parents, the organisation required parental involvement for blocks of time throughout the year. Also, the children were expected to return to their family homes in the school holidays. These two factors differentiated the specialist cerebral palsy boarding schools from the institutions for children with intellectual disability at the time. Funnell (2001) and Mirfin-Veitch et al. (2003) have provided compelling accounts of the experiences of parents and non-disabled siblings of children with intellectual disability who were institutionalised in Australia and New Zealand during the same time period. Funnell and Mirfin-Veitch and colleagues reported that many siblings had limited contact with their brothers and sisters with intellectual disability after their institutionalisation. As non-disabled siblings whose brother or sister was institutionalised as a child, Daly (2009), Goldstein (2009), Gray (2009) and Moyer (2009) have provided strong personal accounts of the impact on their own lives. Similar accounts were given by the participants in the pilot study conducted by Llewellyn, Balandin and Dew with siblings of people with intellectual disability (Dew, et al., 2005). The accounts of the participants in the current study were

different, as contact between siblings was more regular with the child with cerebral palsy going home for school holidays.

Nonetheless, as “holiday siblings” these brothers and sisters shared the relaxed holiday times together while missing out on the routine and potential tedium of everyday family life. Sanders (2004) suggested that it is the daily routines which must be negotiated and navigated taking into account the needs of all family members that forge and strengthen the sibling bond. As the following quote from the historical documents of a specialist cerebral palsy service acknowledges (The Spastic Centre NSW, 2005, p. 5), it can be difficult for children with cerebral palsy to fit back into the family environment after they leave home to go to boarding school:

One difficulty is that families grow away from these children, who may return home from holidays and find they are no longer fully a part of an active family. The siblings have their own interests and the cerebral palsied child with a speech deficit may find it difficult to share.

The experiences of Betty, Bob and Derek illustrate these concerns. The brothers saw Betty during holiday times only, and Bob and Derek indicated that as a result they did not feel as close to Betty as they did to each other. Betty was differentiated from her brothers on three counts: she was the only girl in a family of four boys, she had cerebral palsy and was deaf, and from the age of four she did not live in the family home. Bob indicated that Betty’s visits home during school holidays were a novelty to her brothers and represented a change to the usual family dynamic.

Schaverien (2004), Drapeau et al. (2000) and Eisenberg et al. (1998) have suggested that less warmth might develop between siblings in childhood when one lives away from the family home for extended periods of time. This may be reflected in the intermittent contact Betty has with her brothers Bob and Derek since the death

of their parents. Moreover, Orsmond and Seltzer (2000) have warned that women with a disability who have only brothers “may be at particular risk for limited family support after parental death” (p. 505).

As described by Stoneman and Brody (1993), Orsmond and Seltzer (2007) and Hodapp and Urbano (2007), the complex communication needs of a brother or sister with a disability may be a significant factor affecting the quality of their relationship with their non-disabled siblings. Betty has limited verbal communication and her augmentative and alternative communication methods require close physical proximity. For example, finger spelling is only useful when both communication partners can finger spell. Betty’s brothers Bob and Derek have both learned finger spelling but they live a 3-hour drive away from Betty. They cannot speak to Betty by telephone because of her hearing impairment and lack of speech. Both brothers hoped that Betty might be able to learn to use a computer so they could email her but, reflective of the results in studies of loneliness and cerebral palsy by Ballin and Balandin (2007) and Cooper et al. (2009), Betty was not able to successfully master this technology, possibly as a result of special schooling and a limited focus on literacy skills. Therefore, the nature and severity of Betty’s communication impairments, the type of education she received as a child, and geographic distance have all presented barriers throughout her life to her ability to communicate with her brothers from whom she was separated in childhood.

On the other hand, close geographic proximity in later life might mitigate the effects of separation of siblings in childhood. While growing up, Charlotte and her other two siblings were separated from Bruce by their attendance at boarding school. However, Charlotte returned to live in the same town as Bruce, and their proximity and the support they provide to each other strengthened their relationship over the

years, especially since their mother's death. Bruce stated that he felt emotionally closer to Charlotte than he does to his other two siblings who live further away.

Summary

The stories of the participants in this chapter illustrate that the choices made by their parents about living environment affected their childhood sibling relationships.

However, the relationship between living environment and adult sibling relationship is not straightforward, can change over time, and might be perceived differently by individual siblings, as was apparently the case for Helen, Isobel, and their sister who was not interviewed. Nonetheless, as indicated in this chapter, there is evidence in the literature that is supported by the accounts of participants in this study that childhood sibling experiences influence later life sibling relationships. Furthermore, sharing the family home or, conversely, separation in childhood, can influence the degree of warmth and sense of connection and trust that develops between brothers and sisters. Chapter 8 reports on the next life stage, the transition to adulthood.

Chapter 8

Becoming an Adult

This chapter describes the transition from childhood to adulthood using the stories of one sibling triad and three sibling dyads. The childhood experiences of participants with cerebral palsy and their non-disabled siblings provided a foundation for the pathway they followed in their transition to adulthood. Figure 3 provides a diagrammatic overview of the concepts discussed in this chapter and how, via the dotted lines, they lead into the next chapter.

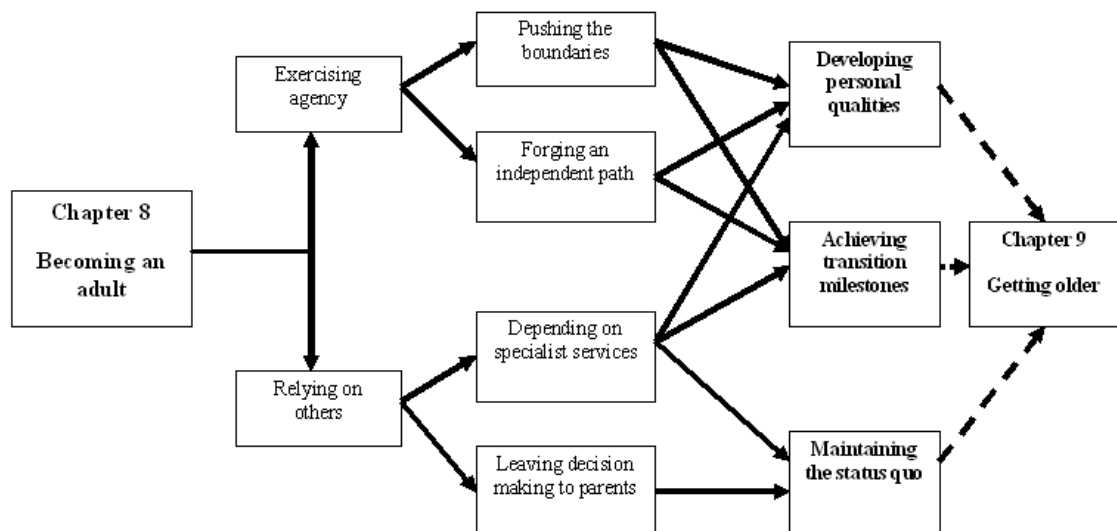


Figure 3 Becoming an Adult

The category “Becoming an Adult” can be understood according to two divergent pathways, “Exercising agency” and “Relying on others”. How these pathways impacted on the relationship which developed between siblings is explored using four themes, “Pushing the boundaries”, “Forging an independent path”, “Depending on

specialist services”, and “Leaving decision making to parents”. Appendix 7 contains the list of focused codes which informed the development of the themes, pathways and categories discussed in this chapter.

As described in the literature review on young adulthood in Chapter 3, there are two approaches in determining whether a person can be considered to have made the transition from childhood to adulthood. The studies by Wells et al. (2003), van Naarden Braun et al. (2006), and Janus (2009) used the transition milestones of leaving school and getting a full time job, going on to further education, leaving home to live independently, and marrying and having children, as indicators of a successful transition to adult status for a person with a chronic lifelong disability. However, as these studies showed, because of the limitations imposed on them by their physical impairments and high support needs, many people with moderate to severe cerebral palsy do not achieve these milestones or achieve them later in life than their non-disabled peers.

White (2001) described the chief developmental task of young adulthood as “individuation, the development of psychological and instrumental autonomy from one’s parents” (p. 556). As young adults in the family pursue their autonomy, Goetting (1986), Laursen and Bukowski (1997) and White (2001) identified that siblings typically have less contact with each other. Goetting therefore referred to sibling interaction during young adulthood as “high in perseverance but low in intensity” (p. 709).

The literature on sibling relationships attests that sharing the achievement of transition milestones with brothers and sisters is one way of young adult siblings keeping in touch with what is happening in each other’s lives. For example, Goetting (1986) referred to young adult siblings comparing their achievement of milestones

against one another. Connidis (1992) noted that siblings were in the unique position of bearing “common witness to more of the changes made across the life course than most other family ties” (p. 972). And, according to Connidis, when siblings share transition milestones, for example, when they get married or have children, they feel closer to each other than when only one sibling experiences the transition. Given the findings of the studies by Wells et al. (2003), van Naarden Braun et al. (2006) and Janus (2009), that a person with a chronic lifelong disability has limited opportunities to achieve transition milestones, this could result in the siblings with a disability feeling out of touch with their non-disabled young adult siblings.

Another approach to determining when young people could be considered to have made the transition to adulthood was proposed by Arnett (1998, 2000) in his studies with non-disabled young adults, and was tested by Galambos et al. (2007) in a study with young adults with cerebral palsy and spina bifida. This approach focuses on the personal qualities which indicate emerging adult status. These include becoming self-sufficient, accepting responsibility for actions and decisions, and having independent control over decisions and finances. This approach can provide young adults with cerebral palsy with an alternative way of viewing their progression into adulthood. Taking control over decisions and life choices might be more achievable for people with moderate to severe cerebral palsy than attaining transition milestones such as study, work, or having children. As with the studies of transition milestones, the studies of personal qualities do not take the sibling relationship into account and there is little in the sibling literature that addresses the development of these personal qualities. Nonetheless, Goetting (1986) highlighted the importance of siblings providing each other with companionship and socio-emotional support based on their understanding of each other’s strengths and weaknesses. Moreover, Avioli

(1989, p. 48) identified the ability of siblings to “validate each other’s perceptions of self and the world around them”. Siblings may know better than others the traits of their brother or sister with cerebral palsy and may support them in applying these traits to the attainment of adult roles.

Participants in this study either exercised agency over the decisions they made during their transition to young adulthood or continued to rely on their parents or service providers to make decisions for them. Exercising agency within a supported accommodation setting through pushing the boundaries is illustrated by the story of Mathew and his sisters, Therese and Kirsty. Caroline’s story, told in conjunction with her sister Margaret, relates how she forged an independent path by using generic services. Relying on others by depending on specialist services is told by the story of Philip and his brother Harry. Finally, the story of Rebecca, told in conjunction with her sister Amelia, illustrates the situation of leaving decision making to their parents with whom Rebecca lives.

8.1. Exercising agency

8.1.1. Pushing the boundaries

Mathew, Therese, and Kirsty

Mathew (43) has cerebral palsy, uses an electric wheelchair to get around, a speech generating device (SGD) to communicate, and requires full assistance with personal care and activities of daily living. Mathew’s parents are both alive and in their 70s. When he was three years old the family moved from a country area to the city for Mathew to access specialist services. For the rest of his childhood and adolescence, Mathew lived in his family home in the suburbs of a capital city and attended the special non-government school for children with cerebral palsy. At the age of 29,

Mathew moved from his family home into a group home run by the same organisation. He acquired his SGD at about the same time. He currently attends a community access program for part of the week. Mathew is the middle child with two sisters.

Therese (46), Mathew's older sister, is married with four children and lives a half hour's drive away from Mathew. His younger sister, Kirsty (39), lives interstate, is married with a child, and works in a professional role.

Indicative of the differences in perception of siblings influenced by their place in the family, age differences, and personality, Mathew's sisters reported different relationships and memories of growing up with Mathew. The oldest in the family, Therese recalled separating herself from the family and having little to do with Mathew or Kirsty during her adolescence:

I wasn't really involved at all. My sister [Kirsty] probably was a little bit more [involved] because she was home in those years, more of those teenage years than I was I think. I was at home but I wasn't really there...I moved out of home probably about 20 or 21 but I don't think I was home very much [before that] so I didn't do a great deal [with Mathew].

On the other hand, Kirsty acknowledged that while they were growing up she had a closer relationship with Mathew than she had with Therese:

I'm the little sister that pays out on him. I'm the first one to have a go at him and he's the first one to have a go at me...we have that banter...and that's our relationship. I think maybe because of the age difference we've [Therese and Kirsty] not been particularly close...we've probably become closer as adults. Whereas Mathew and I, it was just the two of us in the house [after Therese left home] so that's probably how our relationship developed.

At about the time that Kirsty left home, Mathew also moved out. Kirsty saw this as evidence of his desire to establish his independence separate from his parents in the same way as she and Therese had done. Due to her closer involvement with Mathew during this period, Kirsty's view is more prominent in the accounts of Mathew leaving home. Kirsty said: "*We [she and Mathew] both left home at about the same time. He was desperate [to leave home], he was pushing it... [and] Mum and Dad never said 'No, you're not doing it.'*" Mathew's move to supported living in the community was in part also a product of historical events at the time, as Kirsty explained:

[When Mathew] went into independent living I think was the time where the government initiatives were pushing people away from institutions and putting them into the community. Mathew was brought up in that time when they said "You can do anything you want to do. You have the same rights and all the same empowerment as anybody else".

But, according to Kirsty, the decision to leave home was largely due to Mathew's desire to have control over his life and have some level of self-sufficiency separate from their parents. Kirsty described it in this way:

I think one of the big things for Mathew was that he wanted it. It was very tangible for him and he wanted it. He was always very progressive; he was always fighting some fight to be fought with [the specialist cerebral palsy service provider]. He would challenge the [specialist cerebral palsy service] on any topic that looked like infringing upon his personal ability to do things. And I think Mathew just kept pushing and striving for more and more independence. Mum often gets challenged [by Mathew's approach] because Mum is so thankful and grateful she doesn't want to push too hard whereas

Mathew doesn't see that boundary and I'm probably a bit more inclined to think Mathew's way: "Yes, keep pushing because that's the only way that things will change".

Kirsty indicated that Mathew's moving out of home had a great impact on their mother. In particular, Kirsty explained how their mother surmounted her initial reluctance and saw the benefits that would come from Mathew's move into the community at a time when she was still able to assist him:

I think it [Mathew moving out of home] was different for Mum...she really felt it...she was lost for quite a few years I would suggest. [She missed] the boundaries of having to pick him up, for him to be coming home at a certain time and doing certain things. I think Mum then got on a roll of encouraging that because she was always looking at the view that if Mathew could live independently that would be a good thing because she knew she couldn't look after him forever.

Therese recalled another example of Mathew wanting to achieve the same milestones as Kirsty and herself. She reported that some time after his move to the group home Mathew was engaged to be married:

He was engaged at one stage to a girl and I think it was particularly when we were all getting married and engaged and everybody else as well, all the cousins. I think he may have felt that he needed that too but nothing ever eventuated.

Kirsty elaborated, adding her view that Mathew felt his disability was in part the reason for the break-up of his relationship:

He got engaged at one stage to a young lady...they bought a ring, he had a vasectomy, it was all about looking at how they were going to be together,

trying to organise housing for them to be together...I think it was a real growing stage...[but] the young lady returned the ring...[and] as any young man would be...he was devastated...he felt a lot of those feelings were to do with his particular situation, the fact that he did have a disability and he couldn't do certain things.

Mathew also spoke about this relationship and indicated his view that his fiancée's father was the reason for the break-up: *"I get more alone because I don't have a friend...like a girlfriend...she leaved me [because of] her Dad"*. Acknowledging his need for sexual contact, Mathew said: *"People [do] not know disabled people need it [sex]. I pay lots of money [to have sex]. I think this problem needs to [be] look[ed] in[to]."*

The severity of his physical impairments means it is difficult for Mathew to be completely self-sufficient living in the community. The purpose-built group home which Mathew shares with five other people with cerebral palsy suited his needs well when he first moved out of home. However, he no longer wishes to live with so many other people and would prefer to be in a place on his own. Mathew said: *"I would like to live by myself one day."* Despite Mathew's age and ability to make his own decisions, his ability to act on those decisions is dependent on the resources and goodwill of the specialist cerebral palsy service on which he relies. Indicative of the position in which this places Mathew, his sisters elaborated on his dislike of socialising with other people with a disability. Therese said: *"He doesn't like going out with a group of people that are handicapped, which he's entitled to think that way. I think he's been treated so normally with us that he thinks he's normal...which he is."* Kirsty added:

He doesn't like doing the group disability, off to somewhere, and he's never been like that, he's never had to I suppose that's the point. He's always been with us as a family, he doesn't really socialise [with other people with a disability], he'd rather be by himself.

Mathew indicated that while he makes many of his own decisions, his ability to carry them out is sometimes restricted by the group home staff. For example, when asked if he thought he made his own decisions about what happens in his life Mathew responded, “*Lots [but] sometimes [decisions are made for me especially] round about sex...staff can't help us at all [to organise a sex worker] [but] no [staff don't stop me from seeing a sex worker].*” Indicating the changes that he believes have occurred in the group home over time Mathew lamented: *[In the group home now there are] too many rules. [Too much] paperwork [about] everything [because] people tell lies and [providing the service costs] money.*” Kirsty also commented on these changes, which she saw as indicative of greater regulation in Australian society in general:

In all of business, all of the community there's an increased awareness of OH&S [occupational health and safety] and that has had a huge impact on their lives particularly in an independent living situation. The increased accountability, responsibility of staff has really been pushed...you know you can't have your water temperature too high and that was because someone got burnt somewhere else so they've created a new policy to fix that one up. So Mathew can't have a hot shower because he can't get the water temperature to the temperature that he wants to have it at because of the OH&S implications for the staff member. And you know the business side of me goes, “I appreciate that, that's a worker who's entitled to the protection”. But the

worker's entitlement in this situation outweighs, rightly or wrongly, Mathew's rights and entitlement to have a warm shower.

In the early years after moving to the group home Kirsty was the sister more involved in Mathew's life. Therese reported that she was living in a different country at the time and then after her return she had young children. Therefore, initially it was Kirsty who assisted Mathew in an advocacy role, as she put it: "*I'm Mathew's voice sometimes...I've done a bit of advocacy work for him in pursuing issues.* [Therese] *also had the children whereas I never had children so I suppose I had the time and the capacity to [help Mathew].*" In the last two years Kirsty has had a child and has moved away from the city where Mathew, Therese and their parents live. At the same time, Therese's children have grown older, leaving Therese with more time to spend with Mathew, as she explained:

The last 16 years I've been pretty busy with the family and prior to that we were in [country] for 5 years so it's probably now that I really am more free with the children...my 6 year old has now gone to school so I do have a bit more time on my hands...[and] I realise now that I probably should have made a little bit more effort...just to think that he's sitting there not doing a great deal.

Writing a family memoir, a task which Mathew initiated, has brought Therese and Mathew closer together. Therese commented on how much more Mathew remembers about growing up than she does. Mathew receives Therese's practical assistance in recording his memories and she benefits from Mathew's insight into the early years of their lives:

He's [Mathew] writing a book. I'm going down on a Tuesday morning and I type for him for probably about 2 hours. [He prepares it on his SGD] and he

plays it back. I just go in and they [day program staff] have it all ready for me and I just go in and type up what he's written [then] we rearrange it because he remembers bits and pieces throughout his life and we have to try and put all the pieces in the right spots. He's got an amazing memory. He remembers a lot more than what I remember. And feelings are coming out too, that he didn't realise he was thinking about. I think he's really enjoying it and I'm enjoying it too.

Therese has also taken over the advocacy role for Mathew previously provided by Kirsty. Therese recounted an incident in which she helped Mathew negotiate a resolution to a problem he had with his group home staff:

You know they [people with cerebral palsy] want their freedom to do things but they can't because of litigation. We just recently went through [a battle with the group home staff] with medication...he was so ropable...he got sick with a tummy bug and the doctor said "Take certain tablets until you feel better", and he was fine. Then a day or two later he felt sick again and he said, "Just give me another tablet" and they couldn't because they had to go back and get permission again and he didn't like that. So then he rang me up and said, "Can you get me a lawyer?" and I said "What for?" And anyway we sorted it out without the lawyer thank goodness! I think it really didn't give him a great deal more freedom but it made him feel better.

Mathew acknowledged that Therese is playing a greater role in his life and he sees involvement with his sisters as a way of ensuring that when his parents are gone, he will still have family support: *"I worry about things in the future like I may be by myself more at Christmas...I hope I am going to see more of Therese."*

Therese and Kirsty both spoke about Mathew's ongoing financial reliance on his family. Kirsty said:

We've [Therese and Kirsty] always said we would take financial burden to make sure that Mathew didn't miss out on the things that he needed. So you know we might have money in the bank that we would know is Mathew's money. We're prepared to do that because it's important that Mathew still has the things that he needs and obviously living when Mum and Dad are gone, the income is not there. Fortunately we've been in a position that Mum and Dad have been able to purchase things so that Mathew isn't waiting for a particular item of equipment. And you know we've been lucky that Mum and Dad can financially afford that.

Therese added: *"We know that financially if it's something that he needs we'd be happy to do that for him. I've always said if he ever wanted anything just to tell me."*

After growing up in the family home with his parents and sisters, Mathew aspired to take control over his life and become more self-sufficient through the attainment of typical transition milestones in young adulthood such as moving out of home and getting married. Moving out of home was achievable for Mathew in large part due to his strong determination to become independent, backed up by the support he received from his family and also by the availability of support provided by the specialist cerebral palsy service. Getting a SGD provided Mathew with a means of communicating with people unfamiliar with his communication style. Through his SGD Mathew was able to make his needs and wishes known to the paid carers who took over the personal care previously provided to him by his parents. Furthermore, his sisters acted in advocacy roles to assist him to fight for control over some aspects of his life.

Mathew and the next participant, Caroline, have similar needs for personal care and support with activities of daily living. Both have received specialist cerebral palsy services throughout their lives, but in young adulthood they took different paths to exercising agency. Rather than moving into a group home run by the specialist cerebral palsy service, Caroline opted for using generic community services.

8.1.2. Forging an independent path

Caroline and Margaret

Caroline (52) has cerebral palsy, a hearing impairment, and dysarthric speech. She uses an electric wheelchair to get around which she operates with a foot control, and she needs a hoist for transfers. Caroline is unable to perform any personal care tasks or activities of daily living for herself. Both her parents are alive, with her father in his early 80s and mother in her late 70s. As in the stories of some other participants, Caroline's family moved around Australia in order to access the most appropriate educational and therapy services for her. Having worked for many years, Caroline is retired and now attends a leisure program run by the specialist cerebral palsy service. For the past 22 years Caroline has been married to a man who also has cerebral palsy. Caroline is the second eldest in a family of six. Two of her brothers, who are both married with families, live interstate, one brother who is single lives a 2-hour drive away, and one sister is also married with a family and lives overseas. Her other sister, Margaret, lives in the same capital city as Caroline and her husband.

Margaret (50) is the third child in the family, is married with adult children and works in a professional role. As the geographically closest sibling Margaret provides Caroline with as much additional support as she can so that Caroline can use her formal in-home support hours for personal care. Margaret explained the severity of Caroline's disability in the following way:

Caroline cannot even move her hands to protect herself...she can't dial a phone...she is potentially a total victim and all our life there's been this fear that she might end up in a situation where she wasn't being cared for.

Despite this description of Caroline's physical impairments, Margaret acknowledged Caroline's strength of character. Margaret said:

You know she's just the most dynamic person and she's amazing that she doesn't become depressed...she's got this amazing ability to seek out something to give her something to live for. I think people are born with it because you know I was brought up in the same family and I don't have it that's for certain. She has just always had this and she works from it...when something's wrong she is very proactive about doing something about it. We all just accept that she is right because she's got a steel trap memory and because she can't look for things she always remembers. She's very interested in everything that goes on and I think that's what keeps her going. And, she's always been a very engaging person and always had lots of friends.

Margaret provided an example of Caroline's determination in young adulthood to take control of a particular aspect of her life:

Caroline decided when she was 25 that she wanted to have a hysterectomy because of the whole period thing and having to have someone clean her up and also in a vinyl wheelchair it wasn't very comfortable. My mother was just appalled because she thought, "Oh, my God, this is one thing that is normal about you. Do you want to do this?" Anyway, Caroline just said, "No, this is stupid. I can have this done". She's an intelligent person and she was able to do that. But that was shocking for all of us, we were all thinking this is awful, the reality of this kind of thing.

After leaving school and despite a lack of support services for people with a disability at the time, Caroline pursued her desire to further her education as she explained:

All the other kids [at school] wanted to leave school and go to work but I didn't, I loved it. I went to university, twice. The first time I did three years of psychology. The second time I did anatomy and physiology. I loved it. I was a non-degree student. I did the subjects but I didn't do all the subjects for the degree course. I passed everything. I love a challenge; I like to keep my mind active otherwise I get bored. My mother wasn't pleased about me going. I think she would rather I sat at home and watched TV all the time. She didn't want me to get hurt. But Dad was very pleased for me.

Caroline then got a job working for the specialist cerebral palsy service and it was there that she met her husband who was working in the same department. Caroline explained the impact of getting married on her career:

After we married I moved departments. I thought, we both thought, it was best if we worked separately. So I went to another department but I didn't get as much support so eventually I retired and came to [the leisure program].

Prior to and for 4 years following her marriage Caroline lived with her parents and they provided all her personal care and assistance with activities of daily living.

However, Caroline and her husband wanted to live independently and the opportunity to do so came after the government set up an in-home support service to assist people with a disability to live in the community. Consequently, Caroline and her husband moved into a house rented from the government department which provides affordable community housing for people on low incomes, including those with a disability. They used the in-home support hours to provide Caroline's personal care.

As Caroline described it:

We decided that we would live, Mum said that we could live with them. [It worked] for a few years and then we decided it was time to move out. So we applied to the [government department]. It was hard on Mum but I knew we would be able to cope with help from the [in-home support service] and [husband].

Margaret explained what the family thought about their initial move:

At the time we thought that was something they might manage for a year and if they could that would be just a great experience for them. No one ever imagined they would be able to manage as well as they have.

After the move Caroline's parents continued to provide considerable assistance, as Margaret explained: *"They did get [in-home support] hours but I'd say they relied hugely on my parents. Mum and Dad would go down every Saturday and [do] even things like you know changing a light globe or that kind of stuff."* Despite the level of help Caroline requires, Margaret noted: *"Caroline is very conscious and respectful of making demands on other people."* Consequently, Margaret described the assistance she gives to Caroline as similar to that which she would give to any of her siblings: *"[We] would pick up on [extra things Caroline and her husband needed] which of course you are glad to do and you would do anyway whether they were disabled or not."* Nonetheless, some of what Margaret does for Caroline is exceptional and relates to the severity of Caroline's disability. For example, Margaret explained:

It must have been 5 years ago I get a phone call from [Caroline's husband] "[In-home support service] won't come back this afternoon". "Right, why not?" "Because they're not allowed to lift or do transfers without hoists". So that's the first we hear that they need a hoist. The bed needs to be raised and they need a hoist. So that was all systems go, the family running around,

brother-in-law raising the bed, trying to hire a hoist that would fit in the room. But you know, things like that happen and you don't know when they're going to happen.

In return Margaret acknowledges the emotional support she receives from Caroline:

I remember one time Caroline and I having coffee and one of my kids was definitely not giving me a good time and I was telling Caroline about it and I was crying...I could see this person looking at me as if to say, "there you are with that poor woman and you're pouring out all your troubles to her" ...to me she's still my big sister and she's the person who would love my daughter even when I didn't.

According to Margaret, Caroline likes to keep her personal care needs separate from the contact she has with the family:

In fact she actively tries to avoid any sort of care things happening if she can. If I'm going over for the day she'll still often want her toileting aide to come rather than for me to do it. Things like toileting she'd definitely prefer us not to have to do.

As further evidence of Caroline's control over her life, Margaret said Caroline and her husband try to be financially independent from the family:

Now of course they're both on a pension and they just manage their money so well, I wouldn't really know day to day what's going on. Once they needed a hoist and they got in touch with the local [service] club who did that so you know they do try to remain as independent as they can. But if there's something happening that they need well there would never be any question of them not getting it because between us all we'd pay for it. I mean a hospital

bed is \$3-4,000 so those things they have to have some assistance with from the family.

Margaret identified that technological changes have assisted Caroline and her husband to live independently:

They email their butchers with their meat order every week and the butcher knows them now and he delivers it. So technology is making a difference.

When they go to the doctor's [Caroline's husband] will print out a list on the computer of all their medication, what was done last or something that needs to be done. The computer is just an amazing way for them to convey to people that they're not stupid. It's fantastic.

Despite valuing her control over her life and independence, Caroline knows that she can count on Margaret's support and she identified two of the key reasons why she feels this way, Margaret's geographic proximity and personal dependability: *"She is close and she is reliable too. It's just who she is."*

Margaret reflected that part of her motivation for supporting Caroline is the guilt she feels that Caroline is the one with cerebral palsy and not her. Margaret said:

The only person who ever said we should be grateful we're not like her [Caroline] was our neighbour. And you don't need someone to tell you that because it never leaves you, that guilt never leaves you all your life. I would never ask my kids to take the bin out even now because I think "I can take the bin out." Parking a car, I would never drive around to get a parking place closer, I mean if I get it great but I think "I can walk"...I can walk up the stairs, I would never take a lift up one flight of stairs because I can walk up. And it's helped me to achieve things because whenever I've thought, "That's

hard”, and then I think, “Oh yeah, how hard is that?” In a way it’s almost a moral obligation to do something because I can do [it].

It would seem from the interviews that Caroline has always had a strong sense of personal control and self sufficiency which Margaret thinks is innate and was developed through their family environment and the support the family members continue to give to each other. Caroline’s strengths have enabled her to take control over her life as, together with her husband, she has made and fulfilled plans for their life together involving assistance from generic community services rather than relying on the specialist cerebral palsy service. As Margaret put it: *“They make all their decisions and they make good decisions”*. Both Caroline and Margaret see this continuing in the future, albeit with Margaret playing a greater support role in Caroline’s life as their ageing parents’ health deteriorates and they are less able to support Caroline.

In contrast to Mathew and Caroline, Philip’s story is representative of those participants with cerebral palsy who left their family homes in childhood to attend a specialist boarding school. In young adulthood, Philip continued his link with the specialist cerebral palsy service as provider of his accommodation and work environments.

8.2. Relying on others

8.2.1. Depending on specialist services

Philip and Harry

Philip (45) has cerebral palsy and dysarthric speech which I found difficult to understand. During the interviews he sometimes needed to repeat what he said several times before I understood him. Although in recent years Philip has needed a

walking frame to help him get around, when he was younger he competed as a runner in the Special Olympics. Philip is the eldest in the family with one “full” sister and four step-siblings from his father’s second marriage. However, throughout his life Philip has lived separate from his siblings, as he explains:

I was quite little when Mum and Dad split up...and Dad didn't know what to do, quite how to handle me and my sister...and Dad put me in [orphanage]...a place for people who've got no family...and then after that I was put in the [specialist boarding school for children with cerebral palsy] when I was about 5 and they made me a State Ward. My Dad and my sister used to come down and see me to see how we got on. My Dad had my sister at our home. I didn't really have any idea about who my father was, or who my sister was. I knew them but I didn't know who they were.

Being made a State Ward meant that Philip’s father gave legal responsibility for what happened in Philip’s life over to the state government department responsible for child welfare at the time. Philip was a teenager when his father remarried and from that time on he saw more of his family, including travelling to the country to stay with them for school holidays. Speaking about this time, Philip said: “*My step-Mum [name] came, every year came with Dad to see me at the hostel, and then when I was a teenager, I'd go to [their] home.*”

Probably due to Philip’s limited contact with his other siblings, Harry (33) was the only sibling to be interviewed. Harry is a middle child in the blended family and is married with three young children. Harry lives in the country an 8-hour drive from where Philip lives in a group home in a capital city. Harry recalled Philip’s visits to the family:

Every year at Christmas he used to come down and visit us. He'd come up for a few weeks, come and stay with us. [I have] good memories and there were some hard times. All of us used to help with looking after Philip when he came up. Philip used to have a hard time with himself, dressing himself and showering himself. When I was 13 till I was 15 I used to always help with his showers and doing up his buttons, always trying to keep him nice and tidy.

Philip added: *"I remember Harry when he was a little boy when I'd go home. I remember going fishing with all my brothers and sisters."*

Harry reported that during Philip's visits to the family home he and Philip developed a special bond which they still share today. Harry said:

Growing up I was the only person who could really understand what he was saying and other people would have to ask me and I'd have to ask Philip to repeat himself a few times before I could get hold of some of it sometimes as well. [Harry understanding Philip's speech better than others] may have been because of the contact me and Philip had when we were growing up. I was doing most of the things with Philip when he would come and visit...we've got a bond that's a little bit different [to their other siblings].

Although his visits to see his family became more regular after his father remarried, events in Philip's life were still largely determined by the services provided to him by the specialist cerebral palsy service. So, for example, as a young adult Philip moved from the specialist cerebral palsy boarding school into an adult hostel. Then, in keeping with the changes in service philosophy and practice in the 1980s, Philip moved into a group home in the community operated by the specialist cerebral palsy service. It seems from Philip's description that he did not have a great deal of choice or control over his move out of the hostel and into the community. Philip explained:

I had to move out but I'd like to go back to the old days but we can't go back now. Everybody was real happy up there. We were all up there and then we all went to different places everywhere.

However, he seemed to have more control about another move 10 years ago to his current group home which he shares with two other people with cerebral palsy. As he explains, he made the decision to move in order to be closer to his work:

I was living over at [suburb] and I went over there [another suburb] every day for work. Back and forth and then I moved here. It was too much. I was getting up early to get there and I was tired when I got home. [Now] it's about 5 minutes [to work] along the main road.

In addition to accommodation the specialist cerebral palsy service provided Philip with work and recreational opportunities. For example, Philip identified getting a job and competing at the Special Olympics as highlights of his young adult life. Philip said: “*The people I work for are good. [When I was younger] I went overseas to [country] for the Handicapped Games for running. [I went] three or four times.*”

Harry added his perspective on the influence in Philip's life of the specialist cerebral palsy service:

That's my belief, that the [specialist cerebral palsy service] had a lot to do with encouraging him into things. He's been there for so long and to me he's so natural with the place. To him its home and I think over the years they've done a lot of good for him. He's always had a job and actually working for a living and getting into sports. He's travelled over to [country] a few times and done games and the [specialist cerebral palsy service] actually got him into that.

Harry said that during his young adult years he had less contact with Philip than he had as a child or has now:

There was maybe a few years there when I was out and about running around the countryside that I lost contact [with Philip] for a year or two but I always tried to keep in contact, make sure everything was all right with him as well.

However, since Harry married, settled in one place and started a family, the routine of Philip's life with the specialist cerebral palsy service is interspersed with annual visits to stay with Harry. Harry explained the significance of these visits to both himself and Philip:

For some reason me and Philip enjoyed knocking back with each other you know and still to this day he comes and visits. He'll come and stay at my place but he won't go anywhere else. I've got a good bunch of mates and we all look after Philip and take him out. You know a lot of the guys enjoy Philip's company and he enjoys coming up here. We all treat him, everyone treats him like a normal person, we don't give him any advantages because he's a little bit disabled.

Harry reflected on why he thought he and Philip had a closer relationship with each other than with their other siblings:

[Philip sees his other siblings] now and again, not often. It's a bit hard with [the other siblings] because they're not as patient with people like Philip I don't think. I don't think they can accept that looking after someone like Philip takes a lot of your time up in the day [and] sometimes it's a bit mentally stressful but it's just one of those things that you've got to do.

Philip added: *"I have more time for Harry than the others [siblings] I don't know why. It [just] works."*

From childhood, Philip has relied on the specialist cerebral palsy service to provide him with supported accommodation, school, work and friendships. Perhaps indicative of the reportedly high turnover of staff working in disability services, Philip did not mention individual staff members as important in his life. Rather, he spoke about the [Specialist Cerebral Palsy Service]. Apart from the annual visits which Philip made to his family home, brothers Philip and Harry had little contact growing up. Nonetheless, despite the geographic distance and age difference between them, Philip and Harry established a close emotional bond with each other which is different from that which Philip has with his other brothers and sisters. Therefore, while the specialist cerebral palsy service continues to have a key role in Philip's life, his contacts with his father, stepmother and Harry have, over his life course, taken on greater importance in providing him with social and emotional support.

In contrast to Philip's experience of leaving his family home as a child, and in part due to their Italian heritage with a strong focus on family support, Rebecca has lived with her parents all her life and neither she nor her family has considered her living in supported accommodation in the community.

8.2.2. Leaving decision making to parents

Rebecca and Amelia

Rebecca (45) has cerebral palsy, a mild intellectual disability, and Turner syndrome (a chromosomal disorder affecting growth and fertility). Rebecca has some gait problems that affect her getting around, but can walk with assistance. Rebecca mostly manages her own personal care with help from her parents, who make sure she does not slip in the bathroom, help her to manage her money, and take her shopping. Her parents, who migrated to Australia from Italy in the late 1950s, are now 76 and 85 years old. After leaving special school, Rebecca went to work in a sheltered

workshop run by a specialist cerebral palsy service. Rebecca still works for the same organisation, which is now run as a business service.

The initial interview with Rebecca was held at her home with her parents present at her request. Rebecca's parents tended to dominate the interview, answering questions that were posed directly to Rebecca and talking over the top of her when she responded. Rebecca seemed unconcerned by this and sat back while her parents did most of the talking. The follow-up interview was conducted with Rebecca over the telephone and she put her point of view forward without interruption.

Rebecca has one older sister Amelia (52), who is married with two young adult children and lives in a city approximately a 12-hour drive away. Amelia is employed in a professional role. As each others' only siblings and sisters, Amelia and Rebecca reported a close connection to each other growing up. Amelia recalled:

I was just like a second mum to her at times, I'd be there looking after her because Mum would have to work...I remember doing things with Rebecca at a young age...I don't think I felt that it was a burden, I just felt that that was the way she was and that was my part to be with her...I was her big sister and that was my role.

And Rebecca added: *"We got on well together...Amelia was helping me and looking after me and all that."*

According to Amelia, living in a migrant Italian household influenced their upbringing: *"It's partly an Italian thing...I think being a first generation Australian, whether or not Rebecca was my sister, it was the social issue...the pathway that I was going...first generation parents were quite protective of you."* In addition to helping her parents to look after Rebecca, Amelia also had a role helping her parents by filling

in forms in English, and driving them around because her father did not have a driver's licence. Amelia recalled:

We would go out as a family, a lot of visiting friends on the weekend. My Dad didn't drive, we didn't have a car. We used to either take taxis or buses until I got my licence. I was 19 when I got my licence and then I would drive them to their friends' home. And I did help as far as setting Rebecca up to get her where she needed to go because we were trying to get the right [work] place for her and doing all the enquiring and everything. I was there to help them [parents] with that.

Amelia went from school to university and then into a career. During this period Amelia was living at home and she included Rebecca in her social activities:

As I got older I actually wanted to do more for her. I wanted her to be able to get out and do things and I'd often take her out with me and my friends were always very receptive to that. In the latter stages I was working at [hospital] and I actually got her some volunteer work there. But as I say, socially she missed out because I would take her with me when I could but she didn't really have a network of friends or anything like that.

Amelia was in her mid-20s when she met her husband and decided to marry. Her subsequent move to another city was a huge change for all the family. Amelia reported that leaving home was a difficult decision and she explained how she felt torn between wanting to live her own life and continuing to support her sister and parents:

When I first met [husband] and there was talk of us getting together and me moving, that was a really difficult time because we're so close and I always felt that I could possibly do more for her [Rebecca] and then [with] my

moving, I haven't been around. So I felt in a way that I've not done the right thing by her but I mean I had to live my own life and my parents have had to become more independent too because I would do a lot for them. I was 27 when I got married and me getting married was a big transition and leaving that was a big thing. I think that would have affected her [Rebecca] more. I mean I know it affected me but I think it would have affected her a lot. I had this guilt trip for about 12 months that I'd done the wrong thing to them...for 12 months or more I felt really bad. I thought "How could I do that to them, especially [to] Rebecca?"

Rebecca added: *"I missed her [Amelia] a lot. It's not very far but I mean it is a bit hard... [We used to] go out together, sometimes we'd go bowling and sometimes we went to the snow together and played games."*

Meanwhile, Rebecca continued living with her parents and, according to Amelia, at no stage did Rebecca mention, or her parents consider, Rebecca living anywhere other than with them:

No, there's never been any talk about it. It's always been that she's their responsibility. I don't think they could even think about that. You know, that's the way it's got to be. As much as they want her independent they are still very hesitant to let her go out or do anything outside the home because they worry about her...which in a way has been bad for Rebecca because she hasn't been able to integrate with other people that much outside of work. My parents have kept her from doing things for fear that something will go wrong. So she's relying on them to buy things for her, to make decisions whereas she could do it, I'm sure she could but they've just always done it. It's interesting

because when you talk to her she's quite sensible in some ways but quite childish in other ways and a lot of it could just be social background.

Rebecca expressed concern that no one else, including Amelia, would be able to look after her as well as her parents do. When asked if she had friends at work who lived in supported accommodation Rebecca replied:

I could [live in a group home] but that's another thing, if they could look after me properly. If they can't then I have to move somewhere else. When I say "properly" I don't know if they would look after me pretty well...because my Mum and Dad always looked after me and it's going to be hard.

As indicated in the quote above from Rebecca, after Amelia married and left home Rebecca's life became more closely entwined with their parents' lives, as reported by Amelia:

Older Italians are basically her social circle. She goes to church with Mum and Dad to the Italian service, she sings in the Italian choir because Mum sings in it. So she's around little old Italians the whole time and that's just the way it is and everyone loves her and they make a fuss about her...that's good...[but] it's a different world. That's the other thing; it's like Rebecca keeps them [parents] together...the harmony of the family...because I don't think Mum and Dad would have that much to talk about [without Rebecca].

Rebecca also relies on her parents for financial support in addition to her pension and the small wage she gets from work. Amelia said: *"Over the years there hasn't been much funding [so] my Dad and my Mum have financially had to support her all these years."*

Amelia expressed regret that due to her disability Rebecca has missed out on many of life's typical milestones:

There's times when you think, "Oh, I wish things were different", but more for Rebecca's sake than for my sake. You know I feel at times it would be lovely if she could have a family; it would be lovely if she could have a normal life, but not because I've felt that I've missed out. More that I've felt for her that she's missed out.

It would seem from Amelia's description that Rebecca has had limited opportunities to develop independence or self-sufficiency. Rather, Rebecca and her parents have developed a relationship in which they rely on each other. And, by all accounts, the family envisages a continuation of family-based support for Rebecca provided by Amelia. However, Rebecca seemed uncertain about whether she wishes to live with her sister in the long term. Rebecca said: *"I might have to stay with my sister...it's a bit hard because of her family...it would be a bit hard to move to another state [and] I don't know if they would look after me pretty well."*

8.3. Discussion

Three themes are illustrated in the participants' accounts of making the transition to adulthood. The first theme relates to the person with cerebral palsy and the non-disabled siblings' achievement of typical transition milestones which are associated with adult status. The second theme refers to the personal qualities which are developed during what Arnett (1998, p. 312) termed the "emerging adulthood" phase and which denote adult status. The third theme relates to maintaining the status quo and relying on other people to make decisions on your behalf.

8.3.1. Achieving transition milestones

Wells et al. (2003), van Naarden Braun et al. (2006), Janus (2009) and Hendry and Kloep (2010) identified leaving school to study or get a job, leaving the parental

home, and establishing intimate personal relationships and having children as the most important milestones marking the achievement of adult status.

Indicative of the research that reports low rates of achievement of these milestones for people with chronic lifelong disabilities, of the 12 participants with cerebral palsy interviewed in this study, only Caroline, Helen and Bruce had been employed in open employment. Caroline and Bruce had both retired at the time of interviews and Helen was still employed in a full time, professional job. Philip, Rebecca, Kristine, Betty and Oliver were employed full- or part-time in supported work environments earning below award wages. And Mathew, Louise and Thomas had never been employed and instead attended day activity programs. After leaving school, Caroline and Helen had gone on to further education with Helen achieving graduate and postgraduate qualifications. Mathew, Caroline, Helen and Richard moved out of home in young adulthood, and Caroline, Richard and Betty were married; none had children.

There was also diversity in the achievement of transition milestones among non-disabled siblings. For example, not all non-disabled siblings had married. Isobel, Kitty and Stephanie were unmarried and two other non-disabled brothers of Caroline and Oliver, who were not interviewed, were also single. Non-disabled siblings Arthur and Marilyn were married but had no children. Oliver's other brother, who was not interviewed, was still living at home with Oliver and their mother in his mid-40s. After her divorce, Ruth chose to move back to live with her widowed mother. There was variation in the age at which non-disabled siblings had achieved transition milestones. For example, Ruth married at 19 and had two children soon after, whereas Kirsty married later in life and had her first baby in her late 30s. Hodapp et al. (2010) reported that non-disabled siblings of people with a lifelong disability were more

likely to never marry or to marry and have children later than their peers. However, as suggested by Connidis (2001), all people exercise agency in choosing whether to get married, have children, go to university, and pursue one career path over another. Therefore, the pathways of participants with and without disability in this study are reflective of the diversity of life choices.

Nonetheless, although Priestley (2000, 2003) warned against expecting people with a disability to adhere to “normal” transition milestones, some participants in this study spoke about the relevance of these milestones as marking the passage to adulthood. In keeping with Elder’s life course paradigm (1994), participants’ choices were influenced by socio-cultural and historical factors and their timing. For example, Mathew’s sister Kirsty stated her view that Mathew wanted to leave home in young adulthood at least in part because she and Therese had done so and he viewed it as the appropriate thing to do. Additionally, as described by Kirsty, the timing of Mathew’s move out of home coincided with the historic normalisation movement in Australia which advocated that adults with a disability were entitled to independence and self-determination (Parmenter, Cummins, Shaddock, & Stancliffe, 1994). In 1986 the federal Disability Services Act legislated for the right of people with a disability to have access to the least restrictive services and determined the parameters of those services (Commonwealth Government, 1986). Therefore, as described by Kirsty, at the time of Mathew’s move government money was available for supported accommodation in the community and the social climate was shifting to one of more community acceptance of inclusion of people with severe disability.

Caroline spoke about going on to further education as a natural progression from school, given her academic ability and interest. However, she could not complete her university studies because of lack of support at the time for her personal

care needs while she was on campus. Caroline also had to delay moving out of home with her husband until the introduction of a government-funded in-home support service.

Some non-disabled siblings expressed the view that their brother or sister would not be able to achieve the typical milestones which mark the transition to adulthood. These non-disabled siblings had no expectation that their brother or sister with cerebral palsy would marry, have children, or move out of the parental home while their parents were still alive. For example, Amelia expressed her regret that Rebecca would never marry and have children as she had done. Reflecting their Italian cultural background, Amelia agreed with their parents' view that Rebecca would never be able to live independently and she accepted that she would take over the caregiving role for Rebecca previously performed by their parents.

The studies by Stevenson et al. (1997), Magill-Evans et al. (2001), Antle et al. (2007) and the review by Binks et al. (2007) suggest that, because of their significant physical impairments and requirements for support, people with a chronic lifelong disability are likely to require assistance from family members and service providers to achieve transition milestones. For example, Mathew needed his mother's help in doing the "leg work" of finding and negotiating his move into the group home in order for him to achieve his goal of moving out of home. Caroline and her husband need a combination of paid in-home support and family assistance to live independently in the community.

As identified by Roebroek et al. (2009), family members can also act as barriers to achieving milestones. For example, due to her Italian cultural background and gender, Rebecca's family did not consider her move out of home as appropriate or necessary. The combination of being a female and having a disability meant that,

in the eyes of her parents and sister, Rebecca needed the protection and ongoing support of her family. It was not clear whether Rebecca had expressed any wish to move out of home as a young adult.

Darrah et al. (2010) identified that services too may influence the direction that the life of a person with a chronic lifelong disability may take. For example, Philip's move from an adult hostel for people with cerebral palsy to a group home in the community was seemingly initiated by a change in the policy of the service provider rather than by Philip himself. The specialist service provider also managed Philip's progression from school to a sheltered work environment. And, because as a young man he was more physically mobile, Philip was chosen to compete in the Special Olympics. As mentioned by Harry, it was the intervention of the specialist cerebral palsy service that provided Philip with these opportunities.

Despite the reported low rates of achievement of transition milestones by people with chronic lifelong disability, in this study some participants with moderate to severe cerebral palsy aspired to further education, a full time job, living independently, and marrying. Due to their physical impairments they required assistance from family and service providers to fulfil their wishes. For other people their family perceived these milestones as beyond their capabilities and so they were not encouraged or supported to attempt them. The literature, however, indicates that the achievement of transition milestones is not the only way of judging whether a person has attained adult status.

8.3.2. Developing personal qualities

Indicative of Elder's (1994) concept of human agency, the personal qualities of self-sufficiency, responsibility, and independent control over decisions and finances were identified by Arnett (1998, 2000) and Galambos et al. (2007) as important in the

development of adult status. According to participants in Arnett's study, adult status was defined by the development of these attributes rather than by the achievement of specific transition milestones. Fostering independence and self-sufficiency in young adults is likely to result in their increasingly adopting adult roles and responsibilities.

Although parents may recognise the importance of encouraging the independence of their young adult son or daughter with cerebral palsy, as identified by Roebroek et al. (2009), family members may feel a conflicting desire to protect the person from harm or exploitation. This may be particularly the case when the person is a female. For example, Margaret spoke about how vulnerable she felt Caroline was as, due to her physical impairments, she had no way of defending herself from physical abuse. Caroline mentioned her mother's reluctance for her to go to university in case she suffered physical injury. Despite these concerns, Caroline and Margaret provided a number of examples of Caroline making independent decisions on issues affecting her life as a young adult. For example, her decision to have a hysterectomy both shocked the family and demonstrated Caroline's independence and acceptance of the consequences of her action.

Caroline's and her husband's decision to move out of her parental home is another example of Caroline exercising agency. Despite Caroline's family's reservations about the couple's ability to live independently in the community, having made the decision Caroline and her husband put in place mechanisms to assist them and in so doing they exceeded their family's expectations of how well they would manage. Caroline and her husband accepted adult responsibility for the independent decisions they made, and Margaret expressed her admiration of Caroline's strength of character. Recognising and appreciating Caroline's personal qualities contributed to Margaret's commitment to provide Caroline with ongoing support.

Caroline and her husband chose a living environment and support service which maximised their independence and which was separate from the specialist cerebral palsy service. Rather than receiving all their services from the one organisation, they chose the most flexible options from the available community services. Caroline indicated that this was a deliberate strategy: she and her husband wanted control over their lives rather than relying on a specialist service to determine what was available to them. Reflective of Cantor's (1979) hierarchy of support needs, whereby a spouse is higher up the support hierarchy than siblings or friends, being married may have contributed to Caroline's and her husband's ability to determine a more independent course. For example, in the early years of their marriage, Caroline's husband was less physically impaired than she was and was able to help her with many support tasks; thus she then did not need to ask paid staff or family to do those tasks for her.

On the other hand, indicative of Mathew's fiercely independent nature as described by his sisters, he constantly battled with the specialist cerebral palsy service which operated both the group home in which he lived and the day program he attended, for his right to exercise control over decisions affecting his life. As described by Mathew and his sisters, he challenged "the system" for the right to employ a sex worker, he argued for his right to have his shower water temperature hotter than permitted, and he fought the issue of medication restrictions.

Due to his severe communication impairment Mathew enlisted his mother and his sisters, Therese and Kirsty, to act as his voice in pursuing these issues. Also, getting his SGD at about the time that he moved out of home assisted Mathew to communicate his needs and desires to his support workers. Consistent with research by Smith and Connolly (2008) who asked 18 adults with cerebral palsy about their use

of aided communication systems, Mathew's use of a SGD enabled him to present himself to people who did not know him as an independent man with his own voice rather than a passive care-recipient.

Sometimes Mathew was successful in achieving his objectives. For example, provided he did not ask staff to make the appointment, the organisation did not prevent the sex worker from visiting the group home. This raises the question of gender. Would the service have accommodated a female with cerebral palsy employing a male sex worker, or indeed, same sex liaisons? At other times "the system" won. For example, Mathew had no success against the OH&S regulations regarding the water temperature. Therefore, in many respects, the specialist cerebral palsy service wittingly or unwittingly acted in a paradoxical fashion, as described by Darrah et al. (2010): on the one hand championing Mathew's right to live as an independent adult while on the other hand restricting his life and denying him rights through the imposition of rules and regulations, supposedly in his "best interests".

Mathew's sisters' advocacy roles were reflective of the point made by Goetting (1986) and Avioli (1989) that, throughout their life course, siblings play a role in recognising and fostering their brother's or sister's personal qualities. Indeed, many non-disabled siblings in this study demonstrated an awareness of the strengths and weaknesses of their brother or sister with cerebral palsy, and siblings' companionship and the social and emotional support they provided was important to the development of their relationship in adulthood.

Developing the personal qualities of self-sufficiency, responsibility, control over decisions, and independence, as identified by Arnett (1998, 2000) and Galambos et al. (2007) entails a combination of the individual qualities of the person (human agency), fostered by a supportive family (linked lives) and access to community

resources (historical time and social timing). This combination of factors enabled some participants with moderate to severe cerebral palsy to exercise control over how they lived their lives in adulthood. These participants then marshalled resources both from within and outside the family to help them achieve greater independence and self-sufficiency. Not all participants in this study developed or exercised these personal qualities. Some left decisions affecting their adult lives to others.

8.3.3. Maintaining the status quo

Rebecca, Bruce, Oliver and Thomas continued to live with their parents into middle age, with Rebecca and Thomas still doing so at the time of the study. Indicative of the whole-of-life care philosophy espoused by specialist cerebral palsy services in their early years (The Spastic Centre NSW, 2005), Philip, Kristine, Betty and Louise, who moved out of home as children into the specialist boarding school, all still live in accommodation provided by the specialist cerebral palsy service. Rebecca and Philip maintained the status quo by continuing in young adulthood, as they had throughout their childhoods, to rely on others to make decisions for them.

Reflective of the research by Bigby (1997, 2000), Rebecca continued living with her parents and relied on them for instrumental help, transportation, financial support, social interaction and emotional support. An indication of how much Rebecca relied on her parents was that she did not go outside her parents' house alone. Either she was accompanied by one of her parents or she was picked up and taken to work at the specialist cerebral palsy business service. Also indicative of her reliance on her parents, during the initial interview when her parents were present, Rebecca deferred to her parents' views and appeared content for them to answer for her. Although her sister Amelia recognised Rebecca's lack of independence, she

nonetheless had provided their parents with a commitment to continue caring for Rebecca in the same way that they had done.

According to Amelia, the main reason for their parents' approach is their Italian background, and they view caring for Rebecca as their lifetime role and responsibility. Compared to some of the other participants with cerebral palsy, including Mathew and Caroline who exercise considerable agency in their lives, Rebecca's physical care needs are minimal. Therefore, it would seem that Rebecca's parents' concerns are not so much about the level of personal care she requires but more about her vulnerability to exploitation and harm. Goetting cited research by Johnson (1982, cited in Goetting, 1986, p. 707) which found that children of Italian parents had stronger kinship links to each other than those with only one Italian parent or children of European Protestant parents. Furthermore, according to Goetting, Johnson reported that older siblings from Italian families were more likely to take over care of younger ones than their peers of non-Italian background. Rebecca appeared content with her parents' role in continuing to make decisions that affected her life into her middle-age. By the time of her interviews Amelia thought that Rebecca and her parents were mutually reliant on each other, an observation also noted in the work of Bigby (2000), Heller and colleagues (1997) and Grant (1993). Although she had nothing against which to compare, Rebecca was adamant that her parents provided her with the best possible support. Nonetheless, in her follow-up interview without her parents present, Rebecca expressed reservations about the future plans for her to leave her local networks to go and live with Amelia in another state. Perhaps due to the geographic distance between them, Amelia was seemingly unaware of Rebecca's reservations.

It would appear that apart from leaving school to go to work in supported employment, Rebecca neither aspired to or achieved the other typical transition milestones identified by Wells et al. (2003), van Naarden Braun et al. (2006), Janus (2009) and Hendry and Kloep (2010). There was also little evidence that she had developed the personal qualities indicative of adult status, described by Arnett (1998, 2000) and Galambos (2007), which are necessary to successfully navigate the adult world outside the protective environment provided by her parents. Being the younger, disabled daughter of Italian migrant parents meant that, at least for the time being, Rebecca was content with the status quo and with having her parents and older sister plan her future life course.

In contrast, Philip's family play a background role in his life and it is the specialist cerebral palsy support service which has dominated Philip's life since he was 5 years old and which continues to influence his choices. Transition milestones in Philip's life have largely been determined by this service in response to changing government policy and community expectations of how a person with cerebral palsy "should" live. Apart from his last group home move it would seem from Philip's descriptions that he had little say over the succession of accommodation moves he made or the people with whom he lives.

Philip's work environment is similarly managed by the specialist cerebral palsy service and, despite the sheltered environment and low wages, Philip enjoys his job and the people with whom he works. Philip does exercise some control over his life: getting himself to work, socialising with friends from work, and visiting his family. However, perhaps due to the age and geographic distances between them, coupled with their not sharing the family home in childhood, Philip's brother Harry

had little knowledge of specific events which might have shaped Philip's development in adulthood.

When it comes to displaying the attributes of adult independence described by Arnett (1998, 2000) and Galambos (2007), it would seem that Philip has had limited opportunities to develop the personal qualities of self-sufficiency, responsibility, and independent control over decisions and finances. Instead, both he and Harry recognised that Philip falls back on the specialist cerebral palsy service which has supported him all his life to guide him in making decisions about his future.

Summary

The achievement of transition milestones and the development of the personal qualities of independence and self-sufficiency are recognised as important in the assumption of adult roles. The complexity of this process for people with moderate to severe cerebral palsy notwithstanding, a number of participants in this study viewed themselves, and were viewed by their non-disabled siblings, as independent adults who largely determined the direction of their lives. At the same time there was recognition that, due to the physical limitations imposed on them by their impairments, they might require assistance from family and service providers to live independent lives. Part of the process of becoming an adult is to find your own path in life, which may be different from that followed by your siblings. Nonetheless, the connection between siblings can be affirmed by the achievement of similar milestones at around the same time, and by the development of personal qualities such as self-sufficiency and independence. On the other hand, when siblings' experiences of adulthood are very different, it can be difficult for them to relate to each other as they grow older. Chapter 9 explores issues that are important for participants in the middle and later years of their lives.

Chapter 9

Getting Older

This chapter describes the issues affecting the relationship between people with cerebral palsy and their non-disabled siblings later in their lives, using the stories of participants from two sibling dyads and two sibling triads. Figure 4 provides a diagrammatic overview of the concepts discussed in this chapter and, via the dotted lines, how they lead into the following chapter.

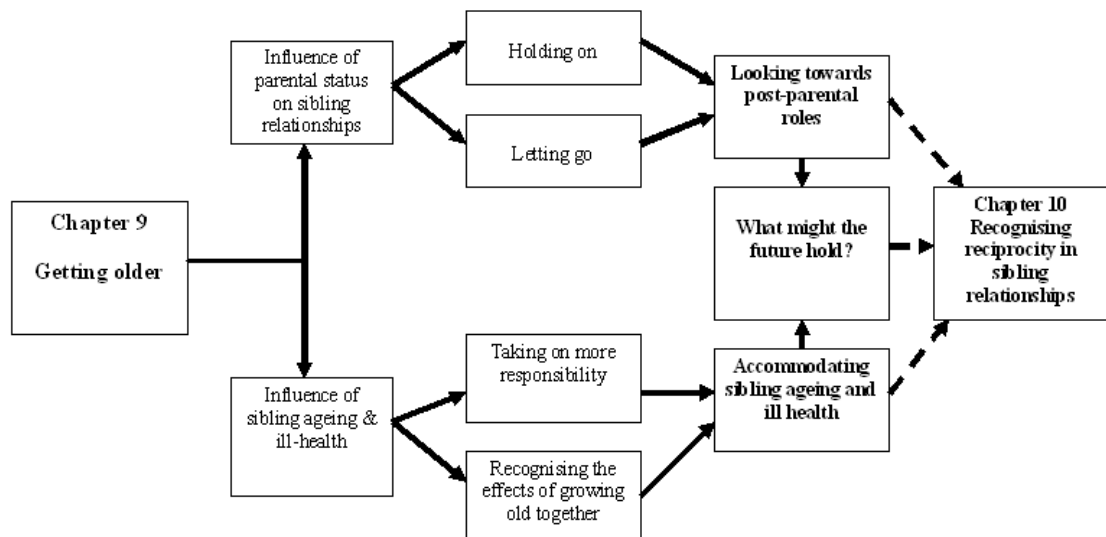


Figure 4 Getting Older

The category “Getting Older” can be understood according to two pathways “Influence of parental status on sibling relationships” and “Influence of sibling ageing and ill-health”. How these pathways impact on the relationship which has developed between siblings is explored using four themes, “Holding on”, “Letting go”, “Taking on more responsibility”, and “Recognising the effects of growing old together”.

Appendix 7 contains the list of focused codes which informed the development of the themes, pathways and categories discussed in this chapter.

Caring for elderly parents and managing their eventual deaths are recognised transition points in middle-age (Connidis, 2001; A. Walker, et al., 2005). According to Connidis, at this time in their lives, it is common for siblings to negotiate the role each will play in supporting their elderly parents, influenced by variables such as gender, geographic proximity, place in the family, number of siblings, parental preference, marital status, and emotional closeness. Connidis pointed out however, that not all siblings negotiate support to elderly parents equitably; indeed conflict between siblings over this issue is not uncommon. Nonetheless, Connidis noted that when parents die, and provided there are no disputes over inheritance, sibling ties may well be strengthened as they recognise their importance to each other as remaining members of their original family.

When one of the siblings has moderate to severe cerebral palsy, there is the additional factor of ensuring that the disabled sibling's needs are considered. Building on the common term of "sandwich generation" (used to describe middle-aged children caring for their elderly parents), Meyer (2009, p. xi) used the term "club sandwich generation" to describe the added complexity for those who also have the needs of a brother or sister with a disability to consider. Regardless of whether their son or daughter with cerebral palsy still lives with them, parents are likely to have provided them with some level of instrumental, social and emotional support. As discussed in Chapter 3, the work by Heller and colleagues (Heller, et al., 2007; Heller & Factor, 1994; Heller & Kramer, 2009) provides evidence that many families with a son or daughter with a developmental disability do not make formal plans for the transition of this support from parents to siblings. Nonetheless, studies by Bigby

(1996, 1997, 2000) and Seltzer and colleagues (2001) suggest that the transition from parental care usually occurs as part of a gradual process involving the deterioration of parental health and an associated increase in the involvement of non-disabled siblings.

Participants in this study discussed two main issues which emerged in middle and later life. The first was the health and wellbeing of their parents. At the time of the interviews, nine participants with cerebral palsy had at least one parent alive, but most reported that, due to age and ill health, their parent/s were gradually taking a less active role in their lives. In these families at least one non-disabled sibling was taking over some aspects of the support to the brother or sister with cerebral palsy previously provided by their parents. Non-disabled siblings' concerns for their parents' health was most acute when their parents were still providing primary care for their brother or sister with cerebral palsy, as was the case for Thomas and Rebecca.

The second and related issue in middle and older age was the health of the person with cerebral palsy and, for the older non-disabled siblings, Jill, Ruth, and Charlotte, their own age-related health problems. Balandin and Morgan (1997) warned that people with cerebral palsy may show signs of ageing and deteriorating health earlier than the general population. At the same time, older non-disabled siblings in this study who reported experiencing age-related health problems themselves commented that it was therefore difficult for them to continue supporting their brother or sister with cerebral palsy in the same way as previously. For example, arthritis can make it difficult for a non-disabled sibling to transfer the brother or sister from wheelchair to car, and this may mean that the siblings can no longer go out into the community together.

This final results chapter focuses on the influences of these two issues on sibling relationships in middle and older age. The story of Thomas and his sisters

Stephanie and Marilyn illustrates the impact on the sibling relationship when older parent-carers seek to hold onto their caregiving status. The story of Oliver and his siblings Kitty and Arthur demonstrates what happens between siblings when parent-carers must relinquish their caring role due to ill health. Illustrating the influence on the sibling relationship of the person with cerebral palsy suffering ill health is the story of Kristine and her younger sister Natalie. Further, Louise and her sister Jill describe what happens when siblings with and without cerebral palsy are both getting older and must adjust their relationship as a result.

9.1. Influence of parental status on sibling relationships

9.1.1. Holding on

Thomas, Stephanie and Marilyn

Thomas (43) has cerebral palsy, dysarthric speech, and uses an electric wheelchair to get around which he operates with a hand control. Thomas can move himself in and out of his wheelchair. Thomas lives in a regional town with his parents who are in their 60s and suffer from chronic health conditions. Thomas attended a boarding school for children with cerebral palsy in the nearest capital city from 7 to 11 years old. Possibly because he is younger than the other participants with cerebral palsy who attended specialist boarding schools, in adolescence Thomas returned to live in the family home and, after school, commenced at a local community access program which he still attends. Thomas is the eldest in a family of four with one brother and two sisters, Stephanie and Marilyn.

Stephanie (37) is the third child in the family and is a single, professional woman. Stephanie left home aged 17 to go to university in the capital city where she still lives. Marilyn (30) is the youngest in the family and is married, has no children,

and runs a small business. Marilyn and their brother, who was not interviewed and is married with children, both live in separate country towns close to their parents and Thomas.

In young adulthood Stephanie, Marilyn and their other brother moved out of their parental home to establish independent lives while Thomas remained. Thomas was clear about why he stayed living with his parents: “*Parents look after you and care for you.*” Moreover, as a result of his early experiences at boarding school Thomas said he did not wish to live in congregate care with other people with a disability:

I've been in that situation before [living away from parents] when I was at school and I didn't really like it. When I went to [boarding] school I used to have tea⁸ about half past four or five o'clock because that's when the staff used to get people in to have showers and to bed and all that. You're really on a time limit if you're in a shared home. My idea is to have tea at a normal time instead of earlier. [I want] more flexibility and to do things when I want to do them.

Thomas clearly articulated the future he saw for himself and he had a fledgling plan for how it could be achieved. Thomas said:

[I will stay with my parents] as long as I can. I'm happy with my life so far. Then I'd like to get a carer in and keep going as I am [either in the same house] or somewhere else in the area because I don't think I could get involved with a lot of people because it's difficult to have advisors all the time. It could be a bit hard [getting carers to come to me] depending on what they earn I suppose. It's not an easy thing to agree on the terms. But we have to

⁸ Tea is a colloquial Australian term for the evening meal.

plan for the future now, and then it might come together. It's in our heads because it's a bit early yet. I've talked about it with my parents but not my siblings yet. Everybody would be involved to talk about what I wanted to do. We'd need to look for a really decent carer and talk about what we need. I'd probably need more than one carer. I'd probably need four or five so they cover all the shifts. I probably need some help with certain times but I haven't thought about it that far. Siblings would come and check on me every day and see if they're [carers] doing everything all right.

As he indicated, Thomas envisaged a role for his non-disabled siblings in monitoring his wellbeing; however, he had not communicated this to his siblings. Indeed, indicative of the diversity of views among siblings in the same family, Stephanie and Marilyn had different views from each other, and from Thomas, about what the future might hold for him after their parents died. Stephanie's view was:

He [Thomas] will be devastated [when parents die] because they've always been there and done everything for him. Wherever it is [that he ends up living] I hope it's somewhere where we can still take him out for extended periods. I mean he's our brother and we love him and we'd want to spend time with him. I'd hate him to be truly institutionalised in the sense that it takes away all that personality.

Perhaps due to her closer geographic proximity and more regular contact with Thomas and their parents, Marilyn had a better idea than Stephanie about Thomas' preference to live on his own. However, Marilyn had reservations about whether this would suit Thomas' personality:

It [the future] worries me and I'm pretty sure everybody else at least thinks about it so there's going to have to be something [done] and I mean not

behind Thomas' back either. But just to let him know that no one's going to decide his fate without him. But he has apparently said to Dad that he'll be happier to be in a place of his own with a carer than living with any of us. But I'd prefer him to try it a little bit now while everyone's still here rather than it be at a really sad time if we lost Mum and Dad and then he was shoved into that as well. I don't think anyone would cope with that. I can't really imagine him living on his own and being happy because he's had his whole life living with family. He's such a social bugger I don't know that he could handle living completely on his own and that kind of worries me a bit. I would hate to see him in a home; I don't like the idea of that. I don't know whether its possible for him to live somewhere on his own with care and then come and stay with us a night or two a week just so he's not completely on his own. As long as he's got an open mind about it too.

Despite their different views about what the future might be for Thomas, Stephanie and Marilyn agreed on why the issue of his future care was becoming more pressing. First, the sisters expressed concerns about their parents' chronic health problems and how much longer their parents could continue caring for Thomas. Stephanie said:

[Our parents] are both alive and in their 60s. Dad hits 70 next year. I'd say they're both in poor health which is a bit of a problem for them because they're Thomas' carers. Mum's got fibromyalgia and Dad's is emphysema [and] I'm sure that being his main carer, because they don't get any help with respite, hasn't helped with their illnesses. I'm not sure what's going to happen because Mum and Dad aren't well.

And Marilyn added:

Dad's nearly 70 and the fact that they still have to get up every morning at a certain time to get Thomas off. If Mum's not well then Dad does it and tiptoes around so as not to disturb Mum. I know it upsets him [Thomas] too when Mum's really sick and at times they try to hide it from him which is pretty silly too. I mean he's a grown-up and he always knows what's going on.

On the other hand, when asked about his parents' health Thomas replied that they were both "still pretty fit and healthy." A second concern shared by his sisters was a view that the older Thomas gets the more reliant he becomes on his parents.

Stephanie explained:

Most often if they [parents] do go away they take him with them. There might be the odd occasion that they leave him at home and Marilyn or [brother] will drop in and give him dinner, they'll help out with that. But that very rarely happens just because he can quite often be cranky with whoever's been asked to feed him. I think [he] gets jealous that Mum and Dad might be doing something without him.

Reinforcing this view, Marilyn described what happened the last time she supported Thomas while their parents went away:

About 6 months ago Mum and Dad went away and my husband and I stayed over at Mum and Dad's and it wasn't like "Go and look after Thomas" thing, it was just "We'll stay with him." And he completely cracked the shits about something and then I spoke to Mum and Dad and said, "Well that's not fair on you guys" and Thomas hasn't been real happy with me since then. So it's a bit of a touchy subject. I mean I understand it's hard for him and no one's saying that you want him locked away; we just want someone to come and stay with him so that Mum and Dad can go away on their own. But he's pretty set

in his ways and I've been stubborn about it too. I don't think it will go back to the way it was [between us].

Thomas made no mention of any friction between himself and his sisters. When asked about how he got on with his siblings he said: “*We get on fairly all right.*” Marilyn indicated that she and Stephanie regularly discussed the issue of Thomas’ future with each other, but she was unsure about the view of their other brother who was not interviewed:

I just think that [brother not interviewed] and Thomas, it's not that they don't get along but they're both a bit defensive about everything and because [brother]'s so busy with his own family I don't know that he'd even think about it much at all.

Stephanie meanwhile thought that because they lived closer to their parents and Thomas, Marilyn and her brother were more likely to be involved in overseeing Thomas’ future support than she was: “*I think it would come down to who ever was closest geographically which puts me out of the picture...ha, ha, how convenient's that!*” Nonetheless, Stephanie also expressed both her frustration with and her empathy for her parents:

In some regards I think Mum and Dad, although they've been brilliant, they've built a rod for their own backs as well. They should have, when he was younger, tried to have more time out both for him and themselves. Because he's just become so dependent on them and then if they want to do something that doesn't include him, he feels like he's being shut out or something like that. [But] you look back and you don't know what you'd do if you were in the same situation.

Both Stephanie and Marilyn had suggested that their parents use respite care for Thomas as a way of getting a break and of Thomas experiencing an alternative living environment. However, according to Marilyn:

Every time you mention it [respite care] to Mum she'll just say "Oh, it's not the right time", which kind of scares the rest of us because if something suddenly did happen it's going to be our problem and Thomas' of course, which is a bit of a worry. It's just always been [something] that none of us talk about and we all just expect Mum and Dad to keep doing it and they do. It's not until one of us steps in that you realise how much they really do every day.

In addition to their concerns about their parents' health and wellbeing and Thomas' dependence on them, Stephanie and Marilyn are worried that Thomas is becoming less independent as he gets older and they view this as detrimental for him. Marilyn reflected:

He's in his early 40s and he hangs out with Mum and Dad all the time. It would be nice for him to have a bit of independence and I know he's probably frightened of it but I think it'd probably be a good thing for him. You go round on the weekend and he just sits in the chair and watches telly most of the time and he hasn't always been like that. He used to have more independence than what he does now I think.

Linked with Thomas' lack of independence and the sisters' concerns about the future was what Marilyn viewed as Thomas' reliance on and monopoly of their parents:

I think the trouble is that he is only with Mum and Dad and he does really listen to everything Mum and Dad say, even just listening in to phone conversations. He might get a little whiff of something and go along with it.

*So if Mum and I are having words about something then Thomas will get upset with me because I've upset **his** Mum. It's starting to look like that's what he thinks, they're **his** parents they're not everyone's parents. He has a very big ownership over Mum and Dad and the house.*

As indicated in these quotes, Stephanie and Marilyn express a degree of frustration with both their parents and with Thomas over the issue of his future care.

Nonetheless, the sisters say they feel powerless to initiate family discussions about future options. Stephanie said: “*We're not big on confrontation our family so I think we're just trying to avoid having to face the reality that Mum and/or Dad won't be here and then what happens with Thomas? That's the big question.*” Marilyn added:

Maybe too because I am the youngest, I feel like I get blown off a lot when it comes to my opinion in the family. But, as far as the long-term future it's hard to imagine it any different [to the way it is now]. I know that sounds like a silly thing to say because I know Mum and Dad won't be here forever but it's really hard to see it any other way.

Some members of this family are still working their way through the possible future options (individually not as a family unit), with seemingly little discussion amongst the siblings or with their parents. However, as indicated earlier, Thomas is quite clear about what he wants and he reiterated this in his follow-up interview:

Like I said to you last time I'd be happy to stay in my own house and get a carer in to look after me because I don't want to be in [supported] accommodation because I've been in that situation before and I didn't really like it.

The story of Thomas, Stephanie and Marilyn highlights the uncertainties about the future facing families in which the older parent carers are still providing care to their

son or daughter with cerebral palsy. The following family story is the one used at the beginning of this thesis to highlight the problems facing middle-aged individuals with cerebral palsy and their non-disabled siblings when, after a lifetime of living with a parent as their carer, the person with cerebral palsy faces a turning point in life due to the ill health of that parent-carer.

9.1.2. Letting go

Oliver, Kitty and Arthur

Oliver (42) has cerebral palsy, dysarthric speech, uses an electric wheelchair to get around, a hoist for transfers, and requires assistance with all aspects of his personal care and activities of daily living. Until 12 months before his initial interview Oliver had lived at home with his mother who cared for him. For the past 25 years Oliver has worked in a business service run by a specialist cerebral palsy service provider. Oliver is the youngest in a family of five.

Kitty (52) is the eldest of the five children, is not married and is employed full time in the education sector. Arthur (47), the third in the family, is married with no children and is a business consultant. The two siblings who were not interviewed include a sister who is next in line to Kitty and who is the only one of the family who has children. There is also a brother who is the fourth sibling, unmarried, and who lived in the family home with his mother and Oliver.

As the eldest daughter, Kitty reflected on the sense of responsibility she felt to support her mother and Oliver, particularly after their father's death:

Dad died not long after my 21st and it was very sudden. I didn't leave home until I was about 30 and I guess Oliver was probably one of the reasons why I didn't...I felt "well I can't really go and leave Mum on her own to cope with

him.” [At 30] I decided I needed to get out on my own but I’ve never lived very far away, 15-20 minutes.

Eighteen months before the initial interview their mother was diagnosed with dementia. Six months after diagnosis her health deteriorated to the point that she could no longer look after herself or provide for Oliver’s significant physical care needs. Arthur explained the early stages of their mother’s dementia:

Mum [had been] Oliver’s primary carer all his life. Mum was diagnosed with dementia 12 to 18 months ago but was probably not coping well up until then and it got progressively worse. We’d started to notice just forgetfulness and repetitive conversations.

As well as being the eldest, Kitty was also the daughter living closest to her mother and she responded to her mother’s deteriorating health by increasing the support she provided:

We [siblings] started to see that she [mother] really wasn’t caring for Oliver as she had in the past and it wasn’t intentional obviously but she just didn’t realise what she was and wasn’t doing. So my main role was helping out with housework and things like that and especially washing and just doing some general housework. And I had to do it really diplomatically because I’d be there doing something and Mum [would say] “You don’t have to do that, I can do it”. So you have to be careful, you can’t just say “No, you can’t”. You have to say “Yes, I know you can but I’m just doing a little bit to help you out”.

Arthur became emotional when talking about the guilt he felt in not recognising his mother’s deterioration and its effect upon Oliver’s situation earlier:

Was I aware of the level of care Oliver needed? I was aware of it but I guess being away from it you forget how hard it is and how regular it is and how constant. Again I think that's an element of the guilt that I feel about what we, and it might not be "we" it might be "me", haven't done in the past. So I go through those times but I also am very conscious that I can't change the past and what I'm trying to do now is influence the future and put my energy into making it different.

Oliver recalled the day when he realised that his mother was not coping:

When Arthur initially told me that Mum was diagnosed with the early stages of dementia it was nearly 2 years ago. Initially I was very surprised but as time went on I started to notice little things. One day about 6 months later I called out for her [mother] to come and get me ready for work and she said "I'll come in a minute" because she was starting to forget and she wouldn't realise the time and this day she said, "Oh, if the taxi comes and you are not ready they will either wait for you or you will stay home for the day". I don't like taking days off. The only time I have days off is if I'm really sick or there's something wrong with my motorised chair. When I got to work I found the transport coordinator and I started explaining the situation to him. I was all right when I was on my way but when I started explaining to him, the enormity of it hit me.

With the assistance of the transport manager Oliver phoned Arthur at work and he came and picked Oliver up. In the meantime, alerted to the situation by a text message from Arthur, their sister Kitty had gone to the house and found their mother on the lounge room floor. That day set in motion a chain of events which led to their

mother's placement in a nursing home. At the same time, the family needed to ensure that Oliver's significant physical care needs were met. Arthur explained:

That was I guess really the call for help, it was a crisis situation and I guess we [siblings] all rallied around there. So when I look back at that I think it was quite obviously a lot more desperate a situation than we realised. So from that time on we needed to take care of Oliver which started basically with rosters amongst ourselves [siblings] and we approached the [government department managing services for people with a disability] and we were able to get some care. This was where we started to play some different roles too. I took on more of an overall coordination role in terms of all Oliver's stuff and my sisters [name] and Kitty took on a coordinating role for finding a place for Mum.

Their mother initially accessed respite care with short periods of time at home.

However, she deteriorated rapidly and the family found her a permanent place in a nursing home. For 6 months the siblings juggled providing support to Oliver at home themselves, supplemented by paid in-home support, and external respite care. Kitty spoke about the benefits at a time like this of coming from a large family: *"All I can think of is thank goodness there's five of us altogether."* Kitty also acknowledged the advantages of living close by: *"In the last 12 months I think, thank goodness [I live close by], because I've had to do lots of trips down there [to family home] at all hours of the day and night."* On a personal note, Kitty spoke about how difficult she found coping with this family crisis without a partner: *"Because I'm single, because I don't have a partner you know, it was harder for me at times because I didn't have anyone specifically to come home and talk to."* On the other hand, Kitty recognised that

facing these traumatic events together has strengthened her relationship with her siblings:

I've got a lot closer to Oliver and even probably to Arthur and [other brother] as well. I mean I've had a lot more to do with Arthur than I have since he got married. I've had lots of talks with [other brother] about things.

Oliver in turn spoke about his sense of being able to rely on his brothers and sisters:

I know if anything, when and if anything ever happens [with their mother] someone will either contact me or if it's really, really serious they will come and see me and talk to me face to face. And, if I need anything I can always contact them by phone. Mostly during the week I am always in contact with someone from the family one way or another and some weekends either Kitty or Arthur drop in to see me and make sure everything is OK. Because I'm here [in the group home] all the time now I don't need to be so reliant on my brothers and sisters. I know that if and when I need them they're always contactable.

Kitty reflected on how she felt Oliver coped with the changes that have occurred mid-way through his life:

I guess we've probably become more aware too of how Oliver felt about the whole thing. He was the one who had to go through the most changes out of all of us...his was the biggest impact and the most sudden because he'd had Mum as a full time carer. I guess I didn't stop and think about it until I was really closely involved and doing some of the daily care...you go through a couple of situations and he [Oliver] made a couple of comments and it does make you step back and think how hard it must be to have somebody helping

you with all those personal things...and especially strangers initially and even I guess close family members doing those sorts of things.

And Oliver was frank in his assessment of what these changes were like for him:

The biggest two changes I found hardest were from always having Mum and then knowing she was never coming home and having, getting used to, new carers and even though they did what Mum used to always do for me, getting used to new carers. The other change I felt hardest was going to respite care. I've never had anyone else look after me, and not knowing what to expect...knowing that I was so reliant on others to do anything and everything for me. I found it frustrating but now I've come to the point where no matter how hard I try I'm always going to have to ask somebody to do it for me.

After 6 months of the siblings managing his care at home, Oliver was offered a permanent place at a group home not far from where Arthur and Kitty live. Managing the competing demands on their time over this period had been a team effort, with the four non-disabled siblings working together to find nursing home accommodation for their mother and a group home for Oliver. Kitty noted the differences in the roles played by siblings, which she related to geographic proximity:

[Other sister] has her own family and she lives further away, she lives the other side of town whereas the rest of us are all pretty close together so she probably hasn't been as involved directly with Oliver. She probably did more of the things with Mum but she still has helped out despite how far away she lives.

Arthur agreed with Kitty's comments about geographic proximity, and additionally noted the impact of other family and work responsibilities on siblings' involvement:

We all played a bit of a caring role. Proximity to the family home and the nature of work and other commitments contributed to the degree to which we could do that. So [other sister] with her family had some challenges at home that meant at times she was less able to participate in certain things. Kitty is single and so has greater flexibility, [other brother] was living at home, and there's only myself and [wife] and we have no kids so I have a reasonable level of flexibility there as well and I am quite lucky [as] I had some really good support from where I work.

Kitty spoke about the role their brother who also lives in the family home played:

I know that [sister not interviewed] feels that [brother not interviewed] could have done more in certain things along the way. But there again, I'm not sure that [sister] appreciates the day-to-day situation that [brother] was in because [he] was virtually caring for both Mum and Oliver for a while there. He was making sure that they both had medication as well as working full time and that sort of thing.

And Arthur added: *"I often wonder whether [brother not interviewed] is still at home because he was just the last one left there and then thought that he maybe couldn't leave."* Arthur also noted that negotiating the transition for their mother and Oliver was not all "plain sailing" between the siblings:

There were elements of conflict [between the siblings] around some things to do with how long Mum might have spent in respite. Not so much a disagreement but more people were on different paths of the journey at different times. The fundamentals were there, it was just whether everyone was up to the same point at the same time.

Kitty agreed: “*Look, you know we’ve had our differences of opinion but I guess we all just care about Oliver and have his best interests at heart.*” Once both their mother and Oliver were settled into their new accommodation the non-disabled siblings had a chance to reflect on what their ongoing role might be. Kitty said:

I guess most people my age are involved with their children and their lives and to still be involved with a sibling at this stage, I don’t think most people understand what that’s like. It’s a lifelong commitment. There’ll always be things to do with Oliver but I guess we’re trying to put in place things so that if and when we’re not around that there will be someone who will be able to look after these things for him.

Oliver too was thinking about what might happen in the future, particularly in relation to his mother’s health. Oliver said:

Some time earlier Arthur discussed it with me and said “If Mum was ever in a situation where she was really sick and it was only a matter of time and we had to choose what to do, what do you think we should do?” And I said “That’s a hard one”. And I thought about it for a minute and I said, “I hope you don’t think I’m cruel for saying this but I think if it came to that and it was that bad, just let nature take its course. Even though at the time it would be sad it would probably be the kindest and most dignified thing to do rather than letting her linger and suffer”. I always think, “Remember the way Mum was, not the way she is now”. But whenever the time comes, we don’t know when that is, I hope when I break down, I hope I’m here [in the group home] rather than in a group of people.

The stories of Oliver, Kitty and Arthur raise a number of important issues related to what happens when a middle-aged person with cerebral palsy, who has lived at home

with a parent as the primary caregiver, finds that they can no longer live together. Kitty and Arthur's stories, and those of other non-disabled sibling participants in this study, show that they are often unaware of exactly what providing day-to-day care to their brother or sister with severe cerebral palsy entails. Indeed, it was only after Kitty and Arthur found themselves in the position of having to provide personal care to Oliver that they realised the physical and emotional demands of doing this. While living at home with his mother, Oliver had not acquired many of the life skills he needed to live independently. However, it was not until he moved out of home in middle-age that he realised this deficit. At his follow-up interview, by which time Oliver had been living in the group home for nearly a year, he commented:

I've learnt to become more independent and more confident in certain situations. About the easiest example I can give you, even though I still need help and probably always will, I have someone come with me every week to the local supermarket. When I first did it I thought, "Can I do this? Am I cut out to do this?" But now it's more or less second nature. I'd never been to the shops for the simple reason that I didn't need to. There was always someone there to do it for me.

Oliver also credited the counselling he had been receiving as assisting him to come to terms with the recent changes in his life:

The best outlet for me, or the most effective outlet for me has been [counsellor], for the simple reason that she's professionally qualified and as an adviser she can look at it from an impartial perspective. And the staff here [group home] have said to me, "Oh you've had lots to cope with and you're doing very well" and [counsellor] said the same thing, she said, "I see other

people who haven't got the physical problems that you've got who wouldn't cope nearly as well as what you do".

Arthur thinks Oliver still has a way to go in developing independent life skills, and sees this as a primary challenge with which he and his other siblings will assist Oliver over the coming years:

He [Oliver] has no intellectual disability but he doesn't have what I would say are a lot of life experiences. In some things you would probably say he's immature but he's very smart and capable based on what he has experienced. We've tried to get Oliver to make decisions about what he wants to do rather than us deciding he should do something. And in my mind this is part of a strategy that he needs to start experiencing this stuff and experience it when we're around to help him.

After an intense and reportedly challenging period for Oliver, Kitty, Arthur, and their other two siblings, the follow-up interviews revealed a more settled time, and Arthur articulated what he hoped for the future in his relationship with Oliver:

I didn't want every conversation with Oliver or every interaction with Oliver to be about organising something about his care. I wanted it to be two brothers having a conversation and talking about stuff without those other things coming up every time.

Oliver, Kitty, and Arthur have travelled the road of transition from parental care to sibling support, and part of their motivation for participating in this study was to tell their story so that other families might learn from their experience.

Apart from the ill health and death of parents, the second issue which emerged as important to siblings later in life was the ageing and ill health of the person with cerebral palsy and/or the non-disabled siblings. The next story presented in this

chapter straddles both issues of parental status and sibling health. It demonstrates how, since their parents' deaths, Natalie has needed to take on more responsibility for Kristine's current and future health needs.

9.2. Influence of sibling ageing and ill health

9.2.1. Taking more responsibility

Kristine and Natalie

Kristine (55) has cerebral palsy and uses an electric wheelchair to get around which she operates by a central hand control. Kristine requires support with all aspects of her personal care. She has dysarthric speech which I found very difficult to understand. As a result, Kristine's sister Natalie's voice is more prominent in this account.

Kristine's only sibling, Natalie (36) is 19 years younger and is married with four children ranging in age from two to 11 years. Natalie's eldest child has an intellectual disability, and two of the other children have epilepsy and speech impairments. Natalie also assists her husband in running their small business.

At some time during her childhood and before Natalie was born, Kristine went to a specialist boarding school for children with cerebral palsy, so Natalie's childhood memories are of seeing Kristine during school holidays. Over time, Kristine moved from the boarding school to the adult hostel, and then into a series of group homes in the community run by the specialist cerebral palsy service. Despite their not living together in childhood, Natalie acknowledges that, as each other's only sibling, she and Kristine share a strong bond: *"I mean she's all I've got and I'm all that she's got, you know in that family."*

Their mother died when Natalie was 16 years old and their father died 2 years prior to the interviews. Natalie reported a conversation with their father prior to his death, regarding ongoing support for Kristine:

We did have a little talk...that I was to make sure that she doesn't need for nothing. But not only like money-wise but just to help her out and keep going to see her. Dad just said, you know, "Just try and see her when you can". And actually Dad did say I've got to do what he wants and it was in his will so I mean even if it wasn't in his will, I'd still do it. I mean that was always going to be the case. When Mum and Dad died I knew that I'd be taking on what they were doing [for Kristine].

After their father's death, and in order to make it easier for them to see each other, Natalie and her family moved nearer to Kristine's group home. According to Natalie she and Kristine are emotionally closer now too: "Since Dad's died we have got a lot closer." Kristine agreed: "I am very close [to Natalie]. Natalie is my next of kin. [Since my Dad died] I can't go home." However, Natalie said that they do not talk about their father's death:

When Dad died that would have been a really big impact [on Kristine] because there was no more parents, [but] nothing was said. I didn't even want to talk about it. I just tried to put it out of my mind. I mean it was harder for her with Dad [dying]. [After Dad died] she was always ringing me up and wanting me to come over. Just to feel I think closer and to be part of the family.

During her follow-up interview, Kristine became distressed when I asked about some of the big events that had happened in her life. It became evident that Kristine was thinking about the death of her parents. She was so overcome by emotion that she

was unable to speak. I turned off the recorder until she was ready to continue with the interview and I noted in a memo written after the interview: “It was really difficult watching Kristine battle with her grief. The emotion was so raw. My heart went out to her.” Speaking about the effect on Kristine of their mother’s death, Natalie said:

I didn’t speak to her much about it. It was upsetting...she understood...she knows when you die you don’t come back, she understands that. I mean it did affect her from what I remember. I mean I was only 16 so I didn’t really speak to her about it.

Natalie does not like to take her four young children to the group home to visit, so group home staff members bring Kristine to Natalie’s house:

Every 3 weeks they bring her and she’ll spend the day here and then go home. They’re [group home staff] always saying “Oh, come over”, but I don’t want the kids to run amok over there. I mean they’ve [group home staff] said, “What else could three little ones do?” Because they’ve got ladies that run into the walls and knock things over [in their wheelchairs] but I mean they live there where we don’t.

Kristine’s disability and the 19-year gap in their ages have resulted in different life trajectories for the sisters. Kristine’s life is regulated by the group home in which she lives and the specialist day program she attends. Meanwhile Natalie’s life involves accessing specialist services for her children and all the other day-to-day tasks involved with a young family. Natalie acknowledged that her busy life means she has little spare time to devote to Kristine. Natalie provided an example of this:

She [Kristine] rang me up the other day...she’s got a chest infection [and] to her a chest infection is a big deal. She wanted me to go and see her and I said, “Listen, I can’t. There’s no way I can. I’ve got so much on. I’ve got

doctor's appointments". She said "Oh". I said, "Maybe in a few weeks, I might be able to but at the moment I've got too much on". [To] which she said "Oh, fine". And one of the girls [group home staff] got on the phone and said, "I think she just wanted to hear your voice". Because she knows I'm busy.

Although Kristine and the group home staff know that Natalie is busy, Natalie is still Kristine's only sibling and surviving family member, so the group home staff often telephone Natalie to get her to talk to Kristine when there is a problem. Although Natalie is Kristine's junior by 19 years, when there are problems she becomes Kristine's confidante and advisor, as Natalie explained:

She relies on me a lot more now. If she's got a problem or something she used to ring Auntie [name] before Dad died but now if she's got a problem, if she's feeling sad, they always ring me. I've got to be the one that's got to try and talk some sense into her because her temper can be bad. She wants to run away from her problems. When there was a problem at work, she was not going to work no more. So they [group home staff] rang me and I told her some things, you know, that in life you cannot run away from things, you've got to face them front on. Sometimes she'll listen.

Kristine identified two issues that are causing her distress. The first is a personality conflict with another person in the group home, about which Kristine said: "*It's bloody awful...it's getting worse...I think I'm going to move out...I'd rather go to work every day than be at home*". The second issue relates to her ageing and increasing inability to digest her food. Kristine said: "*I don't eat very well... [the food] is pureed...it's yuk! I want to get a PEG [percutaneous endoscopic gastrostomy tube] in my belly...because of the vomiting.*"

Natalie is aware of these issues but has a different opinion from Kristine about their importance. In relation to Kristine's wish to move group homes due to incompatibility with one of her housemates, Natalie said:

If she doesn't get her own way, if she doesn't like the people there, if someone upsets her, she wants to move. She's moved quite a few times, numerous times and I mean that's her choice and she obviously has a say and they obviously do move her because she's been moved quite a few times. I mean to me she seems happy there. Every time she comes here she seems happy.

Natalie feels strongly about the issue of Kristine's diet. Indeed Natalie sees no need for Kristine's food to be pureed and did not mention Kristine's wish to have a PEG put in her stomach. According to Natalie:

There is something that she is getting that she doesn't need...they puree her food and make it all baby mushy...in case she chokes. But when she comes here she has no trouble swallowing. I mean we only do spaghetti and something that's good for her to eat, and cake and some bread and that. So it's ridiculous and she does not need it [food pureed]. I mean that's the only thing that I do not agree with. Everything else is fine except for that one little thing.

There is another issue which Natalie is concerned about but has not discussed with Kristine or her group home staff. Natalie explained:

They [group home staff] manage her finances. We've got no idea what they do with it...I know she does have money because she's going away [on holiday]. But I'd like them [staff] to start putting some money away for when she dies because funerals are expensive and we have a mortgage and four kids

and if I'm going to have to be the one to pay for it [Kristine's funeral] you know it's a big thing.

Despite her busy lifestyle Natalie sees an ongoing role for herself in Kristine's life and is looking towards what the future might hold:

In the future depending on when, if, she gets really sick or something well then I'll have to take more of a role because I mean I don't want them [group home staff] making all the decisions if she goes into hospital or something like that. If she's really sick that's when I'll step in. If she's on life support and they give us an option of what to do, I mean we'll be turning...I mean it sounds harsh...but we will be turning if off because I mean she could be worse than what she is now, you just don't know. So I'm trying to just gear myself up. It mightn't happen which would be fine, that would be one thing I don't have to deal with.

Kristine and Natalie have already faced the death of their parents, and although Kristine's personal care needs are met by the group home staff the sisters have developed a relationship which involves Natalie giving Kristine social and emotional support while Kristine provides Natalie with a sense of continuity with her family of birth. However, an increasing concern for both of them is Kristine's deteriorating health. As each other's only sibling their lives are linked as they provide each other with a connection to their parents and earlier life experiences. Additionally, Natalie faces the prospect of making life and death decisions for her much older sister, Kristine. Louise and Jill are the same age and both are finding the effects of age catching up with them.

9.2.2. Recognising the effects of growing old together

Louise and Jill

Louise (65) has cerebral palsy, diabetes, a hearing impairment, dysarthric speech, and uses an electric wheelchair to get around. Louise grew up on a farm in the country and in keeping with the prevailing practice at the time, at the age of 11 she moved to the city to a boarding school run by a non-government organisation providing services to people with cerebral palsy. As a young adult Louise moved from the boarding school to a hostel. Along with the rest of her age cohort who had lived in the boarding school, in the 1990s Louise was encouraged by the specialist service provider to move from the adult hostel into supported community-based accommodation. However, her father prevented her from making this move due to his concerns about her possible physical deterioration and access to future care. Louise remains living in the hostel which now accommodates older people with cerebral palsy. During the day Louise attends a day program run by the same organisation.

Louise has two cousins who were adopted by her parents after their parents' deaths. Jill is one month younger than Louise, and Jill's sister is 5 years older. Jill went to boarding school at about the same time as Louise, and she and Louise then saw each other only in school holidays. Showing great empathy for her orphaned cousin-cum-sibling, Louise remarked: *"I always made sure that I had all the school holidays to be with her and to give her as much time as what I could."*

Jill (65) was 3 years old when her mother died and then 4 years later her father died. Guardianship of Jill and her older sister was given to her father's sister and brother-in-law, Louise's parents. During the week Jill lived with her grandmother in a country town and attended school. On the weekends and holidays Jill lived on the farm with her aunt, uncle, and Louise. Jill regards Louise as her sister, whereas her

older sister does not. Jill acknowledged the sense of obligation she feels towards Louise's parents for taking her in when she was orphaned:

It's an extraordinarily complicated situation. You carry this sense of guilt. You don't realise this when you are growing up but I used to hear the stories of what happened in my family and the weight of responsibility...let's put it this way...I was being cared for and therefore that is reciprocated.

This sense of obligation and gratitude is what has driven Jill to take on responsibility as Louise's legal guardian now that Louise's father is very old (in his 90s) and no longer able to oversee Louise's care. Jill said:

The last 18 or 20 years since my husband's gone, my whole life I've devoted to [uncle] and Louise. I made that conscious decision that I was going to make it worthwhile. And if you want to talk about sibling loyalty, I'd say I feel as strongly about this sibling loyalty as I do about the bond between my daughter and I and it doesn't get any stronger than that. I am absolutely passionate about Louise.

Now in their mid 60s, both Louise and Jill are experiencing problems with their health. Louise reported:

I've got sugar diabetes that I've got under control by tablets. If you eat the proper food you're right. [My hearing has got worse too] I can't stand a lot of noise and if the hostel is full I can't hear what people are saying and it's frustrating because people don't realise that I'm missing half the conversation and therefore they're not talking to me, they're talking between themselves and I hate that.

And Jill noted:

I can't do anything physical [with Louise] any more. I used to take her home at Christmas time and I could do the enemas and the bathing and all that. I did that and then I just couldn't do that anymore.

Jill recalled in great detail an incident which had occurred 4 years prior to the initial interview when Louise was admitted to a public hospital after a fall at the hostel. During her recovery she contracted a bacterial infection and the hostel would not allow her back until it was cured. Jill travelled to the city to support Louise in the hospital and provided her with hands-on care because the nursing staff were unsure how to nurse Louise and the hostel would not provide staff to assist her. After weeks of providing constant care to Louise in hospital Jill recalled:

Then one afternoon my right side went, I lost my peripheral vision and I was carrying her cup of tea and my cup of tea and the tray just went and I sort of, I fell over. And then everyone came from everywhere. I [had] asked 3 nights beforehand for help to be sent down [from the hostel] and I was knocked back three times. You can't leave people to fall over on their own. So that was a real turning point for me and that's one of the reasons I'm speaking to you. I know I can't do what I did in [name] hospital ever again and that frightens me. Physically, my age, physically I will be unable to do it.

At the follow-up interview approximately 12 months after the initial interview, Jill commented that Louise was experiencing frequent bouts of pneumonia:

You know we always go to the ballet...I got her there and I should have realised that she had a chest infection but I didn't think they'd [hostel] send her out with that sort of thing and with a temperature so I let the taxi go and she wanted to go to the ballet so badly so I took her in which was a big mistake because of the air conditioning...I was really worried about her

breathing...within 2 days she was so sick...I just let it go because I thought this is a one-off.

However, it was not a “one-off” occurrence and after two further similar episodes Jill expressed concern about her ability to provide Louise with the physical care that she needs when they are out together:

I feel I'm out of my depth...I'm nervous now about how long I'm going to be able to take her out and when the time is going to come where I can only visit her at [the hostel]. Now I have to come to terms with that and talk her through that. I'm 65 [and] it's caught up with me.

Jill's other sister, now 70, is also unwell and this compounds the concern both Jill and Louise feel. Louise said:

Her [Jill's] sister has [a degenerative disease] so Jill is up there with her sister. I used to go out more with Jill but when [other sister] got sicker and sicker, I said to Jill “She's your sister so you go up and see what you can do for her. I can look after myself”. Jill comes down [to see me] when she can, when she thinks [other sister]'s stabilised and can be left. Jill is looking after her sister so she can't be in two places at once. People don't realise just until you get somebody as sick as she is but you're all the time, “I wonder if I should do this, I wonder if I should do that?” You're too frightened to move too far from the phone.

Louise thinks Jill tries to protect her from knowing too much about what is going on with her sick sister. However, Louise said not knowing makes her more anxious:

*Jill's not saying [but] I know when it's really bad because she goes to [the hostel staff] which I hate. I've said [to Jill] “Talk to **me**.” She says “There's nothing you can do”. I said, “It's all right to say there's nothing I can do, I*

may not be able to do anything but I like to be told. I don't want to see her [sister who is sick]. I'm getting to the stage where I know if I did see her I'd burst into tears. So I'd rather not put myself through that situation. Leave that situation to somebody that can move. But you've got to talk about it or you'd go up the wall.

As she so clearly articulated, Jill has a very strong sense of her responsibility for Louise.

However, she does not regard her relationship with Louise as one in which she receives support in return:

I can't imagine my life without her but I've never depended on her for support because she's incapable of giving it, doing more than she does. But spiritually, mentally, I've never thought about it. I would say, if the three of us were sitting together she would say "yes" that she is a wonderful support to me. And I believe that's the way she's been brought up, that everything she says and does is a positive thing for other people. But I don't feel that support probably because I've realised since I was 5 years old that I'm responsible for her, she's not responsible for me.

As Jill suspected, Louise does believe that she provides Jill with support:

I think why we're [Jill and Louise] so close is because I know, I know in the back of my mind what's going to happen [to sister who is sick] and somebody has to back her [Jill] up. Back her up means if she's in a hard spot she'll come to me."

The story of Louise and Jill provides an example of a sibling bond that developed between two cousins who lived as, and consider themselves to be, siblings. They provide a reminder that the sibling relationship may be defined more broadly than

sharing the same biological parents. The commitment made by Jill to support both her uncle and her disabled sister Louise is, by her own admission, driven in part by the obligation and sense of gratitude which Jill feels towards them for taking her into their family. However, over the years Jill and Louise developed great warmth and love for each other. With Louise's father now very old and having only occasional telephone contact with Louise, it is Jill who oversees what is happening in Louise's life. Nonetheless, their story also identifies the difficulties that can arise in sibling relationships when both are getting older and finding it difficult to maintain their previous level of contact.

9.3. Discussion

Three themes are illustrated by participants' accounts of middle and older age. The first theme relates to the adjustment which participants have to make to the ill health and eventual death of their parents; the second is the re-adjustment they need to make to the ill health which some participants with cerebral palsy and some of the older non-disabled siblings are experiencing; and the third theme relates to the uncertainty of the future.

9.3.1. Looking towards post-parental roles

Both parents of three participants with cerebral palsy, Kristine, Betty and Bruce, had already died at the time of the interviews. Louise, Oliver, Richard and Helen, had one parent still alive but elderly and experiencing health problems. Both parents of Thomas, Caroline, Philip, Mathew and Rebecca were still alive and some were experiencing health issues. Their parents' health was of particular concern to non-disabled siblings Stephanie, Marilyn and Amelia, as their parents provided full time care for Thomas and Rebecca.

According to Connidis (2001), the ill health and death of parents represents a turning point in the lives of middle-aged adults. Connidis highlighted that during this period siblings typically provide assistance to each other in order to adjust to the resulting change in family dynamics. Indicative of Elder's (1994) concept of linked lives, Goetting (1986), Avioli (1989), Connidis (2001) and Settersen (2004) described siblings as being well placed to support each other through later-life transitions, as they can draw on their shared histories, life experiences, and the affection they typically feel for each other. Furthermore, Walker et al. (2005) described the negotiations that occur between siblings over the support they provide to their ageing parents as involving multiple complex factors emanating from siblings' relationships over their life course.

Regardless of whether their adult son or daughter with cerebral palsy lived with them, parents played a significant role in their lives through the provision of instrumental, social and emotional support. Non-disabled sisters, Lucier (2009) and Handler (2009) discussed the changes in the lives of their brothers with disabilities after the deaths of their mothers who were their full-time carers. Their brothers had moved into supported accommodation and developed new interests and more independent lives. Parental ill health and death was also a major concern for non-disabled siblings in this study, and often provided the catalyst for them to become more involved in the life of their disabled brother or sister.

For example, although Jill had over time taken on a greater role in supporting Louise as her father's health deteriorated, she was fearful about the emotional impact on Louise of her father's death. Kitty, Arthur, and their other two non-disabled siblings found they needed to support Oliver practically and emotionally through their mother's decline due to dementia. Arthur in particular indicated that prior to his

mother's diagnosis he had given little thought to what would happen to Oliver when she was no longer able to care for him. On the other hand, Natalie found it painful and too difficult to discuss their father's death with Kristine, and she reported struggling to find a balance between her own busy life with young children and Kristine's need for emotional support. And, despite their concerns about their parents' chronic health problems, Stephanie and Marilyn felt frustrated in their efforts to talk about the future with their parents and Thomas. Instead they shared their concerns with each other and hoped that their parents' health would hold up for a while longer.

Once their parents are no longer able to support their son or daughter with cerebral palsy, non-disabled siblings must make decisions about if, who, and how they will take over aspects of their parents' support role. Indicative of Connidis' (1994) description of sibling relationships as more voluntary than other close family relationships, and of Elder's (1994) concept of human agency, siblings' decisions were influenced by a complex interplay of variables associated with sibling status. Although the number of participants in this study is small, comments may be made about the findings in relation to these well-documented variables.

There is substantial evidence in the literature that sisters are more likely than brothers to provide support to elderly parents (Connidis, 1994, 2001) and to a sibling with a disability (Bigby, 2000; Grossman, 1972; Harland & Cuskelly, 2000; Hodapp, et al., 2010; Orsmond & Seltzer, 2000). This was borne out by the experiences of non-disabled sisters Stephanie and Marilyn, who were more involved than their brother in supporting their parents and Thomas. Conversely, the support Arthur provided to Oliver was indicative of the same-sex principle described by Orsmond and Seltzer (2000), whereby brothers displayed more positive feelings towards a

brother with a disability than they did towards a sister and were therefore more likely to be involved in providing support to their disabled brother. Conversely, it was Kitty and their other sister who took the lead in arranging their mother's nursing home placement.

Van Gaalen et al. (2008) described the impact of family size on the provision of sibling support to elderly parents. According to van Gaalen and colleagues, the larger the sibling group, the more support can be shared among them. This was evident in the team effort of Oliver's four siblings in supporting both their mother and Oliver. Nevertheless, as Bigby (2000) pointed out, and as demonstrated by Stephanie, Marilyn and Thomas, even when there are several siblings, one sibling often takes on more responsibility for supporting both parents and their brother or sister with a disability, due to factors such as gender and geographic proximity. The benefit of coming from a large family can be contrasted with the situation of Kristine and Natalie who, after the death of both parents had only each other to call on for support.

The geographic proximity of siblings is particularly important when it comes to the provision of personal care and daily support tasks to elderly parents (Connidis, 1994, 2001; van Gaalen, et al., 2008) and to brothers or sisters with a disability (Greenberg, et al., 1999; Horwitz, 1993; Orsmond & Seltzer, 2007; Zetlin, 1986). In this study, Kitty commented on the benefit of her mother's house (and then Oliver's new group home) being geographically close to where she and Arthur lived so they had easy access to provide support. Stephanie jokingly indicated that her sister Marilyn, and their brother who was not interviewed, would be more involved in Thomas' and their parent's future support because they lived closer to them than she did. On the other hand, in part due to geographic distance, Jill was finding it

increasingly difficult to support Louise, her elderly uncle, and her chronically ill sister.

Participants with cerebral palsy ranged from 42 to 65 years of age and their surviving parents were therefore at least 60 years of age, with most in their 70s, 80s and one in his 90s. Compounding the issue of ageing parents and their declining health was the concurrent decline in the health of some participants.

9.3.2. Accommodating sibling ageing and ill health

According to Murphy and colleagues (1995), Crawford (1996), Balandin and Morgan (1997), and Overeynder and Turk (1998), adults with moderate to severe cerebral palsy may experience the effects of ageing earlier than the general population. These authors identified a number of health problems that are likely to appear or to be exacerbated as the person with cerebral palsy reaches middle-age. These include: decreased musculoskeletal function which may result in mobility problems; eating, chewing and swallowing problems presenting a risk of aspiration and resulting pneumonia; gastro-intestinal problems including reflux; decreased bowel and bladder control; speech articulation problems which can affect the person's ability to communicate; and depression and anxiety. Overeynder and Turk warned that these health problems can adversely affect people's functional abilities, in turn potentially resulting in a change in their living and work arrangements.

Kristine, Louise, Betty, Philip, Mathew, Helen and Bruce reported age-associated deterioration in their physical and/or mental health. Kristine was experiencing problems with eating and swallowing, and despite her dislike of having her food pureed she was considering the even more intrusive measure of being fed through a PEG in her stomach. Jill reported that Louise was experiencing respiratory problems, with repeated bouts of pneumonia, and Louise herself reported feelings of

anxiety and depression associated with her concern about the health of Jill's older sister.

Avioli (1989) identified that siblings are typically increasingly unable to provide each other with instrumental support as they age, due to common health problems and frailty. A non-disabled sister, Croser (2009) highlighted the impact of her diagnosis with cancer on her plans to bring her disabled brother to live with her when she retired from work. Graff (2009) and McHugh (2009) provided emotional accounts of coping with the deaths of their disabled brothers. The combination of deteriorating health for the participant with cerebral palsy and age-related health problems for their non-disabled sibling/s has the potential to significantly affect their relationship, as demonstrated by the situation of Louise and Jill. Aged in her mid-60s, Jill reported that she was feeling the physical and emotional strain of spreading her support among her elderly uncle, her older sister and Louise. Indicative of the effect of her age on her stamina and physical strength, Jill had already stopped taking Louise to her home as she could no longer cope with the level of physical care Louise required. Jill said she dreaded the time when she would no longer be able to take Louise to the ballet, an activity they both enjoyed and looked forward to.

With increasing age, as reflected in the experience of Louise and Jill, the nature and extent of sibling contact is likely to change. Connidis (1992) found that sharing later life experiences such as the death of parents and siblings' ill health is likely to strengthen the emotional ties between siblings. Connidis (2001) reported that sisters in particular provide each other with more emotional support as they age, through acting as confidants and companions to each other. Connidis' view confirms the point made by Goetting (1986, p. 709) that "despite reduced contact with siblings...older adults express sentiments of greater closeness and compatibility with

siblings when compared with younger cohorts”. Goetting (1986) and White (2001) argued that the value of the sibling relationship in older age is in the life review process through which siblings play a special role due to their shared earlier life experiences and ability to reflect and reminisce about family events and relationships. Siblings who support each other through the declines of later life, according to Goetting, are crucial in helping each other to maintain self-esteem and control over their lives. According to Goetting (1986, p. 710) “sharing of happy childhood experiences and rewarding interactions in adulthood...appeared to be a major source of comfort and pride” to siblings in later life.

Deterioration in the physical and mental health of parents and siblings is indicative that people’s lives are not static and that the support they provide today might not be provided tomorrow, as matters such as ill health can intervene and disrupt an established or planned support routine. All participants in this study spoke about their concerns for what the future might hold.

9.3.3. What might the future hold?

The future is, of course, unknown and planning cannot be completed. Nonetheless, the future also contains elements of the past and so previous life experiences will have some influence on future life course (Elder, 1974, 1998, 1999). As stated earlier, people with moderate to severe cerebral palsy are living longer and outliving their parents (D. Strauss, et al., 2008). Many people with cerebral palsy have non-disabled siblings with whom they have developed warm and loving relationships, as is illustrated in this study. Seltzer and colleagues (2001), Bigby (1997, 2000) and Heller and Kramer (2009) found that non-disabled siblings of people with an intellectual disability said they intended to take over some of the support roles for their disabled siblings previously performed by parents. Non-disabled siblings Kaiser (2009),

Keprios (2009) and Errante (2009) asserted their commitment to their brother or sister with a disability while at the same time admitting their fears about what the future might hold. Similarly, in this study the non-disabled siblings of participants with moderate to severe cerebral palsy anticipated providing support to their brothers and sisters and, in the majority of cases, this was already occurring. Nonetheless, as parents get older and die, and as siblings themselves experience health problems, people's choices and plans might need to change in response to new circumstances. It is this element of the unknown which is unsettling, and this thesis contributes to the existing literature by identifying some of the issues surrounding future uncertainties.

For example, the position in which Louise and Jill find themselves is indicative of the uncertainty of the future, and both expressed concern about what might happen next. They reported feeling anxious and at a loss to know how to cope with the myriad of family health problems that seemed to be piling up: Louise's father's frailty, Jill's older sister's health, and Louise's declining health.

Kristine and Natalie had responded to the loss of both their parents by becoming emotionally and geographically closer to each other. Nonetheless, 19 years Kristine's junior, Natalie voiced concerns about the increasingly likely scenario of Kristine becoming seriously ill and requiring hospitalisation. Natalie believed that in this eventuality, as Kristine's next-of-kin, it would be her role to make life-or-death decisions on Kristine's behalf. Natalie expressed concerns about what decisions she would make when faced with this situation.

At their initial interviews, Oliver, Kitty and Arthur were unable to look too far into the future as their priority was on the present: settling Oliver into his new group home and working out what their roles would be. By the follow-up interview they were all more confident that Oliver was settled and, while they were realistic that

there would be ongoing issues to be worked through, they were also optimistic that the future included greater independence and self-determination for Oliver. Kitty and Arthur reiterated their commitment to be part of supporting Oliver to take advantage of opportunities in his new environment.

Thomas' sisters Stephanie and Marilyn were very uncertain and concerned about his future and their role in it. Their parents were unwilling to enter into discussions about this, and Thomas' plans for his future were largely unknown to his sisters who each had her own rather pessimistic view about what might happen. Their unresolved fears for the future seemed to be affecting the sisters' current relationship with Thomas, as their concerns for their parents' health and ability to continue caring for him spilled over into their interactions with him.

As identified in Chapter 3, studies in the disability literature have tended to focus on the effect of transitions from parental care later in life on the subsequent living environment of the person with a disability and the role of non-disabled siblings in assisting in the transition (e.g., Bigby, 1997, 2000; Seltzer et al., 1997; Heller, 1998). As the views of the people with a disability were not sought in those studies, their concerns for their future after their parents had died and as they grew older were not represented. So too until the current study there has been little understanding of how siblings with and without disability think their relationship will evolve as they grow older.

Summary

The three results chapters have charted the life course of the 28 participants in this study, demonstrating the importance of the childhood years, the impact of making the transition from childhood to adulthood, and effect of the complexities and concerns of growing older together on their sibling relationships. Interviewing both people with

cerebral palsy and their non-disabled sibling/s has provided insight into the similarities and differences of viewpoints of members of the same family about their relationships.

The findings of this study point to the importance of siblings growing up together in the family home as children, sharing the achievement of transition milestones and the development of personal maturity in young adulthood, and supporting each other through the loss of their parents and their own ageing and ill health, to the development of sibling relationships based on warmth, trust and empathy.

While they expressed varying levels of immediate concern about what the future might hold, the one thing which all the participants in this study had in common was the connection they felt to each other as siblings. The bond between siblings was evident in the way participants spoke about the tangible and intangible benefits they received from their relationships. The bond they felt for each other indicated a commitment to an ongoing role in each other's lives. I have characterised this bond and commitment to each other as indicative of reciprocity, and this concept is explained and explored in Chapter 10.

Chapter 10

Recognising Reciprocity in Sibling Relationships

10.1. Identifying the primary finding

Throughout the process of data analysis I was searching to see if I could identify a concept that might explain why the relationship between participants with cerebral palsy and their non-disabled siblings “held together” or “fell apart” after parents were no longer there to act as the “glue” that held the family together. Two major questions exercised my mind when examining the data. These were (1) Why did not the non-disabled siblings leave the care and support of their brother or sister with cerebral palsy to paid professionals in formal services? and (2) Why was an ongoing relationship with a non-disabled sibling or siblings important to the person with cerebral palsy?

10.1.1. Memo-writing and diagramming

Conducting open and focused coding of the data led to the identification of the three categories, six pathways, and twelve themes presented in the results chapters.

Following on from this coding process I wrote a story about each participant, drawing on the original interview transcripts and my memos. In these stories I captured not only the information about participants’ lives but also my emerging analysis of what had occurred in their lives over time and why it might have occurred. This process helped me to restore the inter-related nature of the data, which had become somewhat fractured during the coding process. It also helped me to think more deeply about

participants as a part of their sibling dyad or triad. From the stories I sketched diagrams of the relationships, capturing the themes within each sibling group. An example of a diagram is included in Appendix 6. The stories and the diagrams helped me to gain a clearer picture of the relationship between the siblings in each dyad or triad and suggested some possible answers to the questions I had been asking throughout the study. Following Strauss' (1987, p. 29) advice, I engaged in a process which he called "stepping away into conceptualisation", to move beyond the individual family stories to understand a more abstracted and larger conceptualisation for the findings from my study.

10.1.2. Developing a conceptual framework

Taking this broader view was a necessary process to account for an overarching theme or concept in the life-course trajectories of the participants. To aid my conceptualisation, I also drew upon the literature to enhance my understanding of the importance of each stage of the life course and the impact on sustaining relationships between siblings.

Through the data analysis process it became evident that there was a sense of obligation on the part of some non-disabled sibling participants (e.g., Jill, Bob and Kristine) to provide support to their brother or sister with cerebral palsy in later life. However, obligation by itself did not explain the mutual sense of connection, love, and respect evident to a greater or lesser extent in the way participants spoke about each other. This appeared to go beyond a sense of obligation on the part of the non-disabled sibling, demonstrating reciprocity in the sibling relationship. As identified in Chapter 3, the reciprocal nature of sibling interactions has been previously noted (Avioli, 1989; Horwitz, 1993, 1994; Horwitz, et al., 1996; Howe, et al., 2001; Howe & Recchia, 2005; M. Seltzer & Krauss, 1993). Following this, I delved deeper into

the literature on reciprocity to explore the concept of reciprocity as it appeared to be operating in the relationships between the siblings in this study.

In my view, an overarching concept found in this study is that over the life course reciprocity may be found in the relationship between people with moderate to severe cerebral palsy and their non-disabled siblings. The existence of reciprocity in these sibling relationships is of particular importance in middle and later life, when parents are no longer as actively involved in the life of their son or daughter with cerebral palsy and sibling relationships may take on greater significance. It is likely that siblings who feel part of a reciprocal relationship will be emotionally closer and more supportive of each other later in life.

Before I present the conceptual framework developed in this study it is necessary to understand what is meant by reciprocity, particularly reciprocity in the context of sibling relationships. The literature suggests that feeling part of a reciprocal relationship can enhance self esteem, increase satisfaction, and give an overall sense of wellbeing (Horwitz, et al., 1996; Molm, Schaefer, & Collett, 2007). Furthermore, according to Connidis (2001) and Goetting (1986), feelings of satisfaction and contentment with relationships in middle age are likely to contribute to a happier and healthier old age. As my study did not assess participants' self-esteem, satisfaction, or wellbeing it is impossible to state whether these attributes developed for participants or not. Nonetheless, the results point to the development of reciprocity between siblings over their life course, and feeling part of a reciprocal relationship with one's siblings might contribute to the quality of this relationship in later life. As the oldest non-disabled sibling who participated in this study, Bruce's sister Charlotte encapsulated this quality of reciprocity when she said:

We're here if he [Bruce] wants us or [if] something needs doing we'll go and help him out with it but he's pretty independent really. He doesn't tell us half of what goes on I don't think because he wants to be independent, which is great. But if he needs us we're here and vice versa, if you wanted him [to do something] he would do it, no problems. We never really think of him as having a disability. We've grown up with him like it and you know he's just one of the family and we all love him.

10.2. Reciprocity defined

Antonucci and Jackson (1989, p. 84) defined reciprocity as the “equal or comparable exchange of tangible aid, emotional affection, advice, or information between individuals in return for benefits received.” Molm et al. (2007, p. 199) described reciprocity as “the giving of benefits to another in return for benefits received.” These definitions reflect the assertion by Laursen and Bukowski (1997) that reciprocity in some form is a fundamental element in all human relationships.

Because of the inherently important and long-lasting nature of the bond between siblings, we would expect reciprocity to be found between brothers and sisters. However, in the literature to date, reciprocity has not been identified in the sibling relationships of people with moderate to severe cerebral palsy and their non-disabled siblings. This lack of recognition of reciprocity may be due to the focus on the physical impairments of the person with cerebral palsy, a focus that predisposes towards a view of disabled individuals as recipients rather than givers of support. Yet the findings of this study indicate that reciprocity is an important element in the relationships that develop between people with moderate to severe cerebral palsy and their non-disabled siblings. Gottlieb (1985) suggested that it was a mistake to make the assumption that reciprocity is the same in form or focus for all people and in all

relationships. Due to the physical impairments of the individuals with cerebral palsy who participated in this study, reciprocity was considered in its widest sense encapsulating both practical and esoteric values.

10.2.1. The norm of reciprocity

Gouldner (1960) described the “norm of reciprocity” as a universal and principal component in social life. He distinguished between the social exchange properties then commonly termed “reciprocity” and his hypothesis that reciprocity operated as a general moral norm. According to Gouldner, reciprocity as a pattern of exchange explained how people, through mutual dependence, gave and received goods and services. In addition to the goods and services they received, people gained mutual benefit from the exchange. Gouldner proposed, however, that there was a higher moral norm of reciprocity operating as a general obligation that motivated people to reciprocate and that operated beyond the level of specific benefit. The existence of the higher moral norm meant that people tried to balance reciprocity in their relationships so that they avoided over-benefiting (and to a lesser extent, under-benefiting) in their relationships with others.

Writing in 1960, Gouldner excluded people who he perceived as being dependent on others, stating “clearly the norm of reciprocity cannot apply with full force in relations with children, old people, or with those who are mentally or physically handicapped” (, p. 178). At that time, and perhaps not surprisingly given attitudes towards people with disabilities, people with a chronic lifelong disability such as cerebral palsy were perceived as incapable of reciprocating the support they received from others. Indeed, Gouldner’s assumption that people with a disability were excused from the moral norm to reciprocate might be one reason why no

attention has been given to reciprocity in relationships between people with a disability and their family members, including siblings.

10.2.2. Generalised reciprocity

Much has been written about reciprocity since Gouldner's seminal theoretical paper in 1960. Building on Gouldner's work there has been general acceptance in the literature of the existence of a moral norm of reciprocity which overlies the practical aspects of returning favours received from others. The notion of reciprocity is also now closely linked to the literature on social support. Most significantly, over the past 30 years, Toni Antonucci has written extensively about reciprocity in social relationships (Antonucci, 1985, 1990; Antonucci, Akiyama, & Takahashi, 2004; Antonucci, Fuhrer, & Jackson, 1990; Antonucci & Jackson, 1989; Kahn & Antonucci, 1980). Antonucci and colleagues drew on data from several large national surveys in the U.S. to examine social networks and social support (Antonucci, 1985; Kahn & Antonucci, 1980). From analysis of these data, Antonucci and colleagues developed the concept of people building a "convoy of social support" over their lifetime on which they could draw in times of need (Antonucci, 1985, p. 97).

Antonucci and Jackson (1989) applied this convoy concept to their study of reciprocity in older age and found that the convoy was particularly relevant to older people. According to Antonucci and Jackson, as older people's ability to provide assistance to others decreased due to frailty and ill health, they were able to call upon the deposits they had made throughout their lives into their "social support bank" to provide them with help when they required it (Antonucci & Jackson, 1989, p. 86). At the heart of the convoy are those people who are emotionally close and therefore most important to the individual (Antonucci, et al., 2004). These people are usually, but not exclusively, family members including siblings (Antonucci, 1985). Among close

family members Antonucci (1990) described a generalised form of reciprocity whereby, due to the ongoing nature of the relationships, reciprocity need not be either immediate or in kind but rather may be delayed or deferred. While building on Gouldner's (1960) description of the norm of reciprocity, Antonucci and colleagues also challenged Gouldner's view that older people were excluded from this norm.

Additional criticism of Gouldner's exclusion of people with a disability from the norm came from Horwitz (1994), who introduced the possibility that reciprocity might operate between siblings where one has a mental illness. In his study, Horwitz asked non-disabled siblings about reported help over the previous year, willingness to help, including motivation and ability, and hypothetical help in the future if necessary. A range of scales was used to measure obligation, reciprocity and affection. Despite a seeming imbalance in the relationship between people with mental illness and their non-disabled siblings which could impede the disabled person's capacity to reciprocate, the central finding of Horwitz's study was that reciprocity was important in creating bonds between people with a mental illness and their non-disabled siblings. According to Horwitz, if the non-disabled siblings perceived that their disabled brother or sister reciprocated help by giving affection, presents, and helping with chores, they felt more inclined to continue or increase the help they provided.

In a subsequent study, Horwitz et al. (1996) described the generalisation of reciprocity between family members occurring not only across the life course, as proposed by Antonucci, but also across different types of services. Horwitz and colleagues recognised that people with mental illness might not be able to reciprocate in the same way as other family members but may make other contributions which are valued by their family members and perceived as reciprocal acts. According to the authors, this allowed the person with a mental illness and the family members to view

their relationships as balanced rather than one-sided. The claim that people with a mental illness and their non-disabled siblings could achieve balanced reciprocity challenges the statement made by Seltzer and Krauss (1993, p. 103) that:

When there are long-term inequalities in the sibling relationship [e.g., when one sibling has a disability]...either siblings become estranged from one another, as with negative reciprocity, or the siblingship takes on characteristics of generalized reciprocity, as with a parent-child relationship.

The findings of generalised and balanced reciprocity in the studies of Horwitz and colleagues are relevant to the current study. Because of their physical impairments, individuals with cerebral palsy might not be able to reciprocate with a similar type of help as that offered by their nondisabled siblings, but nevertheless they may make other valued contributions to their sibling relationships.

Along with the recognition of a moral norm of reciprocity and its generalised nature, a debate has emerged in the literature as to what motivates family members to reciprocate the help they receive from others. There are two schools of thought on this: family members reciprocate due to a sense of obligation or due to a sense of altruism.

10.3. Motivation to reciprocate

10.3.1. Obligation to reciprocate

According to the life-course view of reciprocity described by Antonucci and colleagues, family members provide assistance and support to each other due to their sense of familial obligation. Highlighting the powerful effect of obligation on behaviour, Antonucci (1990) suggested that if family members did not provide

support when it was needed other family members viewed this action negatively, whereas when support was provided it was considered “merely appropriate” (p. 215).

Similarly, Connidis (2001) attributed the reciprocity between siblings to “a strong sense of obligation to other family members” (p. 236). Nonetheless, as Connidis (2001) pointed out, not all siblings feel an obligation to support their brother or sister. Furthermore, in old age in particular, the support between siblings is more likely to be social and emotional rather than instrumental. Connidis described the more voluntary nature of adult sibling relationships (compared to the less voluntary relationship between parents and their children) as indicative of the choice siblings make about whether to maintain contact with, let alone provide support to their brothers or sisters. According to Connidis, whether or not siblings like each other might be just as important in determining whether siblings will provide support to one another as the fact that they *are* siblings.

A number of researchers in the disability field describe the motivation of non-disabled siblings to provide support to their brother or sister with a disability as due, at least in part, to a sense of familial obligation particularly towards their parents rather than to their personal feelings towards their disabled brother or sister (e.g., Harland & Cuskelly, 2000; Jewell & Stein, 2002; Rimmerman & Raif, 2001; Taylor, et al., 2008). In the Harland and Cuskelly (2000) study reviewed in Chapter 3, the authors reported that siblings were motivated to provide current and future social and emotional support to their brother or sister with a sensory disability primarily through a strong sense of familial obligation. A heightened sense of responsibility felt by non-disabled siblings towards their brother or sister with a disability was also mentioned by Rimmerman and Raif (2001) in their Israeli study with 76 adult siblings with a brother or sister with intellectual disability aged 40 years and over. Using

questionnaires to obtain information during interviews, the authors proposed that the sense of obligation felt by non-disabled siblings was due to parental and societal expectations which dictated that they should provide future support to their brother or sister with a disability regardless of their personal feelings towards them.

Similarly, in their study of 111 non-disabled siblings of people with mental illness in the U.S., Jewell and Stein (2002) reported that when considering the future care requirements of a brother or sister with a mental illness, “family needs and obligations take precedence over personal relationship factors” (p. 29). Also in the U.S., Taylor and colleagues (2008) reported that among the 268 non-disabled siblings of people with a mild intellectual disability who participated in their study (average age 63.93 years), older age non-disabled siblings’ relationships with their brother or sister “may better be characterized by norms of obligation rather than feelings of closeness” (p. 912).

The studies by Harland and Cuskelly (2000), Rimmerman and Raif (2001) and Jewell and Stein (2002) all demonstrate that obligation is a powerful motivator for providing support to a brother or sister with a disability. In the current study, some non-disabled siblings also spoke about a sense of obligation to reciprocate their parents’ lifetime care and support by providing assistance to their brother or sister with cerebral palsy. For example, Jill spoke about the sense of obligation she felt to reciprocate the support Louise’s mother and father had given her by taking her into their family when she was orphaned as a child. The way Jill returned this earlier support was by becoming Louise’s guardian. The relationship between Jill and Louise is also an example of generalised reciprocity, as Jill reciprocated her uncle and aunt’s caring for her in childhood by providing their disabled daughter, Louise, with social and emotional support later in life.

Amelia felt a cultural and familial obligation to have her sister Rebecca come and live with her when their Italian parents were no longer able to care for her. This was a commitment that Amelia had made to her parents; it existed as a plan for the future which was acceptable to Amelia and her parents but did not seem to be acceptable to Rebecca.

As only siblings, Amelia and Natalie expressed a sense of obligation to maintain family continuity through contact with and assistance to their sisters with cerebral palsy, Rebecca and Kristine. The sense of obligation by non-disabled siblings appeared strongest when parents had already died, as was the case for Natalie, Bob, Derek and Charlotte. Natalie spoke about the promise of ongoing contact with Kristine which her father had sought from her prior to his death. As the eldest in the family, Bob recognised his obligation after their mother's death to maintain contact with Betty and to oversee the formal support services she received. Part of Bob's obligation was to maintain the link between Betty and their other three brothers. Similarly, as the eldest sister and geographically closest sibling to Bruce, Charlotte indicated her commitment to ensure that he was able to live independently for as long as possible after their mother's death. She did this by helping him read his mail, pay his bills, and generally assisting him with other tasks he found difficult because of his physical impairment.

Margaret spoke about the sense of guilt she carried that it was Caroline who had cerebral palsy, and not her. In response to these feelings Margaret acknowledged the obligation she felt to live her life in a certain way, in particular to be grateful she was independently mobile. Undoubtedly, a sense of obligation to reciprocate their parents' help motivated some non-disabled siblings to assist their brother or sister with cerebral palsy. Alongside this sense of obligation on the part of non-disabled

siblings, in each of the sibling relationships, there was a strong sense of liking and valuing each other. This suggests that their ongoing relationships were not based entirely on obligation. Liking each other is linked to an emotional bond between siblings; in the literature this is thought to be indicative of an altruistic motivation to reciprocate.

10.3.2. Altruistic motivation to reciprocate

Altruism rather than obligation provides an alternative rationale for the motivation of reciprocity in adult sibling relationships. In proposing her theoretical model on the social support functions of siblings in later life, Avioli (1989) claimed that siblings provided each other with support due to their emotional bond rather than to a sense of obligation. Indeed, according to Avioli, the idea that siblings were there to support each other was of greater benefit than any actual support received from siblings. Avioli (1989, p. 52) wrote, “Although rarely called upon for instrumental aid, there is comfort and satisfaction in knowing that a sibling is there”. Avioli additionally suggested that a major component of the reciprocity experienced between siblings was supporting the personal autonomy of the sibling rather than being linked to their interdependence. According to Avioli, a sibling had knowledge of a brother’s or sister’s capabilities, based on past experience, and could remind the sibling of this when they were in need of support. Avioli’s view emphasised the importance of emotional aspects, rather than focusing on possible practical support in contributing to the reciprocity in sibling relationships.

Providing empirical evidence to support Avioli’s assertion as to the importance of altruism in the reciprocity between adult siblings, De Jong Gierveld and Dykstra (2008) studied the association between loneliness and support within families. They used self-completion questionnaires to gather data from the first wave

of the Netherlands Kinship Panel Study with adults aged 45-79 years ($N = 727$). Based on descriptive and multivariate analysis of the data, De Jong Gierveld and Dykstra described the generalised qualities of the sibling bond which resulted in siblings not expecting reciprocation from their brother or sister. Rather, they proposed that reciprocity was based upon friendship between siblings and was indicative of altruism. According to De Jong Gierveld and Dykstra, altruism theory highlights the rewards, not just the costs inherent in giving support.

In her study of sibling relationships for people with an intellectual disability, Zetlin (1986), identified warmth, along with frequency of contact and degree of involvement as important relationship dimensions. Zetlin identified a feeling of warmth towards a sibling as a primary factor in engaging in frequent contact and having a greater degree of involvement. This suggests that a feeling of warmth which, according to Howe et al. (2001), is developed between siblings from childhood, is likely to be an important indicator of siblings maintaining an ongoing relationship in later life.

In the current study, the majority of participants who had lived together in childhood and shared common experiences growing up reported a strong sense of knowing and liking each other as individuals. They spoke about playing together and sharing common experiences in childhood, which built enduring sibling bonds. For example, Rebecca and Amelia reminisced about the activities they liked doing together in childhood; Margaret spoke about playing games involving Caroline; Marilyn remembered Thomas teaching her how to dive into the family swimming pool after watching this on TV; Kirsty recalled Mathew sitting in his wheelchair holding the hose while she and her friends ran through the water. In contrast, non-disabled siblings such as Bob, Derek, Natalie, Jill and Harry, who did not grow up

with their brother or sister with cerebral palsy, were unable to relate detailed incidents about their daily life together in childhood and did not have shared childhood memories.

Despite the difference in childhood experience, all participants with cerebral palsy and their non-disabled siblings indicated their warmth and affection for each other. Ruth gave examples of the sense of humour she shared with Richard; Caroline and Margaret spoke about each other's intrinsic qualities of loyalty and courage; Helen and Isobel declared their affection and admiration for each other; Kirsty described the playful bantering in which she and Mathew engaged; Oliver, Kitty and Arthur spoke emotionally about coming to a greater understanding of each other by supporting each other through traumatic family circumstances. When I listened to the way participants described their siblings, their love and respect for each other was evident. It is possible that the sampling strategy adopted in this study recruited participants who had more positive relationships with each other than with their other siblings, if the latter did not want to be interviewed, or with others who were not suggested for this study.

In this study obligation and altruism did not appear to be mutually exclusive. Both provided motivation for siblings to reciprocate the help they received from each other. According to Connidis (2001), support in sibling relationships is typically viewed as more voluntary and less obligatory than in relationships between parents and their children or between spouses. However, as indicated by Murphy and colleagues (1995), when one sibling has moderate to severe cerebral palsy, the physical impairments may necessitate additional assistance with personal care and other activities. This greater need for support may "shift the balance" between siblings such that a non-disabled sibling may feel an heightened obligation to support

the disabled brother or sister (Taylor, et al., 2008). Providing this support may also be perceived as a way of “paying back” their parents for the support they have provided in the past. Although this may be an element in sibling relationships, the present study indicates that the warmth developed between siblings over their life course and their altruistic feelings towards each other also motivated their desire to engage in reciprocal interactions with their brothers and sisters. Motivation to give and receive help is one aspect of, and is linked to, the value that both givers and recipients perceive they get from their reciprocal interactions.

10.4. The value of reciprocity to a relationship

There is general agreement in the literature that the value of reciprocity can be broadly divided into two aspects: a practical value and an “esoteric” value. The term “instrumental” has been used by Antonucci (1985, 1990), Avioli (1989), Connidis (1994), Goetting (1986), Horwitz et al. (1996) and Molm et al. (2007) to describe the practical aid and direct services exchanged between relationship partners.

Various terms have been used to describe the esoteric attributes of reciprocity. For example, Goetting (1986) used the terms “companionship and emotional support”, Avioli (1989) and Antonucci (1985, 1990) both used the social psychological term “affective”, Connidis and Davies (1992) wrote about “expressive” reciprocity, and Horwitz et al. (1996) and Molm et al. (2007) used the term “symbolic” to describe the emotional and social attributes of reciprocity.

A distinction must be made at this point between “reciprocity” and “support”. The terms instrumental and affective are used to describe both the type of support provided *to* people and the reciprocal interactions *between* people. According to Bigby (2000), instrumental support is tangible, direct assistance whereas affective support includes companionship, social interaction, and expressions of interest and

concern. A person might require and be provided with instrumental and/or affective support by family members, including siblings. However, as indicated by Gouldner (1960), the help they receive might not be *reciprocated* and the caregiver might not expect reciprocation. Reciprocity relates to the relationship *between* people rather than to the act of providing support, which may be one-way. There is ample evidence in the literature that non-disabled siblings are more likely to provide affective support (social and emotional) to their brother or sister with a disability rather than instrumental support (e.g., Bigby, 1997; Bigby, 2000; Nolan, Grant, & Keady, 1996; Prosser & Moss, 1996).

Due to their physical support needs, participants with cerebral palsy in this study required varying levels of instrumental support, which they received from a range of sources, such as their parents, non-disabled siblings, friends and paid carers. The reciprocity that developed over their life course between the sibling pairs in this study was distinct from this support. To describe the concept of reciprocity found between participants in this study I have drawn on the terminology and explanations used by Horwitz (1994, 1996) and Molm et al. (2007), based upon earlier work by Ekeh (1974), Haas and Deseran (1981) and Macneil (1986), of instrumental and symbolic reciprocity.

Horwitz' work (1994, 1996) is particularly relevant to this study due to its focus on the non-disabled siblings of people with a disability, albeit mental illness rather than cerebral palsy. There are significant differences between the two groups in terms of the type of support they may require. Nonetheless, using Gouldner's (1960) definition of reciprocity, those with mental illness and those with cerebral palsy would both be excluded from an expectation of reciprocating the support they receive from others. However, Horwitz' findings indicate that reciprocity was an

important element in non-disabled siblings committing to an ongoing role in the life of their disabled brother or sister, and it seems from this study that the same can be said for the non-disabled siblings of people with cerebral palsy.

The second study on which I have drawn to describe the value of reciprocity in the relationship between people with cerebral palsy and their non-disabled siblings is that by Molm et al. (2007), which was not concerned with disability or siblings. In an experimental-design study, Molm and colleagues recruited 48 undergraduate students to test a series of hypotheses about the value people attributed to reciprocal actions. Blinded to the intention of the study, the students were asked to respond to actors simulating constant or intermittent reciprocal behaviour. The authors identified the value of reciprocity in a relationship as operating in two ways: the instrumental value which was the actual benefit received from exchanging goods and services, and the communicative or symbolic value which operated over and above the instrumental benefits and related to the mutual trust, regard, and respect which people received and gave within long-standing, voluntary relationships. Molm and colleagues' description of instrumental and symbolic reciprocity accorded with the reciprocal interactions I identified between siblings who participated in this study.

10.4.1. Instrumental Reciprocity

According to Molm et al. (2007), the value of instrumental reciprocity lies in the actual benefits that a person receives from an exchange with another person. A close, long-term relationship is not necessary for instrumental reciprocity to exist between people; nonetheless, instrumental reciprocity does exist in familial relationships such as those between siblings.

Connidis (1994) examined the social support networks of 528 adult siblings aged 55 years. Drawing on conceptual work by Goetting (1986), Avioli (1989), and

Antonucci (1990), Connidis interviewed participants about three instrumental support functions identified as likely to be performed by adult siblings: (1) help when ill, (2) financial assistance, and (3) help with other things (including tasks such as housework, transportation and shopping). In keeping with Cantor's hierarchical compensatory model (1979), Connidis reported that siblings who had other close network members provided very little instrumental support to each other, preferring instead to ask their spouse and/or adult children for support. Nonetheless, Connidis identified a perception among siblings that their brothers and sisters were available and willing to help them if they required support, particularly in the case of a crisis. Connidis' findings confirm Avioli's (1989) statement reported earlier that a major benefit of having siblings in older age is the knowledge that they are available, over and above any actual assistance they might provide.

For participants in this study, instrumental support of varying levels was provided by most non-disabled siblings to their brothers or sisters with cerebral palsy. However, the reciprocation of instrumental support was indicated for only a few sibling dyads. For example, there was instrumental reciprocity between Bruce and Charlotte. Charlotte read Bruce's mail and helped him with paying bills and attending doctors' appointments. In return, Bruce drove Charlotte to appointments and kept an eye on her house when she and her husband went away. Similarly, Amelia noted that during Rebecca's annual visits she liked to do the dishes as a way of helping out. Isobel said that when Helen came to visit her Helen helped by getting on her motorised scooter and taking the dogs for long walks. Arthur, reflecting on the change in Oliver's life since his move into a group home, said that on Oliver's last visit to watch football with him, Oliver had bought a cake to share. As with the non-disabled siblings interviewed in Horwitz' (1994) study, the reciprocity inherent in

these exchanges was acknowledged by the non-disabled siblings in this study as examples of their brother's or sister's contribution in practical ways to their relationship. Apart from Oliver (who required the assistance of a paid support worker to buy the cake), the other participants with cerebral palsy mentioned above had less severe physical impairments, which meant they were able to give some degree of instrumental help to their non-disabled siblings.

In keeping with the findings of Connidis (1994) and Horwitz and colleagues (1996), the majority of participants with cerebral palsy appeared not to reciprocate the instrumental support they received from their non-disabled siblings. In part this was due to their significant physical impairments, but it seems that it is also reflective of the general findings of low instrumental reciprocity among adult siblings. For the majority of participants, instrumental support was provided by non-disabled siblings to the person with cerebral palsy with no expectation of reciprocation. For example, Margaret helped Caroline and her husband by performing many practical daily tasks for them such as changing light bulbs, and she was there in emergency situations such as when a hoist was required. Because of Caroline's significant physical impairments Margaret did not expect her to reciprocate the practical assistance she gave. Because reciprocity was not specifically asked about during the interviews, instrumental reciprocity between participants may have been underestimated.

Instrumental support was also provided to participants with cerebral palsy by paid service providers. For example, Kristine, Louise, Richard, Betty, Philip, Mathew and Oliver all lived in supported accommodation where paid staff provided the bulk of their instrumental support, although this was often supplemented by additional help from parents and increasingly, non-disabled siblings. For Kristine, Bruce and Betty, whose parents had already died, increased paid support for instrumental tasks

compensated for the loss of this aspect of parental support. As staff members were paid to deliver these services reciprocity was not expected in these relationships. Offering instrumental reciprocity to their non-disabled siblings might have been difficult, sometimes not possible, or perhaps not considered by some participants with cerebral palsy. Nevertheless, the motivation to conform to the moral norm of reciprocity meant that they sought other ways to contribute to their relationship with their siblings.

10.4.2. Symbolic Reciprocity

According to Molm et al. (2007), the symbolic value of reciprocity operates over and above the instrumental value and develops between people over time as a result of voluntary exchanges of benefit.

Within the disability literature, Horwitz (1994) concluded that symbolic reciprocity existed in the relationship between siblings where one had a mental illness. Horwitz proposed that together (1) the norms of kin obligation, (2) reciprocity, and (3) relational quality would mutually reinforce sibling bonds and predispose non-disabled siblings towards supporting their disabled brother or sister. Horwitz found that reciprocal acts on the part of people with a mental illness towards their non-disabled brother or sister were important in promoting the bond between siblings. In a subsequent study, Horwitz and colleagues (1996) reported that siblings with and without mental illness provided more symbolic than instrumental support. Horwitz's results support Connidis' (1994) claim that symbolic reciprocity appears to be more common than instrumental reciprocity between siblings, a feature which was also found in the present study.

Among most participants in this study reciprocity was seen to be operating at the symbolic level as described by Horwitz (1994, 1996) and Molm et al. (2007).

Participants with cerebral palsy and their non-disabled siblings demonstrated symbolic reciprocity by drawing upon the sense of continuity, the solidarity, affection and reliance which had developed between them over their life course, to help them to support each other through the transition from parental support. As an example of the strong emotional bonds which the siblings felt for each other, they all spoke about their regard and affection for each another. Many participants spoke about providing each other with social and emotional support.

Molm et al. (2007) identified symbolic reciprocity as comprising two elements, uncertainty reduction and expressive value. For example, in this study Caroline spoke of Margaret as being reliable. Caroline knew she could depend upon Margaret to come to her assistance in times of crisis (e.g., when the hoist was needed) as well as during the good times (e.g., going out together for coffee). In turn, Margaret relied upon Caroline, in her role as older sister, to provide her with emotional support during difficult times in her life (e.g., when her teenage daughter was causing her distress). Margaret appreciated that Caroline, in contrast to other family members, always remembered her children's birthdays by sending a card. The social and emotional support which these sisters provided to each other was highly valued by each, indicating symbolic reciprocity in this sister relationship.

Symbolic reciprocity was also evident in the relationship between Mathew, Therese and Kirsty. The activity of writing a family memoir was important in the connection between Mathew and Therese which had developed in recent years since Kirsty moved away and Therese's children had grown up, enabling her to have more time to spend with Mathew. Mathew saw sharing this activity with Therese as a way of ensuring her ongoing involvement in his life; Therese in turn said that this activity provided her with a reason to spend time with Mathew and to get to know him better.

Therese and Kirsty noted they had also developed a closer relationship with each other than they had growing up, through working together and talking about their role in Mathew's life.

According to Molm and colleagues, symbolic reciprocity results from voluntary (rather than paid) exchanges of benefit which are built between people over time and, in the case of siblings, over a lifetime. This resonates with Elder's (1994) concept of linked lives. For example, despite living separately all their lives, Kristine and Natalie spoke about sharing an emotional connection which had strengthened since the death of their parents and was largely based on their recognition of the important role they played in each other's lives as each other's only sibling. Natalie acknowledged that despite her own family demands, the contact she maintained with Kristine was due to their shared sibling bond. Again, despite Philip and Harry seeing each other only occasionally growing up, they developed a close emotional bond which meant that they were now in regular contact with each other by telephone, supplemented by annual visits. Kristine and Philip's situations indicate that while paid carers meet the instrumental support needs of people with cerebral palsy, their siblings provide the emotional support which is inherent in the concept of symbolic reciprocity as described by Molm et al. (2007).

Molm and colleagues (2007) also identified that instrumental acts of reciprocity within a relationship can develop a symbolic value. The experience of Oliver and his non-disabled siblings Kitty and Arthur are an example of this. When their mother was no longer able to care for Oliver his siblings took over the significant instrumental tasks which she previously performed. Performing these intimate care tasks for Oliver in adulthood, Kitty and Arthur built upon their shared experiences of living with Oliver throughout childhood to develop greater empathy

for, and an understanding of Oliver's needs and wishes. From Oliver's perspective, he recognised that his siblings were reliable and would continue to care for him after their mother was no longer able to and he had moved into the group home. In the first few months after their mother had been admitted to a nursing home, the focus for Kitty, Arthur and their other non-disabled siblings was to ensure that Oliver's instrumental care needs were met. However, once they were no longer responsible for providing for Oliver's personal care, they continued to care in other ways indicative of the symbolic value of the reciprocity that existed in their relationship with each other and with Oliver. Arthur spoke about his hopes for his relationship with Oliver in the future as two brothers who, rather than having their interactions focused on meeting instrumental needs, enjoyed spending time with each other. From his own perspective, Oliver commented that he enjoyed the time he spent with his siblings engaged in shared leisure activities, such as going out for meals or watching football and horse racing.

For some sibling pairs in this study, their feelings for each other appeared not to be, in their view, indicative of reciprocity. For example, Jill denied that she received emotional support from Louise, despite Louise's feeling that Jill turned to her for this support. Rather than viewing this exchange as indicative of reciprocity, Jill focused on her sense of responsibility and obligation to provide Louise with ongoing support regardless of her own situation. Louise, on the other hand, reported the satisfaction she gained from her belief that she provided Jill with emotional support.

The current relationship difficulties between Thomas and his sisters Stephanie and Marilyn made it difficult for them, at this stage, to know what role they would play in Thomas' life. They believed that Thomas relied too heavily on their parents

and in so doing was distancing himself from his siblings. Nonetheless, Stephanie and Marilyn stated their willingness to provide Thomas with support in the future when their parents could no longer do so, and Thomas spoke about a role for his siblings in his future life. It is not possible to foresee whether reciprocity will develop eventually for Jill and Louise, and for Thomas and his sisters. The ongoing and developing nature of sibling relationships, particularly in the absence of parental care and involvement, does offer the possibility of reciprocity developing over time.

10.5. Conceptual framework for recognising reciprocity

I brought together the categories, pathways, and themes described in the results chapters, along with my theoretical understanding of reciprocity detailed in this chapter, to develop a conceptual framework for recognising reciprocity in sibling relationships when one sibling has moderate to severe cerebral palsy. Four factors form the basis of this conceptual framework: (1) contact, (2) shared experiences, (3) parental status and role, and (4) support needs.

10.5.1. Contact

Ongoing contact between people with cerebral palsy and their non-disabled sibling/s is likely to be crucial to the development of both instrumental and symbolic reciprocity. Howe et al. (2001), Sanders (2004) and Kramer and Conger (2009) identified the importance of sharing the home environment in childhood on the development of strong sibling relationships. According to these authors, and others including Drapeau et al. (2000) and Conger et al. (2009), living together is not a guarantee of siblings remaining in contact with each other. However, children who share the family home are more likely to have ongoing contact with each other throughout life than children separated from their brothers or sisters in childhood.

The experiences of participants in this study reflect this premise. Betty, Kristine, Philip and Louise, all of whom left home in childhood to attend a specialist boarding school for children with cerebral palsy in the city, reported less regular face-to-face contact with their non-disabled siblings than the participants with cerebral palsy who lived together in the family home as children.

As described by Zetlin (1986), Orsmond and Seltzer (2007), and van Gaalen et al. (2008), contact between siblings in adulthood is affected by their geographic proximity to each other. Adult siblings who live geographically close, by choice or happenstance, are more likely to provide each other with instrumental, social, and emotional support and to have opportunities to reciprocate this support. People with moderate to severe cerebral palsy and high support needs require high levels of support, particularly as they grow older, and non-disabled siblings who live geographically close are more likely to be involved in contributing to this.

Eight of the 12 participants with cerebral palsy had at least one non-disabled sibling within a 1-hour drive, with five sibling dyads or triads living within a 5-minute drive of each other. As described by van Gaalen and colleagues (2007) and illustrated in this study by Charlotte, Margaret, Kitty and Arthur, geographic proximity is necessary for the provision of instrumental support. At the opposite end of the spectrum, Helen and Isobel lived in different countries and both spoke about the importance to Helen of having friends and paid support people who compensated for the lack of family help due to geographic distance. Despite the geographic distance, however, and based on their shared experiences in childhood and their mutual regard, symbolic reciprocity was evident in their relationship.

With the exception of Natalie, who chose to move closer to Kristine after their father's death, the non-disabled siblings of the other three participants who had

moved out of the family home in childhood lived some hours drive away from their brother or sister with cerebral palsy. This was because Betty, Philip and Jill continued to live in the city as adults while their non-disabled siblings remained living in a regional area. Geographic distance throughout their lives seemed to have an impact on the expression of instrumental and symbolic reciprocity, which was less evident in the relationships between these participants.

For some participants who lived a considerable distance away from each other the communication difficulties of the person with cerebral palsy exacerbated the problem of keeping in touch. For example, due to Betty's hearing loss and lack of speech, neither she nor her brothers could pick up the telephone and ring each other for a chat. Contact between Betty and her brothers was therefore channelled through Betty's support workers. Similarly Louise, who lived in a hostel with a number of other people, commented that information from Jill about her other sister's health was often relayed to her by the staff who Jill spoke to on the telephone. Possibly due to a combination of separation in childhood, geographic distance, and communication difficulties in adulthood, the siblings of Betty and Louise felt that their sisters did not reciprocate the support they provided. On the other hand, five participants with cerebral palsy could (sometimes with the assistance of others) use telecommunications to keep in touch with their geographically distant non-disabled siblings. Helen, Philip, Caroline, Rebecca and Mathew spoke to their siblings by telephone and Helen, Caroline and Mathew also used email and SKYPE to keep in touch with siblings living interstate or overseas. With the exception of Rebecca, whose parents initiated contact with Amelia, these participants all took responsibility along with their non-disabled siblings of keeping in touch with each other. For the

non-disabled siblings, this indicated that their brother or sister with cerebral palsy was indeed reciprocating contact.

Face-to-face contact between siblings appears to increase the likelihood of reciprocity and instrumental, social, and emotional support between siblings. In the absence of face-to-face contact, keeping in touch with geographically distant siblings can be facilitated by the use of telecommunications and social and emotional support, and reciprocity can be fostered through these media. Associated with contact between siblings is the sharing of lifetime experiences.

10.5.2. Shared experiences

Goetting (1986), Avioli (1989) and Connidis (2001) have discussed the importance to older siblings of sharing experiences throughout life. Howe et al. (2001) highlighted shared experiences in childhood as providing the foundations for the sibling relationship in later life. Goetting (1986) identified shared reminiscences as one of the most important roles of siblingship in old age. Participants in this study showed how the sharing of experiences throughout life had a positive impact on their relationships with their siblings at all stages of their lives, and particularly as they grew older.

As described in Chapter 7, the decisions participants' parents made about where the family would live and whether their child with cerebral palsy would remain living with the family or leave home to live in a specialised boarding school had an impact on the participants' opportunities to share foundational early life experiences. Howe and Recchia (2005) described childhood play as the earliest reciprocal relationship between siblings, through which they learn how to negotiate later life relationships. Participants who lived together in childhood recounted fond memories of playing together in childhood. The non-disabled siblings Marilyn, Margaret, Ruth,

Isobel and Kirsty all talked about how, from a young age, they recognised that their brother or sister had physical impairments which restricted them from participating fully in all activities. Nonetheless, as children they found ways around these difficulties, for example in the case of Margaret and Caroline by incorporating the equipment required by Caroline into their play. As discussed in the literature and borne out by this study, the reciprocity inherent in the play between siblings leads to prosocial attributes which are likely to be important in preparing siblings both with and without disability for the transition to adulthood.

Chapter 8 identified the importance in young adulthood of sharing transition milestones and building personal qualities indicative of adult status. Some participants with cerebral palsy shared with their non-disabled siblings getting a job, moving out of home, and marrying. Participants' high physical support needs meant that they often needed the assistance of paid support workers and family members to achieve these transition milestones. Sharing transition milestones and developing personal qualities of adulthood also enhanced feelings of symbolic reciprocity between siblings.

Rebecca and Thomas continued to live with their parents into middle age. Louise, Kristine, Betty and Philip continued to rely on the specialist cerebral palsy service to provide them with support in all areas of their lives. Their non-disabled siblings had less expectation that their brother or sister with cerebral palsy would achieve adult milestones and qualities. Rather, there appeared to be a stronger element of their sense of obligation to provide support when their parents could no longer do so. Perhaps their life experiences in adulthood had been too different for reciprocity to develop up to this time. Oliver's experience, however, demonstrates that the change in living environment for the person with cerebral palsy due to the ill

health of the parent-carer led to an increase in instrumental support from his non-disabled siblings, Kitty and Arthur. Over time, this may lead to more reciprocal interactions between these siblings.

Reminiscence in older age entails the re-telling of earlier shared experiences and, according to Goetting (1986), is one of the important roles which siblings play in each others' lives. Given the design of this study which required participants to reflect over the life course, there were many examples of reminiscence in the stories told by participants. Past incidents were retold from different perspectives. For example, Isobel remembered Helen as her bossy, brainy older sister, whereas Helen declared she had no recall of taking a dominant role in their games. Siblings in contact with each other and who have shared life experiences recall and challenge each other's memories and perceptions of past events. Mathew and Therese were engaged in this process in writing a family memoir together. The act of reminiscence entails symbolic reciprocity as siblings construct and deconstruct their memories and perceptions of past events.

10.5.3. Parental status and role

Connidis (2001), Heller and colleagues (Heller & Arnold, 2010; Heller, et al., 2007; Heller & Factor, 1994; Heller & Kramer, 2009), Bigby (1996, 1997, 2000) and Seltzer et al. (2001) identified that siblings often negotiate the roles they will play in providing support to ageing parents and to a sibling with a disability. As indicated by participants' experiences and in my own life, the strength of the sibling relationship is tested when parents require support in older age and when coping with their death. One or both parents of 16 of the 28 participants had died at the time of the interviews. As discussed in Chapter 9, sharing this seminal life event was reported by some participants as strengthening their sibling bond, especially after both parents had died.

For example, since their parents' deaths Kristine and Natalie had become closer geographically and emotionally. Similarly, since their mother's death Bruce and Charlotte gave each other more instrumental, social, and emotional support. As the oldest brother, Bob saw it as his role, since their mother's death, to keep in more regular contact with Betty through her support workers.

Twenty one of the 28 participants had one or both parents still alive at the time of the interviews. All the surviving parents were aged in their mid-60s through to over 90 years old, and according to participants the majority suffered some age-related health problems. The majority of participants with cerebral palsy were aware of the issues regarding their parents' age and ill health and shared the concerns if not the physical support provided by their non-disabled siblings to their parents. For example, Helen and Isobel reported that they talked more about their mother's future care than they did about the increased support which Helen might require. Similarly, Oliver was included in discussions with his non-disabled siblings about their mother's future care and Oliver, Kitty and Arthur all reported feeling emotionally closer since their mother's diagnosis with dementia. Yet not all non-disabled siblings thought their brother or sister with cerebral palsy should or could be involved in discussions about their parents' health. Three non-disabled siblings in particular reported that they tried to protect their brother or sister with cerebral palsy from concerns about their parents' ill health. For example, Stephanie and Marilyn acknowledged they had not discussed concerns about their parent's chronic health problems with Thomas, who reported his parents to be in good physical health. Similarly, Amelia had not discussed their father's increasingly poor health with Rebecca, and, for fear of upsetting Louise, Jill had not yet revealed to Louise her 90 year old father's

instruction that Louise was not to travel to the country to attend his funeral when he died.

Despite health problems, most of the parents continued to provide some level of support to their son or daughter with cerebral palsy, regardless of where they lived. Thomas and Rebecca, as the only participants with cerebral palsy still living with their parents, received most of their instrumental, social, and emotional support from their parents. Their non-disabled siblings Stephanie, Marilyn and Amelia were “more distant” in Thomas’ and Rebecca’s lives at this stage and there was little instrumental or symbolic reciprocity apparent in these sibling relationships. Instead, in these sibling relationships there was much concern on the part of the non-disabled siblings about the future when their parents were no longer able to provide support. Each in their own way felt powerless to do anything about these concerns while their parents retained their care-giving role. It seems that for these participants, despite sharing the family home and experiences in childhood and maintaining contact with their brother or sister with cerebral palsy in adulthood, the central care-giving role which their parents still played in Thomas’s and Rebecca’s lives interfered in the development of reciprocity in their relationships.

When the person with cerebral palsy lives away from their parents, such as Richard, Caroline, Helen, Philip, Mathew, and most recently Oliver, it appears that reciprocal interactions are more likely. With the exception of Philip, these participants all shared the family home in childhood. Richard, Caroline, Helen and Mathew shared with their non-disabled siblings the achievement of transition milestones in young adulthood. The combination of shared experiences, ongoing contact, and their parents no longer being the primary carers contributed to a greater display of reciprocity in these sibling relationships.

10.5.4. Support needs

Participants with cerebral palsy in this study had moderate to severe cerebral palsy and, throughout their lives, all except Bruce received instrumental support from paid service providers to supplement the support of their parents and non-disabled siblings. Kristine, Caroline, Mathew and Oliver required full support in all aspects of their personal care and activities of daily living. Kristine, Mathew, Richard and Betty relied on augmentative and alternative communication systems to make their needs known to others. The other participants with cerebral palsy had varying support requirements, with all needing some support.

As indicated by Balandin and Morgan (1997) and Murphy et al. (1995), and as reported by the older participants in this study, people with cerebral palsy's support requirements are likely to increase as they age and experience physical deterioration. When parents can no longer provide assistance, people with moderate to severe cerebral palsy require increased instrumental support to meet their physical care needs. Alongside the most likely paid support, many people access help from their non-disabled siblings, for example, to communicate and negotiate with service providers. The findings from this study suggest that the extent to which non-disabled siblings provide this support is influenced by previous contact and shared experiences across the life course along with the reciprocity that exists or develops in their relationship.

Over time, therefore, the support required by people with cerebral palsy for both physical care and communication may have an increasing impact on the relationship with their non-disabled siblings. As implied by Gouldner (1960), significant support needs may result in the belief that people with a lifelong disability such as cerebral palsy are incapable of having a reciprocal relationship with their non-

disabled siblings. The findings from this study challenge this viewpoint, showing that reciprocity between siblings with and without cerebral palsy operates at an instrumental level as well as a symbolic level, and that when people with cerebral palsy cannot contribute instrumentally they still contribute, and they do so through symbolic reciprocity.

In sum, the framework represented in Figure 5 provides the conceptualisation of the development of reciprocity between siblings where one has moderate to severe cerebral palsy, based on the findings of this study.

Four variables were identified in this study as important for the development of instrumental and symbolic reciprocity in the relationship between people with cerebral palsy and their non-disabled siblings: contact, shared experiences, parental status and role, and support needs. Each of these influences is aligned with the four elements identified by Elder (1994) as important when applying a life-course approach to the study of human relationships, that is, historical time, social timing, linked lives, and human agency.

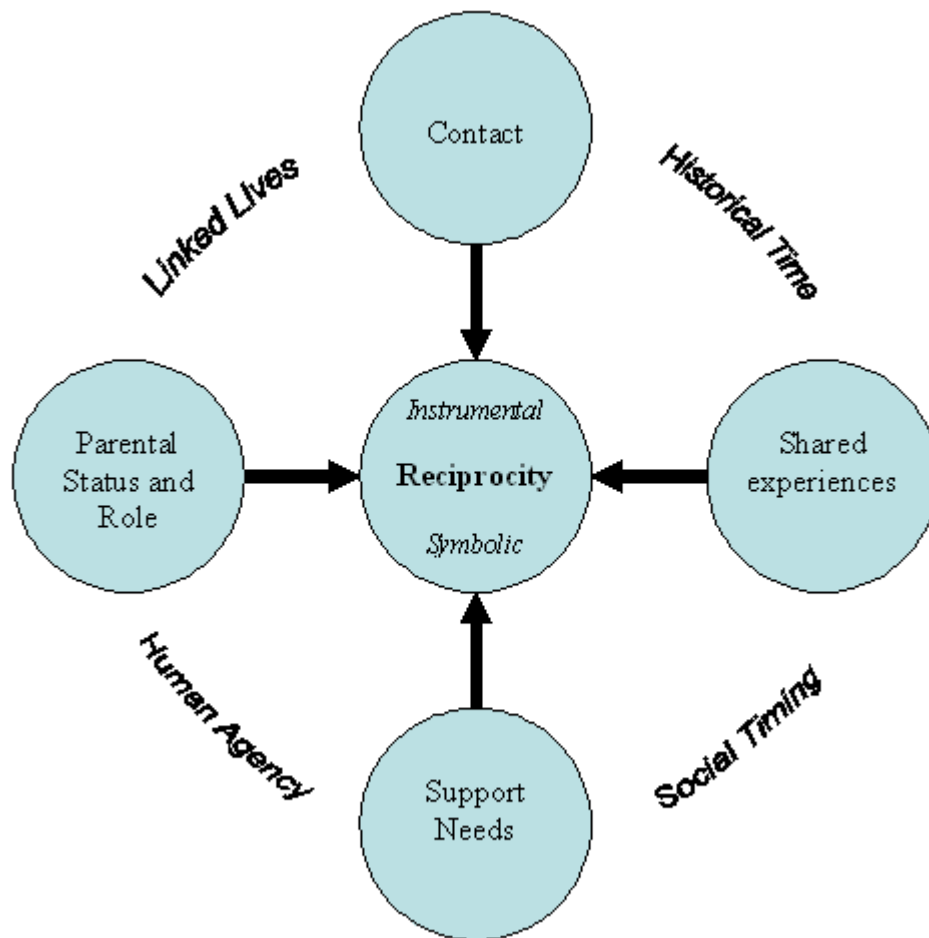


Figure 5 Recognising reciprocity over siblings' life course

10.6. Applying the conceptual framework to sibling relationships in later life

In an extensively cited review, Goetting (1986, p. 711-712) proposed three developmental tasks of siblings in early and middle adulthood related to reciprocity. They are (1) companionship and emotional support, (2) cooperation in the care of elderly parents, and (3) aid and direct services. She added the following two additional tasks in old age: (4) shared reminiscence and perceptual validation, and (5) resolution of sibling rivalry. These five tasks incorporating instrumental and

symbolic reciprocity align with the four facets of this study's conceptual framework, contact, shared experiences, parental status and role, and support needs.

The development of symbolic reciprocity between siblings due to emotional closeness and feelings of reliability may be particularly important when parents can no longer provide support to the person with cerebral palsy. These feelings may predispose non-disabled siblings to take a greater role in the life of their brother or sister. It may be that in middle and older age participants are secure in the knowledge that their long-term sibling relationships will continue. Bruce and Charlotte's situation indicates that as non-disabled siblings become older and experience their own health problems they may turn to their brothers and sisters with cerebral palsy, who have a lifetime of coping with and adapting to functional impairments, to provide them with support. This may further enhance reciprocity in the relationship between siblings or begin reciprocity in their relationship.

As illustrated in this study by Louise, Richard, Kristine and Betty, difficulties in maintaining contact with non-disabled siblings due to geographic distance and communication difficulties can be exacerbated as participants get older and experience health problems. With less face-to-face contact and a subsequent reduction in the ability of the non-disabled brother or sister to provide instrumental support comes a decline in the frequency of social contact, and diminished opportunities for reminiscence. When people with cerebral palsy can use a telephone or computer to keep in touch with their non-disabled siblings, it may be just as effective as face-to-face contact in maintaining symbolic reciprocity.

The findings from this study demonstrate that the combination of shared experiences in childhood and young adulthood, continued contact in adulthood, mutual support through the ill health and death of parents, and having instrumental

support in place contributes to reciprocity in the relationship between siblings as they age.

Chapter 11

Conclusions

11.1. Overview of the Study

A life-course perspective was pivotal in this study to develop an understanding of the relationships of participants with cerebral palsy and their non-disabled siblings as their parents grew older. Elder's life-course paradigm (Elder, 1994, 1998; Elder, et al., 2004) provided the foundation for identifying the historical events that had had an impact on the lives of the participants with cerebral palsy and their non-disabled siblings from childhood through to the present day. Elder's focus on the social timing of life-course events highlighted the importance of milestones and transitions at key points in participants' lives. The interlinked lives of family members and their life choices helped me to think about the development of the bond between individuals with cerebral palsy and their non-disabled siblings and how it might change over time.

The diversity of experiences of the participants, while providing support for the importance of sibling variables such as gender, number of siblings, age differences and place in family, geographic proximity, severity of disability, personality and differential parenting, also demonstrated that, due to the complexity of people's lives, these variables might not be predictive of sibling involvement. To understand the predictive value of these variables would require a different study design. The study design chosen was in line with the suggestions of Goetting (1986) and Connidis (2001) that in middle and older age siblings reach a stage where they can reflect on the mutual benefits they have received from each other, and this in turn can influence their ongoing relationship.

Connidis (2001, p. 14) stated that “the family ties of later life are best understood in the context of a life course perspective [and] when striving to understand such issues as reciprocity in family relationships, one should take a long-term view of the exchanges that have occurred rather than focusing on one point in time (usually the present)”. I adopted that approach in writing this thesis, with each results chapter providing an understanding of how the relationship between participants with cerebral palsy and their non-disabled siblings developed over their life course. An understanding of the lifelong relationships between siblings with and without cerebral palsy led to the primary finding of reciprocity in these relationships. In developing the conceptual framework I identified contact, shared experiences, parental status and role, and support needs as important influences in the instrumental and symbolic reciprocity between participants with cerebral palsy and their non-disabled siblings.

11.2. Limitations of the study

This study focused on a relatively small number of people with cerebral palsy and their siblings. Although parallels may be drawn with other adults with cerebral palsy and their non-disabled siblings and, indeed, with other people with lifelong disability, the experiences, thoughts and feelings expressed by participants in this study are personal and unique. The primary finding of reciprocity emerged during the process of grounded theory analysis; participants were not asked about reciprocity in their sibling relationships. A range of strategies described in Chapter 6 were used in this study to ensure rigour in data analysis and authenticity of results. However, it would be worthwhile to find additional ways to ensure that participants with a disability who may have problems accessing written information are able to have greater input into

data verification. Within a time-limited study such as this one and given the geographic distribution of participants, providing face-to-face feedback throughout the study process was problematic. Nonetheless, the findings from this in-depth qualitative study provide a firm foundation for a future study with a broader population of people with lifelong disability and their non-disabled siblings. Undertaking such a study was outside the scope of this doctoral work.

Due to the recruitment strategies used in this study, participants self-selected to take part. This meant that the people who participated wished to do so and were generous with their time and input, although by definition excluding other participants with potentially different experiences. The pilot project conducted prior to this study and other international literature on adult siblings (e.g., Bigby, 2000; Heller & Factor, 1994; M. Seltzer, et al., 2001) indicate that the issues raised by non-disabled sibling participants in this study generally aligned with the views expressed by non-disabled siblings of people with other lifelong disabilities, particularly intellectual disability. The study attracted participants who represented variables known to influence sibling relationships, such as gender, geographic proximity, severity of disability, parental status, living environment, place in family, and size of family. My recruitment strategy relied on individuals with cerebral palsy to invite their brothers and/or sisters to participate. Therefore, as recorded in Table 1, page 118, non-disabled siblings who had limited contact or who did not get along with their brother or sister with cerebral palsy were possibly not invited or may have declined to participate. In future research it would be important to develop strategies to recruit non-involved as well as involved siblings.

11.3. Implications of the study

Gathering insights into the experiences of individuals with cerebral palsy and their non-disabled siblings led to an understanding of the pathways that sibling relationships take over time. The primary finding of reciprocity in sibling relationships where one person has moderate to severe cerebral palsy has implications for practice, policy, education and research.

11.3.1. Contribution to practice

The results of this study highlight the importance of siblings maintaining contact with each other to the development of a reciprocal relationship over the life course. In practice, maintaining contact between siblings can prove challenging, more so when the non-disabled siblings are geographically distant and the individual with cerebral palsy has communication difficulties. During childhood and into middle adulthood, parents may be the communication conduit between siblings; once parents become ill or die, sibling communication may lapse. Therefore, practitioners may need to “think outside the square” to facilitate the use by people with cerebral palsy of AAC and various telecommunication methods to re-establish or maintain contact with their non-disabled siblings. As described by Horwitz et al. (1996), small yet significant acts of reciprocity such as exchanging birthday cards and phone calls are important contributors to facilitating reciprocity between siblings when one has a disability. There is anecdotal evidence that some service providers do assist siblings to maintain contact with each other. However, participants in this study indicated that more could and should be done in this regard.

Contact between individuals with cerebral palsy and their non-disabled siblings is necessary to provide the opportunity to reminisce about the past.

Particularly if siblings lived together in the family home during childhood, the sharing of memories, photos, and mementos are important to the older age process of reviewing past life experiences. Practitioners can play a role in assisting people with moderate to severe cerebral palsy to engage in structured activities (e.g., Mathew and Therese writing their family memoir) or unstructured opportunities (e.g., Oliver going to Arthur's house to watch sport on TV) during which they can reminisce.

As illustrated by Oliver's experience, a parent's hospitalisation and death is likely to result in a major life change, often requiring emotional as well as physical help. Oliver commented on the benefits to him of not only his non-disabled siblings' support but also the professional counselling he received. Service providers are ideally placed to access psychological counselling services for the person with cerebral palsy, and to work with non-disabled siblings to provide the person with the necessary instrumental, social and emotional support to cope with the loss of parents. When parent-carers become ill or die, non-disabled siblings are likely to also experience a change in their role and relationship with their brother or sister with a disability. Again, as described by Oliver's siblings, Kitty and Arthur, non-disabled siblings may need to provide their brother or sister with intimate personal care in the short or long term. Additionally, they may experience stress in balancing double support roles for a parent and a sibling. Service providers across the aged-care and disability sectors can play a role in providing practical and emotional support to non-disabled siblings who find themselves in this situation.

Practitioners are also likely to play an important role in assisting ageing people with cerebral palsy to adapt to their increasing or changing support needs. Age-related health issues may affect the type and frequency of contact which siblings can have with each other. As described in Chapter 1 and Chapter 9, as siblings with and

without cerebral palsy age, the roles which they, other family members, friends, and paid staff play need to be adjusted to meet the individual's changing needs and circumstances. The lack of planning by family members for the inevitable transition from parental-care to sibling support is identified in the literature and in this study as a concern for parents and siblings. This study indicates that more needs to be done, and commencing much earlier in the life cycle, to assist family members to discuss together and at least tentatively plan for this eventuality. The planning process will have benefits not just for family members but for service providers and policy makers who will gain a better understanding of, and be able to better plan for, the numbers and needs of people with a disability throughout their life course.

11.3.2. Contribution to policy

The results of this study have policy implications for the way in which government departments and non-government organisations define family support for people with a lifelong disability such as cerebral palsy. There has tended to be a narrow conceptualisation of families, with the focus on parents. For example, in 2007 the Australian Commonwealth Department of Families, Community Services and Indigenous Affairs produced a document designed to assist family members of people with a disability to plan for the future (Commonwealth of Australia, 2007). The document uses the term "family" throughout, but on page 1 the authors acknowledge that the resource is targeted to parents. Non-disabled siblings are mentioned only in relation to overseeing the financial provision of support to their brother or sister with a disability after their parents' death. However, with increasing numbers of people with lifelong disability living to old age and outliving their parents, non-disabled siblings are likely to be central to making and implementing decisions on matters much broader than financial provision.

Policy-makers must extend their perspective of family to include non-disabled siblings and to acknowledge their role in discussions about the current and future care needs of their disabled siblings. This requires better understanding on the part of policy-makers of the sibling relationship, its lifelong nature and its various components, as outlined in this study, which facilitate the development of reciprocity in the relationship between siblings, and in particular focus on maintaining ties as siblings age.

Although it is no longer Australian government policy for children with a disability to be removed from their family homes to receive services (e.g., Department of Ageing Disability and Home Care, 2004), the findings of this study provide further evidence of the long-term effects of past policies of out-of-home placement on the relationship between people with a disability and their non-disabled siblings. The findings of this study, albeit with small numbers, suggest that separation of siblings in childhood is an influence that negatively affects their ability to develop a reciprocal relationship in adulthood. Having worked with people with a disability for the past 29 years, I am still amazed and disappointed at how little policy-makers seem to have learned from past mistaken policy approaches. The lessons from history about what worked and what did not work should influence future policy development. It is also important for practitioners working with people with lifelong disability such as cerebral palsy to learn from the lessons of former policies and their impact on family life including sibling relationships.

This study also points to the need for Commonwealth/State, inter-governmental, inter-departmental and across sector consideration of the complex issues of older parent-carers and an adult with a developmental disability. As highlighted in Chapter 1 and described in Chapter 9, current limited coordination

between the aged care sector, funded federally, and the disability sector, funded by the States, results in un-necessary additional stress for aged parent-carers, non-disabled siblings, and the person with a disability.

11.3.3. Contribution to education

This study has significance for the education of health and social welfare professionals who work with people with cerebral palsy and their families. In particular, students need an understanding of the life stages and principles of life-course relationship development when studying how family relationships develop and the importance of historical time and social timing on the experiences of people with cerebral palsy and their siblings. For example, the findings of this study point to the need for professionals to adapt their role in facilitating contact between adults with cerebral palsy (and potentially other lifelong disabilities) and their non-disabled siblings, depending on whether the disabled person left the family home or continued living there in childhood. Adaptation will be required because the historic and social experiences, such as represented in the stories of participants in this study, can influence the nature and extent of involvement between non-disabled siblings and their brother or sister with cerebral palsy in later life. An understanding of the concept of life-course pathways will assist future health and welfare workers to adopt an integrated and long-term perspective when supporting people with a lifelong disability such as cerebral palsy and their families.

This study also has significance for the education of support workers and managers in organisations providing support to people with cerebral palsy. Education of staff working in support organisations should include an understanding of the importance of sibling relationships both in childhood and adulthood, so that staff appreciate the value of participation by siblings and the ways in which staff can best

facilitate siblings' ongoing involvement. This will be crucial, especially for people with lifelong disability who remain living with their parents until middle age and then move into supported accommodation as a result of a crisis in parental health. Staff can play a vital role in assisting non-disabled siblings to recognise and build on, or rebuild, the support and/or reciprocity in their relationship with their brother or sister with cerebral palsy.

11.3.4. Contribution to research

This study adds to the literature on research into adult sibling relationships where one has a lifelong disability. Few studies have considered the adult sibling relationship (Bigby, 1997; Greenberg, et al., 1999; Heller & Kramer, 2009; Krauss, Seltzer, Gordon, & Friedman, 1996; Orsmond & Seltzer, 2000; M. Seltzer, et al., 1997; Taylor, et al., 2008; Zetlin, 1986). Fewer still have focused on the adult sibling relationship of individuals with a physical disability such as cerebral palsy (Begun, 1989; Burton & Parks, 1994; Davis & Salkin, 2005; Grossman, 1972), and, with the exception of the study of Davis and Salkin, none has included the viewpoint of adults with cerebral palsy.

Previous studies have examined the impact on non-disabled siblings of having a brother or sister with a disability, and/or the issue of transition from parental care to sibling support, without taking into account the life-course pathways of participants or recognising the relationships that build and develop between siblings over their life course. This study adds to knowledge by including the viewpoints of people with cerebral palsy, as well as those of their non-disabled siblings. It also adds to the literature by broadening participants' accounts to include interviewing more than one sibling in a family, where this was possible. Moreover, this study transcends examination of the transition from parental care as a single event, understanding it

rather as part of the life course, and in so doing identifies the importance of contact, shared experiences, parental status and role, and support needs across the life course in building reciprocal sibling relationships which are mutually beneficial to siblings with and without disability once their parents are no longer living.

11.4. Future research directions

The results of this study have generated several promising topics for future research which can clarify and deepen the understanding of reciprocity in adult sibling relationships where one has a lifelong disability. These include understanding the optimal conditions for reciprocity to develop between siblings where one has a lifelong disability. Are there other significant influences on the sibling relationship in addition to those identified in the conceptual framework developed in this study? Do these influences differ according to the type of disability or are they common among people with different lifelong disabilities?

Obligation and altruism co-exist within these relationships. It would be helpful to examine whether there is a difference in the way siblings view their relationship and the support and reciprocity offered when non-disabled siblings attribute their involvement in the life of their brother or sister with a disability to an obligation to their parents rather than to altruistic motivation. How does this affect the support provided by the non-disabled sibling/s post-parental care? What conditions or circumstances might result in obligation evolving into altruism if indeed this does occur?

We need to know more about the impact in later life of both instrumental and symbolic reciprocity for people with a lifelong disability and their non-disabled siblings. As a result of physical impairments, is symbolic reciprocity perceived as more important than instrumental reciprocity in relationships between people with

cerebral palsy and their non-disabled siblings? Is this the same or different for people with other types of disability, such as intellectual disability or sensory impairment?

Understanding what reciprocity between siblings means in the lives of people with a lifelong disability and their non-disabled siblings when they themselves reach older age would be helpful in anticipating the future for individuals with cerebral palsy. Do feelings of symbolic reciprocity endure into old age when the frequency of contact may decrease and neither sibling can provide instrumental and social support? What supports might be required to ensure ongoing symbolic reciprocity in sibling relationships when they are older?

Another area for exploration in future research is the role which symbolic reciprocity can play in contributing to the healthy ageing of people with cerebral palsy and their non-disabled siblings. For example, Horwitz and colleagues (1996) found that people with mental illness who demonstrated symbolic reciprocity in their relationships with their non-disabled siblings had “feelings of higher self esteem and self-confidence” (p. 159) and received more help from family members. Overall, Horwitz and colleagues commented that the wellbeing of both parties was improved through their engagement in reciprocal interactions. According to Molm et al. (2007), “the bonds of trust and solidarity created through symbolic communication can potentially influence future behavioral choices” (p. 215). An important question is whether this is also the case for people with cerebral palsy and their non-disabled siblings.

Furthermore, this study pointed to the need for researchers in the disability field to further explore adult sibling relationships using life-course theory, which adds a long-term perspective to what is typically the longest relationship in life. Drawing more fully on the sibling literature would also be helpful to explain similarities in

sibling relationships between individuals with disabilities and their non-disabled siblings, rather than concentrating on differences as has occurred in the past.

11.5. Concluding statement

The aim of this study was to explore the relationships between middle-aged and older people with severe cerebral palsy and their non-disabled siblings in the context of the future when their parents were no longer able to provide care for their son or daughter with cerebral palsy. In the course of this study I identified the importance of living together in childhood and establishing an independent adult sibling relationship in order to develop reciprocity based on instrumental and symbolic benefits to both people with cerebral palsy and their non-disabled brother/s and sisters.

The conceptual framework developed in this thesis identified that contact, shared experiences, parental status and role, and support needs, are important influences on whether reciprocity develops between siblings, and the nature of this reciprocity. I believe that the framework provides a useful way for people with cerebral palsy, their family members, and service providers to consider the role which people with cerebral palsy and their non-disabled siblings might play in each other's lives. People with cerebral palsy, non-disabled siblings, and service providers can use the framework to reflect on the nature of the sibling relationship by asking questions such as: Is the level and type of contact siblings have optimal for facilitating reciprocal interactions? Do siblings have shared experiences from the past and do they have opportunities to discuss them with each other? Have siblings discussed the role their brother or sister with cerebral palsy wants the non-disabled sibling/s to play in their lives post-parental care? What roles are non-disabled siblings able and prepared to play? As they age, what is the best way for the increasing support needs of people with cerebral palsy to be met? What roles can non-disabled siblings and

service providers play in this? Answers to these questions are significant because the results of this study suggest that having a reciprocal sibling relationship may be especially important once parents have died and siblings rely more on each other to overcome later life challenges.

Opening the window on participants' lives through the interviews in this study revealed the complex and inter-related nature of the sibling relationship over the life course. This study is an important beginning in identifying a nuanced relationship between individuals with cerebral palsy and their siblings in which reciprocity plays a significant and previously unrecognised part.

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Appendices

Appendix 1 Ethics approval from The University of Sydney

- Appendix 2 Information Sheets and Consent Forms
- Individual with cerebral palsy information sheet
 - Non-disabled sibling information sheet
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Appendix 1 Ethics Approval



The University of Sydney

NSW 2006 Australia

www.usyd.edu.au/ethics/human

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2 June 2006

Associate Professor S Balandin
School of Communication Sciences and Disorders
Faculty of Health Sciences
Cumberland Campus - C42
The University of Sydney

Dear Professor Balandin

Thank you for your correspondence dated 15 May 2006 addressing comments made to you by the Committee. After considering the additional information, the Executive Committee approved your protocol entitled **"The transition of care from ageing parents: achieving flexible relationships between adults with cerebral palsy, their siblings and service providers"**

Details of the approval are as follows:

Ref No.:	06-2006/4/9056
Approval Period:	June 2006 – June 2007
Authorised Personnel:	Associate Professor S Balandin Professor G Llewelyn Ms A Dew Ms I Novak Ms L Foy

The approval of this project is **conditional** upon your continuing compliance with the *National Statement on Ethical Conduct in Research Involving Humans*. We draw to your attention the requirement that a report on this research must be submitted every 12 months from the date of the approval or on completion of the project, whichever occurs first. Failure to submit reports will result in withdrawal of consent for the project to proceed.

The project is approved for an initial period of 12 months with approval for up to four (4) years following receipt of the appropriate report.

Your report will be due on 30 June 2007.

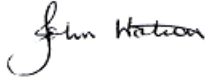
Conditions of Approval Applicable to all Projects

(1) **Reporting of Serious Adverse Events**

Researchers should immediately report anything to the Human Research Ethics Committee which might warrant review of ethical approval of the protocol, including:

- Serious or unexpected adverse effects on participants;
 - Proposed changes in the protocol or any other material given to the participants in the study must be known prior to being actioned, including participant information and consent forms; and
 - Unforeseen events that might affect continued ethical acceptability of the project.
- (2) Modifications to the protocol cannot proceed until such approval is obtained in writing. (Refer to the website www.usyd.edu.au/ethics/human under 'Forms and Guides' for a Modification Form).
- (3) The confidentiality and anonymity of all research subjects is maintained at all times, except as required by law.
- (4) All research subjects are provided with a Participant Information Sheet and Consent Form, unless otherwise agreed by the Committee.
- (5) The Participant Information Sheet and Consent Form are to be on University of Sydney letterhead and include the full title of the research project and telephone contacts for the researchers, unless otherwise agreed by the Committee.
- (6) The following statement must appear on the bottom of the Participant Information Sheet. ***Any person with concerns or complaints about the conduct of a research study can contact the Senior Ethics Officer, University of Sydney, on (02) 9351 4811 (Telephone); (02) 9351 6706 (Facsimile) or gbriody@mail.usyd.edu.au (Email).***
- (7) The standard University policy concerning storage of data and tapes should be followed. While temporary storage of data or tapes at the researcher's home or an off-campus site is acceptable during the active transcription phase of the project, permanent storage should be at a secure, University controlled site for a minimum of seven years.
- (8) A report and a copy of any published material should be provided at the completion of the Project.

Yours sincerely



**Associate Professor J D Watson
Chairman
Human Research Ethics Committee**

Cc: Ms Angela Dew, School of Occupation and Leisure Sciences, Faculty of Health Sciences, Cumberland Campus - C42, The University of Sydney

Encl. Participant Consent Form

Appendix 2 Information Sheets and Consent Forms

- Individual with cerebral palsy information sheet
- Non-disabled sibling information sheet
- Consent form (used for all participants)



The University of Sydney
Faculty of Health Sciences

COMMUNICATION SCIENCES AND DISORDERS

THE TRANSITION OF CARE FROM AGEING PARENTS: ACHIEVING FLEXIBLE RELATIONSHIPS BETWEEN ADULTS WITH CEREBRAL PALSY, THEIR SIBLINGS AND SERVICE PROVIDERS **PARTICIPANT INFORMATION SHEET – Siblings with Cerebral Palsy**

Thank you for your interest in participating in this study. Below is some more detailed information about this research project.

What is the study about?

Assoc. Professor Susan Balandin, Professor Gwynnyth Llewellyn and Ms Angela Dew are conducting a research project to explore and understand the care-taking relationships between brothers and sisters (siblings) in families with ageing parent-carers and an adult son or daughter with cerebral palsy. We aim to use the information we collect to develop a model so that services (such as the [name of organisation removed]) can better support families and adults with cerebral palsy as parent-carers age in the future. This project will form part of Ms Dew's doctoral research program.

Who is carrying out the study?

This study is being conducted by the above researchers at the Faculty of Health Sciences, the University of Sydney. Staff from the [organisation name removed] will assist the researchers to contact participants.

What does the study involve and how much time will the study take?

As a person with cerebral palsy who has a brother or sister, we would like to interview you. We would like to interview you up to four times however it may only take one or two interviews. We will also interview your brother or sister; however we will interview you separately. Each interview will last approximately 1 ½ hours and will occur at a day, time and venue that suits you (this may be your house or you may wish to meet at another venue). With your permission we will audio-tape the interview so that we can analyse what you have told us in more detail later. You may ask a friend, family member or staff member to be with you at the interview if you wish.

During the interviews we will ask you to tell us, in your own words, about your experiences of being an adult with cerebral palsy and the impact this has had on your relationship with your brother or sister. We are particularly interested to know about the role your brother or sister has in your life now, and how you see that role changing in the future. We will also talk to you about your opinion on the role services can take to support you and your family in the future. Later interviews will provide you with an opportunity to reflect on and review what you told us and talk about wider

themes we have discovered from interviews we have conducted with other siblings. If you use an Augmentative and Alternative Communication System (AAC) we will take special care to ensure we accurately understand your opinions and the experiences that you are discussing.

You may also be invited to be involved in one focus group discussion approximately 12 months after your initial interview. During this group discussion we will ask you to review a draft of the model we have put together for staff of services, which support families and people with cerebral palsy. This group discussion will last approximately 1 ½ hours. You do not have to be involved in the focus group; you can just participate in the individual interviews if you wish.

The information you provide to us will not be reported with any individually identifying details. All information provided to the researchers will be kept strictly confidential. You may listen to the audio-tape of your interviews and delete any or all material you do not wish to be used in the study.

Once the study is finished, you will be invited to a meeting to discuss the results of the whole study.

Discussing and recalling the experiences of your family and living with a disability may cause some people to become upset or distressed. Should this happen to you, any interview can be suspended until you feel ready to continue. Interviews may be stopped completely at your request. If you wish to discuss feelings or experiences raised in the interviews in more detail, we will help by referring you to an appropriate counselling service.

Can I withdraw from the study?

Your participation in this study is completely voluntary and your decision not to participate, or to withdraw at any time, will not affect you or your family's access to any services or your relationship with the [name of organisation removed] or the University of Sydney now, or in the future.

Will anyone else know the results?

All parts of the study, including results and any information we collect from you, will be strictly confidential. Only the researchers will have access to information on participants except as required by law. All information we collect during the study will be stored in a locked office at the School of Communication Sciences and Disorders at the University of Sydney. Only the researchers will have access to audio-tapes and transcripts.

The combined results from this study may be published in reports or presented at conferences; however the information will be presented in such a way that no person will be identifiable.

Will the study benefit me?

Through talking about your experiences with cerebral palsy you will be given the opportunity to frame, relate and reflect on the meaning of these experiences within your own life. It is hoped that sharing your story will give you an opportunity to understand your experience on your own terms.

Results of this study will be used to create a model which will be incorporated into policy and practice of services such as the [organisation name removed]. Once implemented, this model will lead to better support for families and improved

transition of care in the future as parent-carers' age. However, we cannot and do not guarantee or promise that you will personally receive any benefits from the study.

Can I tell other people about the study?

Yes.

What if I require further information?

If you have any further questions or would like to find out more about this research, please call either Angela Dew on (02) 9351 9050 a.dew@usyd.edu.au or Susan Balandin on (02) 9351 9334 and they will be happy to talk to you.

What if I have a complaint or concerns?

Any person with concerns or complaints about the conduct of a research study can contact the Manager for Ethics Administration, University of Sydney on (02) 9351 4811 or email gbriody@mail.usyd.edu.au.

If you wish to take part in this research please complete the attached Agreement to Participate Form and return it to us with contact details in the reply paid envelope.

Thank you for considering this project.

This information sheet is for you to keep



THE TRANSITION OF CARE FROM AGEING PARENTS: ACHIEVING FLEXIBLE RELATIONSHIPS BETWEEN ADULTS WITH CEREBRAL PALSY, THEIR SIBLINGS AND SERVICE PROVIDERS
PARTICIPANT INFORMATION SHEET – Siblings without Disability

Thank you for your interest in participating in this study. Below is some more detailed information about this research project.

What is the study about?

Assoc. Professor Susan Balandin, Professor Gwynnyth Llewellyn and Ms Angela Dew are conducting a research project to explore and understand the care-taking relationships of adult siblings in families with ageing parent-carers and an adult son or daughter with cerebral palsy. We aim to use the information gathered to develop a model so that services (such as [name of organisations removed]) can better support families and adults with cerebral palsy as parent-carers age in the future. This project will form part of Ms Dew's doctoral research program.

Who is carrying out the study?

This study is being conducted by Susan Balandin, Gwynnyth Llewellyn and Angela Dew at the Faculty of Health Sciences, the University of Sydney. Staff from the [name of organisation removed] will assist the researchers to contact participants.

What does the study involve and how much time will the study take?

As a sibling of a person with cerebral palsy, we would like to interview you. We would like to interview you up to four times although one or two interviews may be sufficient. We will also interview your sibling with cerebral palsy; however we will conduct both interviews separately. Each interview will last approximately 1 ½ hours and will occur at a day, time and venue most convenient to you (this may be your house or you may wish to meet at another venue). With your permission we will audio-tape the interview so that we can analyse what you have told us in more detail later. You may bring a friend or family member to the interview with you if you wish.

During the interviews we will ask you to tell us, in your own words, about your perceptions and experiences of being an adult sibling of a person with cerebral palsy. We are particularly interested to know about the role you play in the life of your sibling with a disability now, and how you see that role changing in the future. We will also talk to you about your opinion on the role services can take to support you and your family in the future. Subsequent interviews will provide you with an opportunity to reflect on and review what you told us in the initial interviews and the wider themes we have distilled from interviews we have conducted with other siblings.

You may also be invited to be involved in one focus group discussion approximately 12 months after your initial interview. During this group discussion we will ask you to review a draft of the model we have put together for staff of services, which support families and people with cerebral palsy. This group discussion will last approximately

1 ½ hours. You do not have to be involved in the focus group; you can just participate in the individual interviews if you wish.

The information you provide to us will not be reported with any individually identifying details. All information provided to the researchers will be kept strictly confidential. You may listen to the audio-tape of your interviews and delete any or all material you do not wish to be used in the study.

Following completion of the study, you will be invited to a meeting to discuss the outcomes of the whole study.

The process of discussing and/or recalling the experiences of your family and sibling with a disability may cause some participants distress. Should this occur, any interview will be suspended until such time as you feel ready to continue. Interviews may be terminated completely at your request. If you wish to discuss feelings or experiences raised in the interview in more detail, we will assist by referring you to an appropriate counselling service.

Can I withdraw from the study?

Your participation in this study is completely voluntary and your decision not to participate, or to withdraw at any time, will not affect you or your sibling with cerebral palsy's access to any services or your relationship with the [name of organisation removed] or the University of Sydney.

Will anyone else know the results?

All aspects of the study, including results and any information we collect from you, will be strictly confidential and only the researchers will have access to information on participants except as required by law. All information obtained during the study will be stored in a locked office at the School of Communication Sciences and Disorders at the University of Sydney. Access to audio-tapes and transcripts will be restricted to the researchers.

The combined results from this study may be published in academic journals or presented at conferences; however the information will be presented in such a way that individual participants or any other person mentioned will not be identifiable.

Will the study benefit me?

Through talking about your experiences with your siblings and cerebral palsy you will be given the opportunity to frame, relate and reflect on the meaning of these experiences within your own life. It is hoped that sharing your story will give you an opportunity to understand your experience on your own terms. Results of this study will be used to inform the development of a model which will be incorporated into policy and practice of services such as the Spastic Centre. Once implemented, this will lead to better support for families and optimal transition of care in the future as parent-carers' age. However, we cannot and do not guarantee or promise that you will personally receive any benefits from the study.

Can I tell other people about the study?

Yes.

What if I require further information?

If you have any further questions or would like to find out more about this research, please call either Angela Dew on (02) 9351 9050 a.dew@usyd.edu.au or Susan Balandin on (02) 9351 9334 and they will be happy to talk to you.

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If you wish to take part in this research please complete the attached Agreement to Participate Form and return it to us with contact details in the reply paid envelope.

Thank you for considering this project.

This information sheet is for you to keep

PARTICIPANT CONSENT FORM

The transition of care from ageing parents: achieving flexible relationships between adults with cerebral palsy, their siblings and service providers

I,.....[name]
of.....[address]

have read and understood the Participant Information Sheet for the research project named above. In giving my consent I acknowledge that:

The procedures required for the project and the time involved have been explained to me, and any questions I have about the project have been answered to my satisfaction.

I have read the Participant Information Sheet and have been given the opportunity to discuss the information and my involvement in the project with the researcher(s).

I freely choose to participate in this study and understand that I can withdraw without penalty at any time. I understand that withdrawal will not affect my relationship with the researcher(s) now or in the future.

I understand that my involvement is strictly confidential and no information about me will be used in any way that reveals my identity.

I hereby agree to participate in this research study.

Signature:.....

Name:.....

Date:.....

Signature of Witness:.....

Name of
Witness:.....

Date:.....

Appendix 3 Interview Guides

Initial Individual Interview Guide

All interviews will be conversational in style and discussion will be centred on the following areas:

- Describe your family starting with your **childhood** and what it was like growing up as/with a sibling with cerebral palsy.
- The **current relationship** between you and your siblings, including the:
 - amount of contact between you;
 - nature of this contact;
 - feelings you have about your relationship.
- How your relationship has **changed since you became adults**, including:
 - details about the changes;
 - why they occurred;
 - how you feel about them;
 - how you think this might impact on your future relationship as you get older.
- **Possible future changes** in your relationship including:
 - why these may occur;
 - how you would like your relationship with each other and service providers to develop ideally;
- Your view on what **resources are required**, and what role service providers might take, to ensure successful transitions as you get older.

Topic areas will be introduced with the natural flow of the conversation. It may be unnecessary to introduce a topic or ask a particular question if the participant has already addressed it. As such, these areas are merely a guide and not a set interview regime.

Follow-up Interview Guide

Specific questions for individual follow-up interviews were developed based on areas from their initial interview. The individual questions were asked at the beginning of the follow-up interview as a way of leading from the initial interview and filling in the gaps in the intervening period. In addition to the individual questions, the following broad life course areas were addressed:

- **Historical time**
 - How have changes in disability policy and service provision impacted on you/your brother/sister?
- **Social Timing**
 - What do you see as the key transition points in your life?
 - How are these the same or different to key transition points for your brother/sister?
- **Linked Lives**
 - What does having [name] as your sibling mean to you?

- In what way are they important to your life? Give an example.
- How important to you/brother/sister is family support compared to paid support? How do they compliment each other? Is there friction between them?
- Under what circumstances would you see [name] being more involved in your life?
- How will the sibling support role of [name] be negotiated with other siblings?
- **Human Agency**
 - To what extent have you/brother/sister made your/their own decisions? (e.g., about where to live, who to live with, work etc.);
 - What strategies might you/family use to make decisions about the future?
 - Who would be involved in this?
 - What do you need to plan effectively for the future? (e.g., resources, finances, assistance etc.);
 - What is your/brother/sister's ideal future living environment?
 - What do you think the future holds for you/[name]? Where will you/they be in 10 years time?

Appendix 4 Participant Attributes in NVivo

Sorted by age of participant from youngest to oldest.

PSUEDONYM	AGE RANGE	COMMUNICATION	DISABILITY	GENDER	LIVING ENVIRON	NO. OF SIBLINGS	PARENTAL STATUS	PLACE IN FAMILY
Marilyn	30-39	Clear Speech	No disability	Female	Not Applicable	2 other	Both alive	Youngest
Harry	30-39	Clear Speech	No disability	Male	Not Applicable	5 other	Both alive	Youngest
Natalie	40-49	Clear Speech	No disability	Female	Not Applicable	1 other	Both dead	Youngest
Stephanie	30-39	Clear Speech	No disability	Female	Not Applicable	3 other	Both alive	Middle
Isobel	30-39	Clear Speech	No disability	Female	Not Applicable	2 other	Mother alive	Youngest
Kirsty	30-39	Clear Speech	No disability	Female	Not Applicable	2 other	Both alive	Youngest
Oliver	40-49	Dysarthric Speech	Cerebral Palsy	Male	Family home	4 other	Mother alive	Youngest
Thomas	40-49	Dysarthric Speech	Cerebral Palsy	Male	Family home	3 other	Both alive	Eldest
Mathew	40-49	Voice Output Device	Cerebral Palsy	Male	Family home	2 other	Both alive	Middle
Philip	40-49	Dysarthric Speech	Cerebral Palsy	Male	Supported accommodation	5 other	Both alive	Eldest
Helen	40-49	Dysarthric Speech	Cerebral Palsy	Female	Family home	2 other	Mother alive	Eldest
Therese	40-49	Clear Speech	No disability	Female	Not Applicable	2 other	Both alive	Eldest

Arthur	40-49	Clear Speech	No disability	Male	Not Applicable	4 other	Mother alive	Middle
Rebecca	40-49	Dysarthric Speech	Cerebral Palsy	Female	Family home	1 other	Both alive	Youngest
Margaret	50-59	Clear Speech	No disability	Female	Not Applicable	5 other	Both alive	Middle
Kitty	50-59	Clear Speech	No disability	Female	Not Applicable	4 other	Mother alive	Eldest
Amelia	50-59	Clear Speech	No disability	Female	Not Applicable	1 other	Both alive	Eldest
Caroline	50-59	Dysarthric speech	Cerebral Palsy	Female	Family home	5 other	Both alive	Middle
Betty	50-59	Low tech AAC	Cerebral Palsy	Female	Supported accommodation	4 other	Both dead	Middle
Kristine	60-69	Dysarthric Speech	Cerebral Palsy	Female	Supported accommodation	1 other	Both dead	Eldest
Derek	50-59	Clear Speech	No disability	Male	Not Applicable	4 other	Both dead	Youngest
Bob	60-69	Clear Speech	No disability	Male	Not Applicable	4 other	Both dead	Eldest
Jill	60-69	Clear Speech	No disability	Female	Not Applicable	2 other	Both dead	Youngest
Richard	60-69	Low tech AAC	Cerebral Palsy	Male	Family home	3 other	Mother alive	Middle
Bruce	60-69	Dysarthric Speech	Cerebral Palsy	Male	Family home	3 other	Both dead	Youngest
Louise	60-69	Dysarthric Speech	Cerebral Palsy	Female	Supported accommodation	2 other	Father alive	Middle
Ruth	60-69	Clear Speech	No disability	Female	Not Applicable	3 other	Mother alive	Middle
Charlotte	70-79	Clear Speech	No disability	Female	Not Applicable	3 other	Both dead	Eldest

Appendix 5 Example of a Memo

Caroline

Date XX 2007 2:46 PM

Initial Interview

Caroline has severe cerebral palsy. She uses an electric wheelchair for mobility which she operates using a foot control. One arm is loosely strapped to the side of her chair to prevent it flying about when she has a spasm. Caroline's speech is dysarthric and can be quite difficult to understand. She was happy for me to ask her to repeat things and for me to clarify that I understood what she was saying. Despite her speech she is a very competent communicator with a good sense of humour displayed in her responses to my questions and her comments.

The initial interview with Caroline was set up with her husband using email. Her husband also has cerebral palsy. They have been married for the past 25 years and her husband used to provide her with more support than he is currently able to due to his physical deterioration. The interview was conducted at the venue of Caroline's day activity.

Caroline was quite pragmatic about the increased level of support which she and her husband would require as they got older. She saw this as just part of life. Caroline acknowledged that this increased level of support could be needed sooner rather than later. This was in contrast with the views of her sister, Margaret who did not believe that Caroline was ready to accept a higher level of support at this stage. This is interesting – why haven't the sisters discussed this? What would it take for them to do so?

Date XX 2008 3:33 PM

Issues to cover in second interview:

Caroline and her husband have now moved to their new accommodation closer to Margaret. I want to explore what this move has meant for them.

- Has it meant increased contact with Margaret?
- What does this mean for their contact and relationship?
- How have their lives changed as a consequence of their move?
- Has this changed Caroline's views about the possible future support they will need?
- What strategies might they, and the family, use to make these decisions?
- What does having Margaret (and other siblings) mean to her?
- What are their significance in her life?
- How important is family support compared to paid support? How do they compliment each other? Is there friction between them?

Date XX 2008 5.15PM

Follow-up interview

This interview was much more free-flowing [maybe I'm getting to understand people's dysarthric speech better!] and Caroline told me a lot about her earlier years – going to university, leaving her job. I got a much stronger sense of who she is. And when I think about the way Margaret describes her – as dynamic and proactive – I can see this much more clearly after this interview.

The move closer to Margaret has been a great success and clearly is working for both of them. But there is no sense that Caroline is dependent on Margaret. They both appear to be very independent. Given Caroline's very high physical support needs you might expect more dependency but this was not evident at all. Caroline [along with her husband] organises her own life and support. Margaret backs this up but doesn't take over. What is it that creates this separate, 'independent' relationship?

Thoughts:

'Independent' relationship between siblings – this sense of an 'independent' relationship is something I'm seeing in some, but not all, sibling relationships. It's interesting because it's an 'adult' relationship – not the non-disabled sibling feeling sorry for, or responsible for their brother or sister with cerebral palsy. It seems to be a two-way thing. How/why does this develop between some siblings but not all?

What variables create this?

Is it about larger versus smaller family size?

Is it about being sisters? – a gender thing?

Is it about living together as children?

Is it about geographic proximity?

Is it about moving out of home in adulthood?

Is it about Caroline being married?

It doesn't seem to be about level of disability.

What about parental ill health and distance?

Need to explore these variables more with others.

Appendix 6 Initial Codes

Family Relationships

Participant Siblings

- Childhood Relationship
 - Doing Things For
 - Doing Things With
- Current Contact
 - Difficulties in the sibling relationship
 - Becoming independent
 - Nature of Contact
 - Advocacy role
 - Appreciating time together
 - Desiring more contact
 - Increasing contact
 - Methods of contact
 - Having contact with participant's children
 - Perception of sibling with disability by nondisabled sibling
 - Sharing things
 - Type of Contact
 - Activities of daily living
 - Providing back-up support
 - Providing emotional support
 - Closer sibling relationships
 - Helping sibling cope with change
 - Sense of guilt
 - Helping with medical issues
 - Providing personal care
 - Having social contact
 - Interacting with paid carers
- Future Support
 - Fitting in with lifestyle
 - Nature of contact
 - Helping nondisabled sibling
 - Sense of responsibility for sibling
 - Making the future right
 - Type of contact
 - Assisting with activities of daily living, medical issues, personal care and social
- Participant's spouse contact
- Views of Spouse
- Proud of sibling
- Sibling with cerebral palsy living with non-disabled sibling

Parents

- Age and health
 - Alzheimers
 - Crisis situation

- Counseling for person with cerebral palsy
 - Empathy for sibling
 - Emotional support for non-disabled sibling
 - In-home care
 - Respite care for sibling with cerebral palsy
 - Lessons for others
 - Linked lives
 - Informing mother about sibling with cerebral palsy
 - Preparation for mother's death
 - Hospitalization of mother
 - Emotional reaction to
 - Nursing home accommodation
 - Visiting mother
 - Providing help to mother
 - Understanding mother's role
 - Respite care for mother
 - Role of siblings
 - Changing roles
 - Dividing up roles
 - Guilt
 - Managing the process
 - Disagreements
 - Proximity
- Concern for the future when parents are not around
 - Being alone
- Estranged mother
- Facilitating parental contact
- Isolation from family
- Keeping the peace
- Proximity to parents
- Remembering dead parents
 - Participation in the funeral
 - Role of father
- Still living at home with parents
 - Anticipated future problems
 - Availability of respite care
 - Not wanting parents to have time to themselves
 - Part of their lives
 - Juggling care and careers
 - Keeping them together
 - Quality of life
 - Resistant to change
 - Service use
 - Helpful individuals
 - Lack of service coordination
 - Need for holistic family view
 - Support provided

Support

- View of sibling contact
- View of child with cerebral palsy
- View of service provision

Other siblings (non-participating)

- Brothers
 - Contact with
 - Help from
 - Intermittent contact
 - Social
 - Deteriorating health
 - Offer to live with
 - Protecting
 - Proximity
- Sisters
 - Closeness of the relationship
 - Resentment
 - Unwelcome
 - Welcome
 - Contact with
 - Help from
 - Intermittent contact
 - Other commitments
 - Social

Spouse

- Failed relationships
- Family view of
- Spouse's ill health
- Support from spouse

Extended family

- Adopted
- Contact with
- Impact on
- In-laws
- Receiving help

Friends

Growing Up

Childhood

- Adoption
 - Feeling isolated
- Communication
- Early intervention
- Family holidays
- Getting a diagnosis
 - Getting therapy
- Impact on sibling relationships
 - An unsettled baby
 - Sympathizing with mother

- Caregiving activities by siblings
- Community reaction
- Friendships
- Jealousy
- Just one of the kids
- Missing out on sibling interactions
- Playing together
- Importance of love
- Parental divorce
- Parental remarriage
- Relationship with Spastic Centre
 - Challenging the rules
 - Treatment
- Rituals

Schooling

- Difficulties at school
- Impact of leaving home to go to school
- Receiving therapy at school
- Going to university

Adolescence

- Boyfriends
- Career choice
- Change in sibling relationship
 - Banter
 - Disagreement
- Time for self

Moving out of home

- Decision to move out of home
- Importance of religion
- Maintaining family contact
- Mother's help
 - Impact on mother
 - Impact on siblings left at home
- Non-disabled sibling leaving home
- Reluctance to move out of home

Living environment

- Adaptations to
- Country life
- Living at home with parents

Interests and hobbies

Personal view of disability

Family moves for services

Involvement with other children with disabilities

The Future

Accommodation

- Dissatisfaction with accommodation
- Financial management
- Geographical location

- Holidays
- In-home respite care
 - Safety
 - Skills of carers
- Independent living in the community
 - Changing requirements
 - Family resistance to
 - Non-disabled siblings' roles
 - Recent move
 - Achievement
 - Adapting to change
 - Change in siblings' roles
 - Changing interests
 - Choosing the place
 - Having needs met
- Pets
- Possible future options
 - Decision making process
 - Getting a carer in
 - Group home
 - Living with sibling
 - Arrangements for
 - Part time
 - Support provided
- Support required
- Support staff
- Views about the future
 - Access to
 - Fears
 - Reassurance
 - Reluctance to discuss as a family
 - Responsibility for
 - Use of respite care

Building networks

Changes in disability services over life time

- Negative
- Positive

Decision Making

- Barriers
- Facilitators

Planning

- Ensuring financial security
- Having family discussions
- Independence of sibling
 - Support networks
- Role of sibling with cerebral palsy

Sibling involvement

- Contacting support agency

- Personality
 - Reliance
 - Type of support
- Health*
- Using Botox
 - Communication
 - Managing continence
 - Experiencing depression
 - Considering end of life decisions
 - GP doctor
 - Experiencing hospital admissions
 - Bequeathing money
 - Employing a private aide
 - Formal complaint to organisation
 - Impact on sibling
 - Lack of support
 - Refusal to take person with cerebral palsy back to hostel
 - Life threatening illness
 - Little change in health
 - Experiencing loneliness
 - Making decisions about
 - Managing medication
 - Mobility
 - Non-disabled sibling's ill health
 - Experiencing pain
 - Building resilience
 - Sensory impairments
 - Swallowing and eating
 - Using the gym
 - Views about health
 - Managing weight
- Work or day activity*
- Getting assistance to update skills
 - Desiring to work
 - Building on past work history and experiences
 - Making retirement plans
 - Getting support at work
 - Traveling to work
 - Having work options
 - Working in disability area
- Non-family support*
- Acquiring independent living skills
- Maturing*

Appendix 7 Focused Codes

Category: Growing Up

Exploring the childhood relationship between siblings
Recounting school experiences
Receiving therapy
Moving the family for services
Influence of sibling variables (e.g., gender, place in family)
Living environment – country or city; living in family home or elsewhere
Experiencing community reactions to disability

Pathways:

1. Coming from the country
2. Coming from the city

Themes:

- Moving out of home for services
- Growing up without specialist services
- Moving the family for services
- Tapping into specialist services

Category: Becoming an Adult

Changing relationship in adolescence
Striving for independence
Leaving or staying in parental home
Getting married
Making friends
Going to work or day program
Ongoing contact between siblings
Maintaining communication between siblings
Feeling the impact of geographic proximity/distance

Pathways:

1. Exercising agency
2. Relying on others

Themes:

- Pushing the boundaries
- Forging an independent path
- Depending on specialist services
- Leaving decision making to parents

Category: Getting Older

Feeling the impact of geographic proximity/distance
Coping with parental ill health and death

Accommodating changes in siblings' health
Planning for the future (or not)
Considering future support needs of all siblings

Pathways:

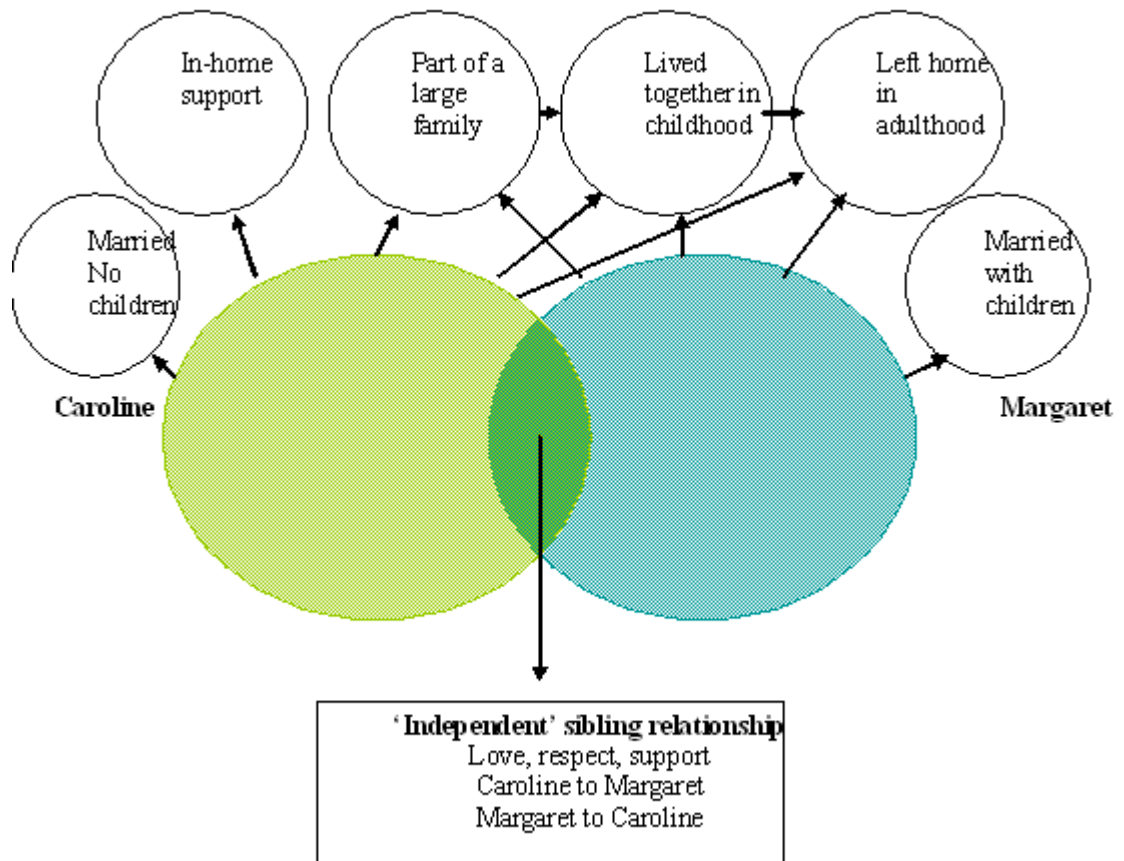
1. Influence of parental status
2. Influence of sibling ageing and ill health

Themes:

- Holding on
- Letting go
- Taking on more responsibility
- Recognising the effects of growing old together

Appendix 8 Example of a Diagram

Emerging ideas and themes related to the relationship between Caroline and Margaret.



Appendix 9 International Peer Reviewed Journal Publications

Dew, A., Balandin, S., Llewellyn, G. (2008). The psychosocial impact on siblings of people with lifelong physical disability: A review of the literature. *Journal of Developmental and Physical Disabilities, 20*, 485-507.

Dew, A., Llewellyn, G., & Balandin, S. (2004). Post-parental care: a new generation of sibling-carers. *Journal of Intellectual & Developmental Disability, 29*, 176-179.

Appendix 10 Conference Presentations

International Conference Presentation Publications

The theoretical and empirical work arising from this doctoral research has resulted in the following refereed publications in international peer-reviewed journals (reverse chronological order):

Dew, A., Balandin, S., & Llewellyn, G. (2009). Impact of historical time and social timing on the life course of adults with lifelong disability and their non-disabled siblings. *Journal of Policy and Practice in Intellectual Disabilities* (6), 2, 103. Published abstracts of the 2nd International Association for the Scientific Study of Intellectual Disability (IASSID) Asia- Pacific Conference, Singapore.

Dew, A., Balandin, S., & Llewellyn, G. (2009). The importance of 'linked lives' in the life course of adults with cerebral palsy and their non-disabled siblings. *Developmental Medicine & Child Neurology* (51), Supplement 2, 44-45. Top 100 published abstracts of the Third International Cerebral Palsy Conference, Sydney.

Dew, A., Balandin, S., & Llewellyn, G. (2008) Instrumental, social and emotional support offered by non-disabled adult siblings to brothers and sisters with cerebral palsy. *Journal of Intellectual Disability Research*, 52(8&9), 714. Published abstracts of 13th World Congress International Association for the Scientific Study of Intellectual Disability (IASSID), Cape Town, South Africa.

Dew, A., Balandin, S., & Llewellyn, G. (2008) Building networks for independence: the experience of adults with cerebral palsy. *Journal of Intellectual Disability Research*, 52(8&9), 717. Published abstracts of 13th World Congress International Association for the Scientific Study of Intellectual Disability (IASSID), Cape Town, SA.

International, National and State Conference Presentations

Abstracts published in conference proceedings (reverse chronological order):

International Conference Presentations

Dew, A., Trembath, D., Dark, L., & Balandin, S. Practitioner Update: Reflection:

Encouraging and Enabling People with Cerebral Palsy to Narrate their Stories.

February, 2009. *Third International Cerebral Palsy Conference*, Sydney,

Australia.

Dew, A., Balandin, S., Llewellyn, G. Adult siblings of people with developmental disabilities: The Australian experience. November, 2007 *Siblings Leadership Network*, Washington, DC., USA (Invited Presentation).

Dew, A., Balandin, S., Llewellyn, G. “What Now?” Negotiating Ongoing Future Support: The views of people who use AAC and their siblings. August, 2007 *Pittsburgh Employment Conference*, Pittsburgh, USA. (Invited Presentation).

Dew, A., Balandin, S., Llewellyn, G. Transitions of Care: Ageing Parents to Adult Siblings. June, 2007. *Molde University College*, Norway. (Invited Presentation).

Dew, A., Balandin, S., Llewellyn, G. Being a Brother June, 2007. *International Association for the Scientific Study of Intellectual Disability (IASSID) Aging Special Interest Group Roundtable*. Oslo, Norway. (Invited Presentation).

Dew, A., Balandin, S., Llewellyn, G. Growing up and growing older: the experiences of seven siblings May, 2007. *Nordic Conference*, Oslo, Norway.

Dew, A., Balandin, S., Llewellyn, G. Sibling Stories: Am I My Brother's Keeper? August, 2006. *International Society for Augmentative and Alternative Communication (ISAAC) Research Symposium*. Dusseldorf, Germany. (Invited Presentation).

Dew, A., Llewellyn, G., Balandin, S. 'I don't know what will happen...it's a worry': Pathways to sibling-caretaking. *Australasian Society for the Study of Intellectual Disability (ASSID), National Annual Conference.* October 2005, Auckland, New Zealand.

National Conference Presentations

Dew, A., Balandin, S., Llewellyn, G. Adult Brothers and Sisters: Different Views and Roles. April, 2007. *National Disability Services (NDS) Annual Conference.* Adelaide, Australia.

Dew, A., Balandin, S., Llewellyn, G. Renegotiating the adult sibling relationship. May, 2006. *National Disability Conference: Ageing.* Melbourne, Australia.

State Conference Presentations

Dew, A., Balandin, S., Llewellyn, G. 'Caring About Each Other': The experiences of adults with and without cerebral palsy. November, 2009. *Brothers and Sisters: Their role in the life of a person with a disability.* Forum held at Centre for Disability Studies, Sydney (Invited Presentation).

Dew, A., Balandin, S., Llewellyn, G. Care Transitions: Adults with cerebral palsy and their siblings. November, 2007 *Post Graduate Research Conference, Faculty of Health Sciences, University of Sydney.* Lidcombe, NSW.

Dew, A., Balandin, S., Llewellyn, G. The transition of care from ageing parents: achieving flexible relationships between adults with cerebral palsy, their siblings and service providers November, 2006. *Cell to Society Research Conference.* Leura, NSW.

Appendix 11 Awards

1. 2006-2009 Australian Research Council (ARC) Australian Postgraduate Award Industry (APAI) Scholarship, A\$76,124 (total for 3 years).
2. 2007 Semantic Compaction Systems (USA). Travel grant of US\$500.00. This grant supported my travel to present at the Biennial Pittsburgh Employment Conference.
3. 2008 SPOT on DD Research grant of \$1,240.00. This grant supported my travel interstate in Australia to interview research participants.
4. 2008 International Society for the Scientific Study of Intellectual Disability (IASSID) Special Interest Group on Ageing travel scholarship to attend and present at the IASSID International Congress in Cape Town, South Africa, August, 2008. US\$300.00.

Appendix 12 Sources of Funding

1. ARC APAI Scholarship A\$76,124 (total for 3 years - October, 2006 to October, 2009)
2. The University of Sydney Postgraduate Research Support Scheme funding grants \$2,219.00 in 2008, and \$928.27 in 2009
3. Faculty of Health Sciences, The University of Sydney Postgraduate Research Support Scheme funding grants \$800 in 2008, and \$690.00 in 2009.
4. SPOT on DD research grant of \$1,240.00 in 2008.