Being the bottom line:

Mothers' experiences of fostering networks that will support their son or

daughter with disabilities

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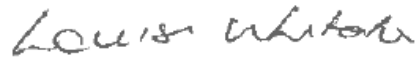
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Declaration

I, Louise Whitaker, 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, Louise Whitaker, understand that if I am awarded a higher degree for my thesis entitled "*Being the bottom line:* Mother's experiences of fostering networks that will support their son or daughter with disabilities" 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.

Louise Whitaker

Signed: Date: 25.3.2013

Dedication

This thesis is dedicated to my mother.

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Chapter One

Context - Why this study?

"Even the death of a carer does not ensure a place in a group home will be allocated to the disabled person left behind. Instead government officials twist the arm of any brother, sister or other relative who can be found, suggesting they take over "just until we find something". Years later, the substitute carer can still be waiting." (Corrigan, 2009)

Corrigan's article, appearing in the Australian weekend papers in 2009, captured public concern about support for people with lifelong disabilities who are facing the death or incapacity of the family members who care for them. Like the public, parents of people with lifelong disabilities worry "Who will look after my child and in the way that I have done?"(Llewellyn, Gething, Kendig & Cant, 2003). Those who have made plans, as the above quote suggests, anticipate that their sons and daughters with lifelong disabilities will be supported by a key person, people associated with the residence in which their son or daughter live and/ or their own financial bequest (Bigby, 1996). However, despite being aware of and worried about impending crises, parents remain reluctant to plan for the future (Prosser, 1997; Pruchno & Patrick, 1999; Walker & Walker, 1998; Weeks et al, 2009; Williams & Robinson, 2001).

Initiatives have developed to promote and support parents' future planning (Etmanski, 2000). These initiatives encourage parents to identify who they want to look after their child into the future and what this care and support might entail. If parents fear that the personal contacts that support their son or daughter with lifelong disabilities, that is, their son's or daughter's support network, are unsustainable in the post-parental phase, these initiatives provide ideas about how their son's or daughter's networks might be revised (Disability Policy & Research Working Group, 2011). This study

examined the networks that parents envisaged supporting their son or daughter with lifelong disabilities into the future.

1.1 The Project : "Moving beyond crisis management: Creating futures for people with disabilities living with ageing parents"

This study was one of a number that were conducted within an ethnographic research project examining personal support networks. The "Moving beyond crisis management: Creating futures for people with disabilities living with ageing parents" research project was funded by the Australian Research Council in 2007 to investigate the networks that support adults with lifelong disabilities[1] and care succession. Participants were purposefully recruited to the research project because of their involvement in networks that were committed to actively developing a positive, meaningful future of an adult family member with lifelong disabilities. An advertisement in the paper for a PhD scholarship to work on this research project caught my attention and I joined the team in 2007. I was recruited to collect and analyse the project data and to design and undertake a concurrent unique study.

Prior to joining the team I had managed the delivery of government programs. In part, my work involved improving access to government funded services. We do not have a family member with lifelong disabilities. However standing alongside my mother as she has declined in recent years, has given me further personal insights into the difficulties involved in securing appropriate and relevant support. I commenced this study as a relative novice to the area of intellectual disability with an interest in the care provided by networks of support and the delivery of government programs that

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[1] The sons and daughters at the centre of the networks that participated in the research project had been diagnosed with intellectual disabilities. However as one of the mothers in this study acknowledged that her son had disabilities but questioned the accuracy of this diagnosis, I have referred to all of the sons' and daughters' disabilities as lifelong.

offer people, particularly those who are socially disadvantaged, services that are accessible and relevant to their needs. Thus, consistent with qualitative research design, this study evolved out of and within the context of this broader research project (Denzin & Lincoln, 2008; Silverman, 2005).

1.2   The Study: "*Being the Bottom Line*: Mothers' experiences of fostering networks that will support their son or daughter with disabilities."

This study investigated mothers' lived experiences of, and ideas about, the networks that support their son or daughter with disabilities. I focused on mothers' experiences because preliminary analyses of both the project data and the literature revealed mothers were integral to the networks that support their son or daughter with lifelong disabilities. The mothers in these networks had an historical perspective of network development and a view of the overall network. Mothers had been described in the literature as "allies and mediators on the ground" (Read, 2000, p.107). However, while the centrality of the mothers in the networks in this study was acknowledged by other network members, elsewhere the care work of women has been deliberately rendered invisible and overlooked (Fine, 2007; Kittay, 1999). By privileging the experiences of mothers, this study avoided perpetuating the invisibility of the care and support provided by women (Fine, 2007).

I examined mothers' ideas about these networks using a phenomenological approach. Using this approach meant that the study did not make any assumptions about mothers' ideas about these networks. It recognised that the term has been used to refer to a range of concepts and looked beyond existing definitions (d'Abbs, 1982; Gottlieb, 1981; Tracy & Whittaker, 1990). Thus, the term "support network" might refer to the sum of the personal contacts by which someone is supported. For example, the networks that support people with lifelong disabilities have been described as "family-dependent" and occupying a "distinct social space" that is dominated by people associated with

human services supporting people with lifelong disabilities (Prosser & Moss, 1996; Todd, Evans & Beyer, 1990). Alternatively, it might refer to the "network of support" that future planning initiatives encourage parents to foster for their sons and daughters with lifelong disabilities (Dillenburger & McKerr, 2010; Etmanski, 2000). Particular network configurations such as a circle of support, neighbourhood networks and/ or webs of interconnected circles of relationships are referred to as the network of support (Etmanski, 2000; Hole, 2007; Klees, 2007; Richards, 2007). Fundamentally, the term is evoked to capture the idea of supportive relationships. However, network relationships may not necessarily be supportive and the support may not necessarily be provided in the context of an ongoing relationship (Tracy & Whittaker, 1990). Thus the concept of a support network is contested and various concepts are referred to as networks that will support sons and daughters with lifelong disabilities into the future. Therefore this study delved into mothers' ideas and experiences of their son's or daughter's networks to ascertain what these networks meant to them.

Future planning is associated with the life stage of late adulthood. In addition to planning for the distribution of their assets and the allocation of their responsibilities, for parents of adults with lifelong disabilities future planning involves securing the trajectory of their son's or daughter's life on a desirable and sustainable course. Life courses are influenced by social and temporal contexts and the networks that support sons and daughters with lifelong disabilities embody these social contexts (Elder, 1994; Hutchison, 2008). Support networks hold the trajectory of lives on course (Kahn & Antonucci, 1980). Mothers are integral to these networks (Grant, 1993; Wellman & Berkowitz, 1997). Through their involvement, they have witnessed the influence of social and temporal contexts on their son's or daughter's lives and networks. Therefore I anticipated that mothers' experiences in these networks would reveal the influence of these contexts.

In summary, I embarked on this study because I was interested in exploring ideas about and influences on networks of support. However, I was equally keen to listen to, explore and acknowledge women's experiences in these networks. I was concerned that an analysis of support networks that focused solely on the person at the centre of the network and/ or features and characteristics of the network might overlook the work involved in fostering these networks and thereby perpetuate the invisibility of women's care work.

1.3   The structure of this thesis

This thesis starts with this chapter and proceeds like a story with three sections: the beginning, the middle and the end. This thesis tells the story of addressing a gap in the literature. However the sequencing of the chapters does not reflect the temporal sequencing of the study. Consistent with qualitative research methods, key elements of the research design, including the research questions, emerged out of the data analysis in the middle, indeed the heart, of the story of this study.

1.3.1   The Beginning

In this, the first chapter I describe why I embarked on this study. In the second chapter, called "Who will look after my child and in the way that I have done?", I argue that the networks parents envisage supporting their sons and daughters with lifelong disabilities when they, that is, their parents, are no longer able to support them, warrant further examination. This argument is based on a review of the literature about the features of the networks that support people with lifelong disabilities. It argues that key features leave sons and daughters vulnerable to their parents' declining capacities. The chapter also describes future planning research and future planning initiatives. The life course perspective provides the basis for the theoretical framework that I describe in Chapter Three. I referred to this framework to conceptualise the nature of the gap in the literature that this study

addressed. This framework incorporates theories about support networks (d'Abbs, 1982; Gottlieb, 1981; Wellman, 2003), social capital (Bourdieu, 1986), social care (Fine, 2007) and social inclusion (Clapton, 2009) into the life course perspective (Elder, 1994; Hutchison, 2005). In Chapter Four, the final one in this section, I identify the research questions and describe the research design.

1.3.2   The Middle: Mothers' experiences

The second section of the thesis consists of five chapters of findings that describe mothers' experiences in the support networks of their sons and daughters with lifelong disabilities and their ideas about networks for the future. Each chapter discusses one of the five scenarios that were identified. The scenario I describe in Chapter Five, "*bringing enquiry*", reveals the influence of mothers' experiences during the childhood of their son or daughter with disabilities. The mothers that highlighted this scenario described the importance of *bringing enquiry* to decisions about their son's or daughter's support. They anticipated t*he family*, actually sisters, and/ or a *circle* will *monitor and advocate* with the *services* that support their brother or sister with disabilities into the future. In Chapter Six, I describe networks that were fostered for the purposes of supporting the *truly adult… life* of a son or daughter with disabilities. Multilayered networks will provide *checks and balances* for the safety of the sons with disabilities in Chapter Seven. The sons described in this scenario live with complex health issues and therefore have high support needs. The networks I describe in the fourth scenario, in Chapter Eight, entitled "*I'll do it one day*", have stalled because steps towards the *independence* of the daughters discussed in this scenario were hampered by parents' inability to agree on a course of action. A fiancée and/ or siblings will be central to these networks into the future. In the final scenario, described in Chapter Nine, entitled "*preparing for… moving on*", *circle thinking* enabled the family to *prepare* for elderly parents *moving on*. In this scenario the family's anticipation of their parents' lives coming to an end prompted the revision of the network that supported the person with disabilities. The networks were revised such that they would be compatible with the support siblings would be able to provide *after the changeover.*

1.3.3   The End

The final section of this thesis consists of two chapters. In Chapter Ten, "*You're the bottom line I guess:*
Fostering networks that will support sons and daughters with disabilities *after the changeover"*, I draw
together a collective story of these mothers' experiences in, and expectations of, the networks that
support their sons and daughters with lifelong disabilities. The narrative of each of the mothers
revealed a network that was uniquely configured to support her son or daughter with lifelong
disabilities. Their collective story reveals commonalities between the networks that they envisaged for
the future and offers a narrative explanation of the network's features and functions. The networks
emerged in layers with the negotiation of transitions and turning points and the agency of mothers as
the bottom line. In the final chapter, Chapter Eleven, "Implications of this Study", I consider
implications for future planning initiatives and for further research into fostering networks for the
purposes of future planning.

Chapter Two

"Who will look after my child and in the way I have done?": Reviewing the literature about the networks that support people with lifelong disabilities; future planning research and future planning initiatives.

One of the greatest concerns of parents of people with lifelong disabilities is "who will look after my child and in the way that I have done?" (Llewellyn, Gething, Kendig & Cant, 2003, p.13). Future planning initiatives encourage parents to address this concern by adequately planning for the future care of their son or daughter with lifelong disabilities (see for example, Barrett, 2007; Bartnik, 2008; Bigby, Ozanne & Gordon, 2002; Botsford & Rule, 2004; Carers Queensland, (n.d); Etmanski, 2000; Family Advocacy NSW, 2007; Jay, 2003). Future planning, also referred to as parental planning, involves parents making provisions for their son's and daughter's future guardianship, financial and residential arrangements (Bigby, 2000). Parents anticipate siblings and/ or services will 'look after ... (a) child' into the future (Bigby, 1996). However, future planning initiatives encourage parents to foster the networks that support their sons and daughters with lifelong disabilities (Disability Policy & Research Working Group, 2011). Siblings and/ or services associated with a residential arrangement might be incorporated into these networks. This chapter argues that while key elements of parents' future plans have been discerned, such as, siblings and/ or services, the networks that parents anticipate supporting their son or daughter with lifelong disabilities into the future have not been fully examined.

It describes parental planning models (Bigby, 2000) and the networks of support promoted by future planning initiatives. The gap in knowledge about these networks, that is, parents' ideas about the networks that might support their son or daughter into the future, which this study assisted in addressing, is highlighted at the end of the chapter. The next chapter describes the theoretical framework through which this gap was conceptualised. Concepts such as support networks,

transitions and turning points which are referred to in this chapter are defined in the next chapter. In brief, for the purposes of this study, social support networks are "that set of personal contacts through which the individual maintains his (or her) social identity and receives emotional support, material aid and services, information and new social contacts" (Walker, MacBride & Vachon, 1977, p.35). [2] These personal contacts might include family, friends, neighbours, support workers and other professionals. However, the study set out to revisit the idea of support networks and therefore this definition is indicative of what might be entailed in a network of support rather than prescriptive. The chapter describes the strategies employed in reviewing the literature before considering why the networks that support sons and daughters with lifelong disabilities might need to be fostered in anticipation of their parents' decline. It identifies what it is about the networks that support adults with lifelong disabilities that leave these sons and daughters vulnerable to the declining capacities of their parents.

2.1 Reviewing the literature

A deliberately inclusive process was used to identify information about the networks that support people with lifelong disabilities and planning for their support into the future. The Web of Knowledge and PsychInfo databases were mined using search terms that included "future planning", "parental planning", "learning disability", "intellectual disability", "social support", and "support networks". Initial searches, conducted on 2007, investigated the research to date. Repeated up to and including 2013 tracked subsequent developments. Future planning programs were also identified through web searches of relevant government and non-government sites. Thus the opinions of parents, policy and program designers and academic researchers were all taken into account in order to understand who parents envisage looking after their son or daughter with disabilities into the future.

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[2] I have adopted the following conventions. When referring to the networks that:

- support adults with lifelong disabilities, I refer to "networks that support";
- parents are encouraged to develop for the purposes of future planning I refer to "networks of support"; &
- parents are purposefully and progressively fostering I refer to "networks that will/ would support".

**2.2	Networks that support people with lifelong disabilities leave them vulnerable to their parents' declining capacity.**

The lifestyles of sons and daughters with lifelong disabilities are vulnerable to the declining capacities of their parents in part because of the nature of the networks that support people with lifelong disabilities. The networks that support sons and daughters with lifelong disabilities cluster around their parents and/ or families and/ or people associated with human services that support people with lifelong disabilities (Clement & Bigby, 2009, Cummins & Lau, 2003; Forrest-Jones et al, 2006; Hall & Hewson, 2006; Lippold & Burns, 2009; Myers, Ager, Kerr & Myles, 1998). Read (2000) suggested that the broader community, including people associated with human services, are "hostile" (p.89) to people with lifelong disabilities, and Stehlik (2000) claimed parents, particularly mothers, "struggle" (p.170) against these attitudes. As such, because of these social contexts, the lifestyles of sons and daughters with lifelong disabilities are reliant on their parents', and particularly their mothers', advocacy. Therefore, in the absence of the purposeful revision of the networks that support their sons and daughters with lifelong disabilities, as parents decline, their sons' and daughters' lifestyles might be threatened or rendered unsustainable. This section examines key characteristics and features of the networks that support people with lifelong disabilities.

### 2.2.1.	Family-dependent, self-sufficient, and rarely extending beyond immediate family

Many people with lifelong disabilities are supported by networks that have been described as "family-dependent, self-sufficient, and rarely extending beyond immediate family" (Prosser & Moss, 1996). Grant (1993) described a culture of family embeddedness in which parents anticipated and accepted little help from people outside the household. They accepted moral support, help in crises, tolerance and a respect for privacy, but little else. People with lifelong disabilities mostly live and socialise with their parents until well into their midlife (Qu, Edwards & Gray, 2012; Bigby, 1996). As their parent's friends are predominantly older than sons and daughters with lifelong disabilities, as parents age the

networks that support these sons and daughters shrink. If the person with lifelong disability has no spouse, after parents, the next closest kin will be siblings, followed by aunts and cousins (Bigby, 2000). Siblings, aunts and cousins, are therefore vital parts of the networks that will support sons and daughters with lifelong disabilities into the future. Siblings may constitute one quarter of the social support network of adults with lifelong disabilities (Krauss & Seltzer, 1993). Whether living with their mother, father or another relative, living with and sharing a life with a few family members leaves the living arrangements and lifestyles of sons and daughters with lifelong disabilities vulnerable to the changing circumstances of those few people.

2.2.2 Distinct social space

People with lifelong disabilities occupy a "distinct social space" (Cummins & Lau, 2003; Clement & Bigby, 2009; Todd, Evans & Beyer, 1990, p.215). This space is distinguished by smaller, dense networks that cluster around family, described above, and groups of people with lifelong disability and/ or human services staff. Whether living in residential settings or not, people with lifelong disabilities typically circulate in situations that, in addition to immediate family members, are characterized by interactions with co-residents or co-participants in day programmes, and service workers who are paid to support them (Forrester-Jones et al., 2006; Robertson et al, 2001; Verdonschot et al, 2009). Contact with non-disabled members of the public is likely to be mundane, impersonal and fleeting, characterized at best by casual acquaintances rather than supportive friendships. Despite living in the community, people with lifelong disabilities "remain outside looking in" (Myers, Ager, Kerr & Myles, 1998). Therefore, in the absence of parents, apart from a few family members or parents' friends, the people sons and daughters with lifelong disabilities might turn to for support are service personnel and/ or people who may have limited capacity to provide the variety of support needed.

2.2.3   Sites of Struggle

The networks that support people with lifelong disabilities are also characterised by "sites of struggle" (Stehlik, 2000). Stehlik (2000) identified sites at which differences of opinions about attitudes to people with disabilities collide and struggle for influence. For Stehlik (2000) differences were associated with differences in narratives about disability. Llewellyn (2003) also described a division in the networks that support people with lifelong disabilities. She described a division between categories of network members, that is, family versus services. Each is discussed next.

Llewellyn's (2003) older parent carer biography describes the evolution of a site of struggle between professionals/ services and families/ parents. Llewellyn's (2003) biography begins with parents' discovery of their son's or daughter's impairment. As parents sought help for their child, and became increasingly disappointed and frustrated with the help that was available, they developed what Llewellyn (2003) referred to as "an enhanced sense of parental responsibility" (p.152). They became steadfastly protective of their son or daughter with lifelong disabilities. Parents developed their own expertise, formed from experiences "outside the circle of experts" (Llewellyn, 2003, p.159). They drew on and developed this expertise as they faced what were described as "life challenges" (Llewellyn, 2003, p.159). Thus parents grew to trust their own wisdom and experience before they would trust professionals working in services associated with the disability sector. The struggle between services and parents emerged over a life time. This struggle related to differences in opinions about the lifestyle and support of a son or daughter with lifelong disabilities. Some of the current population of aged parents disengaged from services to avoid these sites of struggle. Divisions emerged in the networks that supported a son or daughter with lifelong disabilities. The networks split between services and family. Paradoxically, therefore, older parents who had soldiered on ensuring the best for their sons and daughters with lifelong disabilities, almost despite professional opinion and the services they were offered, found themselves asking people and services which they had experienced as hostile to support their son or daughter into the future. As they anticipated their reducing capacity to protect

their sons and daughters with lifelong disabilities from this hostile environment, parents looked to it

for their son's and daughter's support. When planning involved trusting the support of their son or

daughter with lifelong disabilities to those with whom they had struggled, parents were reluctant to

plan for the future (Llewellyn, 2003). Parents had stood alongside their sons and daughters with

lifelong disabilities as they negotiated with professionals and/ or services. Without this support, they

feared their son or daughter with lifelong disabilities would be vulnerable to professional opinions that

did not account for the uniqueness of their circumstances.

Stehlik (2000) described a similar, yet more pervasive struggle. She described the struggle against the

changing meta-discourses that circumscribe the lives of people with disabilities. She referred to the

custodial/ eugenics perspective and a technocratic/ corporate perspective (Stehlik, 2000). These

perspectives differ but they share a view of people with lifelong disabilities as problems to be

managed. Public opinion and social policy reflect and embody these meta-discourses. Institutional

living enacts the "custodial / eugenics discourse" to which Stehlik (2000, p. 175) referred; whereas

social integration represents the "technocratic/ corporate perspective" (Stehlik, 2000, p.180). For

Stehlik (2000) therefore, the struggle in the networks about the preferences of an individual son or

daughter with lifelong disabilities was only one dimension to the conflict. The struggle also related to

different perspectives and narratives about disability. Sons and daughters with lifelong disabilities rely

on their parents to stand alongside them in these struggles. Therefore the incapacity of their parents

potentially exposes sons and daughters with lifelong disabilities to opinions and services reflective of

these meta-discourses.

2.2.4   Mothers

Parents, particularly mothers, hold a significant and central position in the networks that support

adults with lifelong disabilities (Grant, 1993; Stehlik, 2000). Their central and pivotal location in their

son's or daughter's network is indicative of their primary responsibility for their sons' and daughters' support. Their position also indicates that mothers are integral to their son's and daughter's lifestyles. The networks that support sons and daughters with lifelong disability change considerably over time. However the most stable part of the network is the "main supporter", which is mostly mothers (Grant, 1993). Therefore the loss or decline of parents, and particularly mothers, challenges the integrity of the overall network. Grant's (1993) analysis of the networks that supported 78 people with lifelong disabilities confirmed the hands on responsibilities of mothers. Fathers provided practical day to day help but they did so with much less regularity than mothers. What is involved in this hands-on responsibility?

2.2.5   Extended caring role

Mothering is most commonly associated with personal care, in particular intimate personal care. However, the care mothers provide their sons and daughters with lifelong disabilities also includes negotiating their son's or daughter's interaction with the community. Studies into mothering of people with lifelong disabilities have revealed the sophisticated nature of the work that is involved (Kittay, 1999; Panitich, 2003). It includes complex therapeutic routines, supporting sons' and daughter's negotiations with their surrounding environment, advocating and mediating and; social action. Read (2000) described mothers' role as that of "ally and mediator on the ground" (p. 99). The demands of various therapeutic routines made this "direct caring work" (Read, 2000), "maternal work" (Kittay, 1999), or "caring for" (Traustadottir, 1991), more exacting and more complex with sons and daughters with lifelong disabilities than with other sons and daughters. This hands-on care is not the only gap in care that might be left when mothers are no longer able to provide this support.

Mothering also involves both interpreting the social environment to a son or daughter with lifelong disabilities and socialising sons and daughters into their surroundings. The inaccessibility of the physical environment and the emotional costs of insensitive, discriminatory comments are examples of

the many challenges the social environment poses. Mothers negotiate difference in the contexts of these environments. They do so by either expecting their son or daughter to conform and / or influencing society to accept the difference that their son or daughter represents. Grant (2007) described how privacy and trust are protected by "tactics of concealment" (p.18) in which the work involved in protecting the dignity of sons and daughters with lifelong disabilities is rendered invisible. By necessity this work is both discrete and subtle. Their emphasis is their son's or daughter's integration into, or inclusion by, society rather than the care and support that they provide to achieve it. Mothers are "constantly presenting an alternative image of [their] child to the outside world ... constantly changing their [that is, society's] minds" (Kittay, 1999, p. 396). This constant negotiation of difference is emotionally challenging and associated with the vicarious experience of exclusion (Kittay, 1999; Read, 2000). Mothering also requires involvement and negotiation with a multiplicity of human services.

Intervening in relation to people with disabilities and their position within society is unique to mothering a child with a lifelong disability (Carpenter, 2009; Darling, 1988; Goodley, 2007; Green, 2007; Landsman, 2005; Leiter, Krauss, Anderson & Wells, 2004; McKeever & Miller, 2004; Panitich, 2003; Reiger, 2000; Ryan & Runswick-Cole, 2008; Wickham-Searl, 1995). This work has been described as the "extended caring role" (Traustadottir, 1991), "political activism" (Wickham-Searl, 1995), social reform (Wickham-Searl, 1995), "crusadership" (Seligman and Darling, 1997,) and/ or acting as "mediators and allies on the ground" (Read, 2000). These interventions were born out of frustration and disappointment with human services and community attitudes (Kittay, 1999). Examples of this work include: developing educational programs; initiating parent support groups; educating professionals and; work on committees and boards (Darling, 1988). Mothers work to change practices and policies in the field of disabilities or, in some cases, to develop services where none exist (Wickham-Searl, 1995). Those with sufficient resources, such as those who were well educated and supported by friends and family for their public work, were more likely to engage in social reform.

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Despite limited prior political experience they were extremely successful in their pursuits. Their efforts promoted changes in policies and practices that reached far beyond their immediate families (Barkmann, 2002). However the advocacy, education and program development they undertook were related directly to their family's needs (Wickham- Searl, 1995). While mothers relied on relationships with experts in the field of disabilities to support their cause the authority of their vision originated in their lived experiences of caring for children with disabilities (Kittay, 1999). This work developed the contexts from which their sons' and daughters' support was drawn. Without their work, their sons and daughters with lifelong disabilities would not have access to appropriate facilities and services and /or be included as citizens.

2.2.6 Summary

The networks that support people with lifelong disabilities may not hold when parents of sons and daughters with lifelong disabilities are no longer able to provide the support they once had because:

- parents, particularly mothers, are pivotal in the networks that support their son or daughter with lifelong disabilities;
- there are few people in the "distinct social space(s)" (Todd et al, 1990) occupied by people with lifelong disabilities that are able to assume the role of parents into the future;
- sons and daughters with lifelong disabilities rely on parents, particularly mothers, in their negotiations at "sites of struggle" (Stehlik, 2000);
- the inclusion of sons and daughters with lifelong disabilities is contingent on mothers lobbying for change in the broader social environment in their "extended caring role" (Traustadottir, 1991); and
- the quality, expertise and nature of the support provided by mothers is hidden, therefore unrecognised and difficult to emulate.

Thus, in the absence of the purposeful nurturance of alternatives to the support provided by parents, that is, planning for the future, it is unlikely that the networks that support sons and daughters with lifelong disabilities will sustain the lifestyles of sons and daughters into the future.

2.3   Future Plans

Parents' planning for the future care and support of their sons and daughters with lifelong disabilities has been subjected to examination for more than 20 years (Grant, 1993; Joffres, 2001; Krauss & Seltzer, 1993; Llewellyn, 2003; Mansell & Wilson, 2010; Prosser, 1997; Pruchno & Patrick, 1999; Walker & Walker, 1998; Weeks, Nilson, Bryanton & Kozma, 2009; Williams & Robinson, 2001). Future planning has increasingly been recognised as part of a lifelong process (Llewellyn, 2003; Pruchno & Patrick, 1999; Senate Committee Report, 2011; Stehlik, 2000). Four possible plans have been described in the research to date: avoidance of planning resulting in "crisis resettlement" (Prosser, 1997); "key successor" plans (Bigby, 2000); residential plans (Bigby, 2000); and the bolstering networks of support (Dillenburger & McKerr, 2010). However, as summarised in Table 1, research has primarily focussed on the pre-planning, planning and post-parental phases immediate to this transition.

2.3.1   Phases of Planning

This section discusses the phases of planning, from pre-planning to post-parental care. However, the pre-planning phase dominates the research reported to date (Bowey & Mc Glaughlin, 2006; Grant, 1993; Haley & Perkins, 2004; Mansell & Wilson, 2010; Prosser, 1997; Weeks et al, 2009; Walker & Walker, 1998). This phase has been described as a phase in which parents are reluctant to plan or are contemplating options (Joffres, 2001). Parents in this phase are reluctant to plan, because the options before them do not offer appropriate, alternative arrangements. The factors that influence parents' contemplation, and are associated with their reluctance, are summarised in the far left column of Table 1.

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Parents prefer the status quo and hope to maintain it for as long as possible (Freedman, Krauss & Seltzer, 1997). The lives that they have established with their sons and daughters with lifelong disabilities, often over many years of changes and adaptations, are comfortable; possibly the best imaginable (Chou, Lee, Lin, Kroger & Chang, 2009; Heller & Factor, 1993; Prosser, 1997). Parents often enjoy mutually supportive relationships with their sons and daughters with lifelong disabilities (Bowey & McGlaughlin, 2007; Grant, 1993; Walker & Walker, 1998; Williams & Robinson, 2001). Parents appreciate their sons and daughters with lifelong disabilities "helping out at home" (Williams & Robinson 2001, p.60). In turn, their sons and daughters enjoy caring for their parents (Shaw, Cartwright & Craig, 2011). These relationships have been described as intense and interdependent. Joffres (2001) identified that the parents who preferred to maintain the status quo had minimal responsibilities for care-giving and care-giving was central to their self-concept. Thus, when the living situation parents share with their sons and daughters with lifelong disabilities are stable and mutually supportive, parents want to maintain the status quo. They defer planning because they are still coping (Gilbert, Lankshear & Petersen, 2007). Fundamentally the known costs and benefits of the current situation are preferred to unknown possibilities (Grant, 1993). However, this is not to suggest that parents are not worried about the future. As indicated by the title of this chapter, families might have settled upon comfortable arrangements, but they worry about who will support their sons and daughters with lifelong disabilities into the future (Eley, Boyes, Young & Hegney, 2009; Mansell & Wilson, 2010; Pruchno & Patrick, 1999; Taggart, Truesdale-Kennedy, Ryan & McConkey, 2012; Walker & Walker, 1998).

Table 1:

Parental plans in the pre-planning, planning and post-parental phases.

Pre-planning	Plans/ planning	Post-parental phase
Crisis Resettlement Plans Maintaining the status quo associated		

with: • Mutually supportive parent/ child relationships • Minimal care-giving • Care-giving as concept of self • No viable alternatives **/**No successor • Freezing with indecision / **"**the hardest and most painful decision of my life!" • Fear of name on waiting list will trigger loss of control • Fears that living independently will result in lack of support		
Residential Plan Reluctance to make residential plans associated with: • "Right' residential situation not available • Long waiting lists • Political instability and possible funding cuts • History of difficult relationships with service providers • History of unsatisfactory services from the public sector • Lack of information, support and guidance	• registration on a waiting list • Supported accommodation living with peers with disabilities: companionship, sense of community, protection, permanency & home-like • Care-giving by ageing mothers is a career that transcends co-residence	• Group home
Key Successor Plans Implicit (unspoken) plan for key successor associated with: • oral agreements with a family member • siblings have other family caring responsibilities	Key person responsible for advocacy rather than personal care • Sisters call to "fix the mess"	• Transition a gradual process managed by the successor. • Formal services could not substitute 'key person' role. • Key person exerted considerable control. • Having a 'key person' did not equate to residential stability.
Network of Support Plan	• Extended family, friends, financial security, accommodation, statutory bodies, employment and day care.	• Formal services replace 'primary carers'. • Family provide affective support incidentally. • Friendship tied to a specific context.

Parents are concerned that the comfortable co-residence that they have established with their son or

daughter is not only unsustainable, but also increases the dependence of their sons or daughters with

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disabilities on them (Eley et al, 2009). Grant (1993) described basic personal conflicts parents faced when they were weighing up interdependence and reciprocity against the 'right' of a son or daughter with disabilities to independence. Some researchers associate parents' anxieties about future planning with parents' fears of confronting their own mortality (Walker & Walker, 1998) or the relinquishment of a significant role in their lives (Joffres, 2001) .

Even though the parent who said, it was "the hardest and most painful decision of my life!" was referring to her decision to place her child in a residential service prior to the 1990s, the emotion she expressed reflected the difficult emotional terrain future planning traverses (Mirfin-Veitch, Bray & Ross, 2003, p.99).   While 'letting go' in this situation is likely to imply a move to a group home rather than a larger institutional setting, the prospect of a move out of home provokes similar emotions (McConkey, Kelly, Mannan & Craig, 2011). Parents avoid facing the prospect of their relative living elsewhere (Prosser, 1997). They have witnessed the disregard and rejection of sons and daughters with lifelong disabilities in residential settings. "Letting go" raises fears for safety (Grant, 1993, p.51). Researchers have equated it with the "the launching phase" (Freedman et al, 1997; Prosser, 1997). 'Letting go' is also associated with feelings of guilt (Bowey & McGlaughlin, 2007). Even though mothers' care-giving career transcends residential placement, mothers fear that their son or daughter with lifelong disabilities will feel unwanted if they encourage them to move out of the family home (Bowey & McGlaughlin, 2005; Seltzer, Greenberg, Krauss & Hong, 1997). Parents are particularly concerned that others might take advantage of their son or daughter when in a more independent situation. Indeed the word 'independent' triggers parents' anxieties. It signals a decline in support rather than the increased support that might be required (Bowey & McGlaughlin, 2005). Even discussing the possibility of the future can be cause for upset (Bowey & McGlaughlin, 2007). As an example, one mother had disallowed further social work visits because the social worker:

> ... would say, when something happens to me, where do you want him to go? ... She was making me poorly, so I didn't let her come again. ... They kept coming to see him and upsetting him. (Bowey & McGlaughlin, 2007, p.46)

Older parents are also reluctant to seek help for fear that once they come to the attention of services and/ or extended family, they will lose control of the process of change (Gilbert et al, 2007; Walker & Walker, 1998). Some parents are simply holding on and "waiting for the next crisis" (Joffres , 2001, p.307).

Parents postpone residential planning because alternative living arrangements to those they currently enjoy with their son or daughter with lifelong disabilities are not desirable or appropriate. The 'right' alternative would offer companionship, a sense of community, protection, permanency and a home-like environment (Bowey & McGlaughlin, 2007; Eley et al, 2009; Seltzer et al, 1997; Shaw et al, 2012; Weeks et al, 2009). Alternatives to the family home rarely meet these standards (Bowey & McGlaughlin, 2005). Rimmerman & Muraver (2001) found mothers who live with their sons and daughters with disabilities have fewer "undesired life events" (p.202) associated with the support of their son or daughter than those who supported their son or daughter with disabilities to live away from home. Their lack of confidence in service provision has been repeatedly identified as influencing parent's propensity to plan (Llewellyn, 2003; Mansell & Wilson, 2010; Stehlik, 2000). Parents failed to plan and / or that parents planned to avoid service use because of inadequate supply. Dillenburger & McKerr (2010, p.7) concluded that "inadvertently the huge amount of high quality care given freely and willingly by parents unintentionally reinforces ... inactivity of service providers" and reduced service demand. However, it is unreasonable to expect parents to carry full responsibility for care and future planning against a back drop of severe shortage of both services and networks. Paradoxically therefore, poor and unpredictable services not only deter parents from making residential plans for the future, they also reduce pressure on service demand, which in turn reduces the options available.

Parents postpone planning because they know service change is inevitable. Human services associated with the disability sector change unpredictably in response to changing social policy, changes in political will and funding cuts and opportunities (Gilbert et al, 2008; Joffres, 2001). Parents postpone planning to exercise influence over the actual choices they make (Gilbert et al, 2007). Parents' inability to conceptualise viable alternatives was also associated with a lack of information about options (Grant et al, 1998; Heller & Factor, 1991; Walker & Walker, 1998).

Parents also defer planning because they are unwilling to impose care responsibilities onto other family members (Heller & Arnold, 2010). Being involved in disability-related activities, living in closer geographical proximity to their brother or sister with disabilities and, family closeness predisposes siblings to taking on a significant caring role into the future (Greenberg, Seltzer, Orsmond & Krauss, 1999; Heller & Kramer, 2009). An implicit plan, involving an implied understanding with a family member often precedes an explicit plan (Bigby, 1996). Planning stalled when multiple midlife roles "pulled" siblings from involvement (Greenberg et al, 1999). Parents postpone planning to accommodate sisters as they balance the demands of caring for their parents, their brother or sister with disabilities and their own family.

Conversely, planning is triggered by a crisis or dramatic change (Prosser, 1997). The declining health of sons and daughters with lifelong disabilities and/ or their mothers are common triggers (Freedman et al, 1997; Seltzer & Heller, 1997). When such crises trigger the formulation of a plan, Smith, Tobin & Fullmer (1995) revealed parents' provisional plans are tested. Discussions might begin with a person who has implicitly agreed to accept responsibilities into the future. Families who had engaged with services in the past were more likely to make plans associated with services (Heller & Factor, 1991; Krauss & Seltzer, 1993; Prosser, 1997). The four types of plans that have been identified to date are discussed in the next section.

To my knowledge, only one study has investigated and described the implementation of plans or the post-parental care phase (Bigby, 1996). Bigby (1996, 1997, 2000) identified three types of plans: key person succession plans, residential plans and financial plans. These are discussed in more detail later in this section. Bigby's (1996) study investigated parental planning, the nature of transition, changes of residence and primary carers and the nature of informal and formal support. She analysed data from in-depth, semi-structured interviews with 62 adults with lifelong disabilities aged over 55 years, who had lived with their parents until at least the age of 40. People with whom they had close relationships were also interviewed. Bigby (1996) discovered parents had indeed realised their ambition of holding on for as long as possible. Most plans were implemented following the death or incapacity of parents. Yet the process was gradual rather than a sudden event. Even where a residential or a financial plan, such as a will, were successfully implemented, which most were, the key person or parents managed the process of transition. The transition was described as a time of enormous emotional upheaval however elements of stability were maintained through on-going contact with familiar family and friends. Change continued in the "post-parental phase" (Bigby, 1996, p.306). It included changes to the skills of the son or daughter with lifelong disabilities as well as changes to their circumstances. For example, several changed address a number of times. Compared with residential plans, key person succession plans resulted in more stability over time.

In summary, future planning is clearly an emotionally challenging process that is negotiated over time and is influenced by numerous factors. It is hampered as much by the paucity of available alternatives as by the difficult emotional terrain it traverses. Planning is positively associated with higher family income, higher levels of family social support, greater abilities of sons and daughters with lifelong disabilities, increasing parental stress, previous engagement with services and, having a sibling who will accept caring responsibilities.

2.3.2 Parental planning models

Four types of parental plans have been described: "crisis resettlement" plans (Prosser, 1997, p.30); key person succession plans (Bigby, 1996), residential plans (Bigby, 1996) and plans for "networks of support" (Dillenburger & McKerr, 2010).

2.3.2.1 Crisis Resettlement

 "Crisis resettlement" refers to the circumstances that might arise in the absence of a clear plan for the future (Prosser, 1997). This is the situation to which Corrigan (2009) referred in the weekend newspaper article. It involves the urgent resettlement of a son or daughter with lifelong disabilities following the death or decline of the parent with whom they have lived and shared their lives. Resettlement might involve moving into an unfamiliar home in an unfamiliar neighbourhood. In fact, it was the story of the resettlement of a gentleman in a crisis that prompted the application for the funding for the research project to which this study contributed. Crisis resettlement is to be avoided because it is traumatic for the person with lifelong disabilities and stressful for the people responding to the crisis. The lives of family and friends are interrupted and it creates unplanned demand on community resources.

2.3.2.2 "Key person" successor plans

"Key person" successor plans refer to parents' plans to appoint someone to assume responsibilities for the support of a son or daughter with lifelong disabilities into the future (Bigby, 1996). When parents anticipate their son or daughter with lifelong disabilities will continue to be cared for by family it will most likely be their sibling, probably their sister, to whom they are referring (Bigby, 1997; Burke, Taylor, Urbano & Hodapp, 2012; Davys, Mitchell & Haigh, 2010; Grant, 1993; Greenberg et al., 1999; Heller & Arnold, 2010; Heller & Factor, 1991; Heller & Kramer, 2009; Krauss & Seltzer, 1993). The siblings that will assume responsibilities into the future are most likely to be daughters, who have provided care to elderly parents and have a close relationship with a brother or sister with lifelong

disabilities (Bigby, 1993). Sisters will accommodate co-residence for periods of time. However, they anticipate supporting their brother or sister with lifelong disabilities in an alternative living arrangement (Greenberg et al, 1999). Grant (1993) described a hierarchical progression of support from mothers to fathers, daughters, daughters-in-law, sons and, sons-in-law.

A 'key person' is responsible for the 'oversight of well-being' (Bigby, 1996). "Key successors" assume responsibility for three or more instrumental tasks. These include: "decision-making, financial management, formal or legal roles, mediation, monitoring, primary care provision, managing medical needs, coordinating, skill development and, back up of other network members" (Bigby, 1997, p.337). They have a strong advocacy role and many manage the process of transition from parental care. Key people are stable members of the network and are not affected by the residential or occupational mobility of the person. These relationships are based on love and affection and/ or duty and responsibility, such as having made a commitment to a parent.   Further, they are acknowledged and respected by service providers whether or not formal guardianship arrangements are in place. Sisters rather than brothers are usually key people. Key people are the "overseers"; direct personal care is provided by "informal primary carers" (Bigby, 1997).

McGraw and Walker (2007) mapped the complex socio-cultural terrain sisters negotiate as key people. Their study examined the relationships between siblings with lifelong disabilities and their sisters who were their "successor carers". They found that like mothers, sisters were constantly presenting an alternative image of their brother or sister with lifelong disabilities to the outside world. Sisters challenged the devalued position of their brother or sister with disabilities. However sisters failed to challenge the gendered family care role that had been socially prescribed for them. Rather, they were described as perpetually stricken with guilt about the inadequacy of the care they provided. Arnold, Heller & Kramer's (2012) subsequent study signalled a possible alternative voice. Unfortunately the study referred to siblings when the participants were actually sisters. The sisters in this study wanted to be included in future planning and informed about the system. These women also called for

someone to "fix the mess" of the disability support system (Arnold, Heller & Kramer, 2012, p.378). Thus, these studies indicate sources of future support and relationships between different aspects of support but they do not map out a network of support.

2.3.2.3 Residential Plans

The third model of parental planning was a residential plan (Bigby, 2000). Residential plans ranged from sharing the family home with siblings and/ or paid support people, living in one's own home and / or residential services. As stated above, parents were looking for situations that offered "protection, permanency and a home-like environment" (Weeks et al, 2009, p.186). Others preferred homes that were located in familiar geographical areas, offered excellent staff support, and accommodated smaller groups (Bowey & McGlaughlin, 2007). Others wanted ageing in place (Shaw , Cartwright & Craig, 2011). Some wanted their sons and daughters to have companionship and a sense of community (Eley et al, 2009; Seltzer et al, 1997). However, simply placing a son's or daughter's name on a waiting list of a residential service was also considered a residential plan for the future (Krauss & Seltzer, 1993). To my knowledge, only one study described a networked approach to future support.

2.3.2.4 Network of support

Dillenburger and McKerr's (2010) study recommended parents plan for a "network of support" to ensure sustainability of their son's or daughter's lifestyles. They proposed a network that included: extended family, friends, financial security, accommodation, statutory bodies, employment and day care to "break the cycle of low supply/ high demand" (Dillenburger & McKerr, 2010, p.5). This network of support, they proposed, would hold even when parents were no longer able to contribute to the networks in the way they once had.

2.3.3 Summary

In summary, these studies revealed adults with lifelong disabilities will be supported by combinations of sisters and/or services associated with their future living arrangement. They may have a key successor. Plans will emerge through the negotiation of difficult emotional terrain. However, apart from one study that indicated a network of support was needed for the future, to my knowledge, the connections between various aspects of support have not been fully examined (Dillenburger & McKerr, 2010). Future planning initiatives, discussed next, persuade parents to conceptualise a network of support.

2.4 Fostering networks of support for the purposes of planning for the future.

Future planning initiatives encourage parents to plan (Barrett, 2007; Bartnik, 2008; Bigby, Ozanne & Gordon, 2002; Botsford & Rule, 2004; Carers Queensland, (n.d); Etmanski, 2000; Family Advocacy NSW, 2007; Jay, 2003). These initiatives describe a process for planning, support families in planning and, identify varying features of the networks of support, and the functions they might serve.

2.4.1 Planning processes

The planning processes described in future planning initiatives follow person centred (O'Brien, 2000; Sanderson, 2007; van Dam, Ellis & Sherwin, 2008) and strengths based planning approaches (Saleebey, 2006). A person centred plan "reflects what is important to the person, their capacities and the supports that the person requires" (van Dam, Ellis & Sherwin, 2008, p.6). Person centred approaches are associated with positive changes to people's lives (Emerson & Stancliffe, 2004; Robertson et al, 2001). These approaches align the person and their allies around a common understanding of what is desirable for the person now and into the future (O'Brien, 2000). The emphasis is on reinforcing what

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sons and daughters with lifelong disabilities are able to do and enjoy doing rather than on what they are unable to do. The focus on the person's wishes and goals may at times be in conflict with their parents' wishes. Nevertheless, for the purposes of future planning, parents are encouraged to describe the futures that they want their son or daughter with lifelong disabilities to experience, identify how that future will be supported and make arrangements for that support to be in place. Parents are persuaded to engage with others, that is, to foster networks of support, to implement the plans. There are three stages to planning.

In the first stage of planning, parents articulate what would be entailed in a 'good life' for a son or daughter with lifelong disabilities. The "good life" for sons and daughters with lifelong disabilities is derived from their hopes and dreams rather than what is obvious or readily available (Etmanski, 2000; Reinders, 2002). Future planning initiatives provide guidelines to assist parents to think about what a good life for their son or daughter might entail. The preferences of the authors of the planning processes are written into these guidelines. For Etmanski (2000), for example, plans should address "fellowship, home, meaning, choice and wealth". Other programs talk about aspiring to "a life that is closely aligned to normal as possible... an ordinary life" (Hole, 2007, p3). "What life is like for young people" of a similar age was another reference point (Hole, 2007, p3). Another program, referred to the "five valued experiences" of "friendships and relationships; sharing ordinary places; making choices; being respected and having valued social roles and; contributing" (Sanderson, 2007). Thus these are not simply a person centred, strengths based approach. They are influenced by the meta-discourses to which their authors prescribe. Hole's (2007) privileging of 'normal' for example, reflects ideas associated with philosophies of Normalisation and Social Role Valorisation (Wolfensberger, 1972). This first stage of the planning process also addresses the emotional terrain of planning.

Future planning initiatives acknowledge parents are worried and their fears might be heightened as they plan. Fears of death, change and dreaming are acknowledged alongside the "courage" to enable sons and daughters with lifelong disabilities to move into their own lives (Etmanski, 2000, p.7). Parents reassure one another, through their personal accounts in manuals and information sessions and during story telling in group sessions, of the importance of nurturing a 'good life' for their sons and daughters with lifelong disabilities (Etmanski, 2000; Klees, 1996; Hole, 2007). Fundamentally, parents implore one another to not allow their fears to deter them from planning.

The second stage of planning involves identifying resources that enable plans to be implemented. Parents are invited to look beyond a human service response and mobilise their own assets in the first instance (Etmanski, 2000). Assets might include parents' lifelong capital in terms of what they know about their son or daughter and their support preferences, the family's social capital in terms of their family and friends and their economic capital in terms of their will and estate. Person-centred planning has been critiqued for its emphasis on planning rather than implementation (Claes, Van Hove, Vandevelde, VanLoon & Schalock, 2010; Mansell & Beadle-Brown, 2004). However, these initiatives encourage parents to implement their plans. These initiatives focus on motivating parents to plan through their descriptions of planning processes and inspirational stories of the experiences of other parents. A few however, provide ongoing support for parents as they implement their plans.

The third stage in planning involves actually mobilising networks by inviting people to join circles and, welcoming new people and interests into the lives of their sons and daughters with lifelong disabilities. "Pushing hands" involves exploration, development and maintenance of personal networks (Etmanski, 2000). Klees (1996) and Hole (2007) described the experiences of two groups of parents who came together to enable their plans for their sons and daughters with disabilities to be realised. The next section describes the range of support provided by these initiatives in the planning process.

2.4.2 Support provided by future planning initiatives

Future planning initiatives support parents to plan in several ways. Initiatives provide:

- information about planning processes. Local examples of these include "Planning for the Future Project" (Carers NSW, 2007) and "The Odyssey" (Family Advocacy NSW, 2007). In addition to providing practical information about wills and family trusts, these initiatives encourage families to plan through their stories about the experiences of other families endeavours. They describe the unique networks parents have developed to support their son or daughter with lifelong disabilities and the processes they have used to go about it;

- skilled facilitators to support the planning process and the establishment of personal support networks. "Pave the Way" (Mamre Association, 2007) is an example of one such program. These facilitators work alongside parents. They facilitate the process of planning. They do not make the plan or foster the network;

- meetings of family groups over several weeks for planning and executing support networks. "Pathways to Leadership", the "Carer's Support Initiative Program" and, "Family Collective Program"(Carers Queensland, 2012) are examples of these. These programs lead a group of families through the process of planning. Group programs enable families to witness, and learn from the experiences of other families as they plan for the future support of their son or daughter with lifelong disabilities and foster their networks;

- skilled case managers for individualised support (Bigby, Ozanne &Gordon,2002). The case management described in these programs encompasses facilitation while supporting parents through the process of 'letting go' and the creation of support networks; and

- funding for individualised support packages to resource the plans parents have made. The "Community Living Initiative" (Department of Communities, 2011) and the "Support Living Fund" (Department of Family and Community Services- Ageing, Disability and Home Care, 2012) are examples. Eligibility for funding under the "Community Living Initiative" is based on

a Community Living Plan. The plan needs to describe how the dreams and visions for "my own life, my own home, in communities where we all belong" will include:

- a network of family, friends and supporters;
- clarity in, and support for, decision making and governance;
- plans for participation, contribution and community engagement;
- a place to live that's home;
- appropriate technical assistance with information and planning;
- opportunities to 'imagine better' and explore new alternatives;
- a practical plan including any resources required to support community living; and
- partnerships and shared responsibility(Department of Communities, 2011, p.7).

These are local examples of the future planning initiatives that are now available to support parents in planning for the future. Consistent with the "extended caring role" (Traustadottir, 1991), some parents have chosen to join together to implement the plans they had made.

Planned Life Advocacy Network Inc. (Etmanski, 2000), Homes West Inc. (Hole, 2007) and Deohaeko Support Network (Klees, 1996) are non-government organisations that have been created by parents to enable the implementation of plans for the future support of their sons and daughters with lifelong disabilities. The parents who are involved in these organisations have planned for the future support of the sons and daughters with lifelong disabilities. Joining with other parents over many years enabled their plans to be realised. In addition to enjoying the support of other families, joining Homes West Inc. meant individualised support funding could be channelled through an organisation over which members exercised influence (Hole, 2007). The parents involved in Deohaeko Support Network chose to create an intentional community in which their sons and daughters with lifelong disabilities would be supported to live into the future. In each case, a group of parents chose to work together over many years under the auspice of the non-government organisations they had created, to build a comprehensive network that would support their sons and daughters into the future. Their

documented experiences (Etmanski, 2000; Hole, 2007; Klees, 1996) inform other future planning initiatives. Community Resource Unit, Queensland, for example, regularly invites Janet Klees from the Deohaeko Support Network (Klees, 1996) to share her experiences with groups of parents who are considering planning for the future. The Community Living Initiative (Department of Communities, 2011) acknowledges the influence of a similar funding program initiated by the Western Australian Disability Services Commission (Disability Services Commission, Western Australia) model, which in turn acknowledge Planned Life Advocacy Network Inc (Etmanski, 2000). The next section considers the features of the networks these programs encourage parents to plan for.

2.4.3 Features and functions of the networks of support described by future planning initiatives

The networks of support described in future planning initiatives enable sons and daughters with lifelong disabilities to pursue a 'good life' (Etmanski, 2000). This section provides an overview of the features and functions of networks of support that will result from these planning processes.

2.4.3.1 Features of the Network of Support

Future planning initiatives often refer to a "network of family, friends and supporters" (Department of Communities, 2011); a "circle of support" (Falvey, Forest, Pearpoint & Rosenberg, 2003; Jay, 2003; Richards, 2007; Rodgers, M. 2006); neighbourhood based networks (Hole, 2007) and; webs of relationships (Etmanski, 2000). Fundamentally, future planning initiatives encourage parents to foster relationships between their son or daughter with lifelong disabilities and as many other people as possible. The implication is that the more people a son or daughter is known by, and with whom he or she shares common interests, the better his or her life might be. Introductions through family, friends and school/ work colleagues are encouraged (Etmanski, 2000).

"Circles of support" refer to a "group of people who meet together on a regular basis to help somebody accomplish their personal goals in life" (Rodgers, 2007, p.1). Decisions are made in accordance with the wishes of the person at the centre of the circle of support. Circles of support are described as spaces in which support is freely given, "holding and inviting relationship" (Klees, 2007). The best circles involve listening well and with heart, personal commitment, inviting and welcoming, taking thoughtful action, mutuality, and determination and perseverance in the face of adversity (Klees, 2007). However, the term is often loosely applied. Etmanski (2000) for example, uses the terms "personal networks" or "circle of friends" interchangeably with "circles of support".

The relationship between the circle of support and broader relationships is also discussed. Hole (2007) for example, referred to the layering of circles: innermost is the person; inner circle (anchors); second circle (allies and associates) and outer circle (assistance and agendas). Etmanski (2000) encouraged a web of relationships by reinforcing links between circles members and other people with whom a son or daughter might relate. The web was strengthened by the connections between people in the network of support. In knowing one another, information flows freely and people can share tasks with one another.

Geographically based, neighbourhood networks of support were also described. Homes West families for example, described making "hard choices", perhaps sacrifices (Hole, 2007). By "stay(ing) put in one place, becom(ing) connected and involved" in communities themselves, their sons and daughters with disabilities became known in the neighbourhood as a member of a family (Hole 2007, p.54).

2.4.3.2 Functions of the Network of Support

Networks will enable a son or daughter with lifelong disabilities to pursue their lives by providing "fellowship, home, meaning, choice and, wealth" (Etmanski, 2000). Fostering "fellowship" potentially addresses several of the network features that rendered sons and daughters with disabilities vulnerable to the declining capacities of their parents. Increasing the number of people in the network

addresses concerns about the network size. While inviting parents' friends might perpetuate the ageing nature of the network, these invitations encourage relationships with people outside the "distinct social space" associated with human services targeting people with disabilities. Neighbourhood relationships also break away from this "space". The welcoming, respectful spaces provided by circles of support contrast with the discriminatory "hostile" societal context parents had guarded against.

Parents were encouraged to pursue their ideal living arrangement for their son or daughter with lifelong disabilities; to secure a location which was safe and accessible, where there was good public transport, easy access to services and, convenience to parents. The living arrangements these initiatives encourage parents to pursue for their sons and daughters with lifelong disabilities looked beyond group homes and/ living with siblings. Housing arrangements that offer security of tenure and comparability to their sons' and daughters' peers were favoured. While options were listed, group homes were the least desirable. Planned Life Advocacy Network (Etmanski, 2000) for example, created future homes for sons and daughters with disabilities from the existing housing stock. They expressed a clear preference for parents giving their sons and daughters with lifelong disabilities the opportunity to live in a home that they owned. They suggested sons and daughters might be supported by roommates paid in-kind through rent relief and funded support workers. The sons and daughters with lifelong disabilities in the Deohaeko Support Network lived in an intentional community established by their parents (Klees, 1996). Government funding was secured for the personal support of the Homes West sons and daughters and was channelled through the Homes West organisation (Hole, 2007). Thus the responsibility for the future homes of sons and daughters with lifelong disabilities was clearly seen to reside with their parents.

The provision of valued social roles was a further function of the networks these programs encouraged. "Making of a contribution", paid or otherwise, was seen to bring meaning to the lives of sons and daughters with lifelong disabilities (Etmanski, 2000). Valued social roles were also seen to

confront discrimination (Klees, 1996). Occupying a valued social role would in and of itself bring the respect due to the person in that role (Wolfensberger, 1972). Therefore, as an example, following on from the previous section, as the role of home owner was more valued than that of tenant. Home ownership was preferred for the status it represented.

Future planning processes recommend the documentation of the preferences of sons and daughters with lifelong disabilities to enable their active participation in the decisions that affected their lives. It was assumed that the support network would advocate for these preferences into the future (Etmanski, 2000). However, how they would do so was not specified.

Planning ensured sons and daughters with lifelong disabilities would inherit parents' financial and social capital. In part this was through the provisions parents made in their wills. However, it was also due to future returns on the social and financial capital parents invested in the networks. Some initiatives involved several families working together to establish and manage organisations through which housing was secured, funds for support were distributed or future support was guaranteed (Carers Queensland, n.d.; Etmanski, 2000; Hole, 2007; Klees, 1996). Etmanski (2000) referred to families of people with lifelong disabilities as "the Tribe". He promoted this tribe as more trustworthy than the greater population, because of their shared experiences of shared connections with people with lifelong disabilities. The relationships parents had developed with this tribe therefore represented a form of social capital.

2.5   Need for further investigation

Future planning initiatives encourage parents to address the vulnerability of their sons and daughters with lifelong disabilities to their, that is, parents', declining capacities by fostering the networks that will support their sons and daughters into the future. Future planning initiatives encourage parents to foster a network of support for their son or daughter with lifelong disabilities. Networks of support will

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extend the range and number of network members, secure connections with "the tribe", foster a circle to hold ideas about the "good life" and, guard against unpredictable change by articulating the preferences and lives they envisage for their sons and daughters with lifelong disabilities (Etmanski, 2000). In doing so, reconfigured networks will extend beyond the "distinct social space" and "family-dependent" membership of the networks that support people with lifelong disabilities (Todd et al, 1990). Rather than an identifiable 'key successor', these networks would include a 'circle of support'. To date, while sisters and living arrangements have been identified as integral to the future support of sons and daughters with disabilities and the interactions between these have been acknowledged, the networks parents envisage, as opposed to the networks future planning initiatives suggest, have not been fully analysed. This study addressed this gap. It investigated the networks that parents envisage supporting their sons and daughters with lifelong disabilities when they, that is, their parents, are no longer able to.

2.6   Conclusions

This chapter argued that more needs to be understood about the networks that will support people with lifelong disabilities when their parents are no longer able to. To date aspects of the future support of sons and daughters with lifelong disabilities have been identified. Sisters and /or their living arrangements will feature in these networks. However, the interconnections between various elements of future support have not been comprehensively mapped. Future planning initiatives promote the fostering of networks of support, but the nature of these networks has not been discerned. This study addressed this gap by examining the networks parents envisage supporting their sons and daughters with lifelong disabilities into the future. The next chapter maps out the theoretical framework through which this study conceptualised the networks that will support a son or daughter with lifelong disabilities into the future.

Chapter Three

Theoretical framework

"Nothing is intelligible without the past. Not because it is the past but because it is the missing body of the present." **(Nicolson, 2008)**

When Nicolson (2008) redesigned Sissinghurst, his inherited garden, the changes he made were not only inspired by the garden he envisaged for the future. His ideas accounted for the landscape that had surrounded the garden for centuries. Like a garden, the networks that parents envisage supporting their sons and daughters with lifelong disabilities through the transition to post-parental care and into the future, are influenced by the temporal and social contexts in which they are embedded. The life course perspective recognises these influences on the networks parents, like gardeners, nurture for their sons and daughters with lifelong disabilities (Hutchison, 2008).

This chapter describes the theoretical framework through which I conceptualised the networks parents foster with their son or daughter with lifelong disabilities. This framework incorporates theories about support networks (d'Abbs, 1982; Borgatti et al, 2009; Buskens, 2002; Gottlieb, 1981; Tindall & Wellman, 2003; Wellman & Berkowitz, 1997), social capital (Bourdieu, 1986; Daly &Silver, 2008), social care (Daly & Lewis, 2000; Fine, 2007; Rutman, 1996) and social inclusion (Abrams, Hogg & Marques, 2005; Clapton, 2009) into the life course perspective (Elder, 1994; Hutchison, 2008).The chapter begins with a brief overview of the framework. It then reflects on future planning research and initiatives from the perspective of each component of the framework. The chapter concludes by theorising about the gap in current research that was described in Chapter 2, that is, the features and function of the networks that parents foster for their sons and daughters with lifelong disabilities for the purposes of future planning.

3.1 Theoretical framework for this study

This study was informed by the life course perspective (Elder, 1994; Hutchison, 2008). As depicted in Figure 1, the life course perspective acknowledges the influence of social and temporal contexts on stages of human development. Planning for the distribution of assets and the allocation of responsibilities is associated with the life stage of late adulthood. Social network theory (d'Abbs, 1982; Borgatti et al, 2009; Gottlieb, 1981) was incorporated into the framework to explain structural features of the person's immediate social context. It provides a language to describe and analyse these features. Some of the assets parents distribute were explained by Bourdieu's (1986) ideas about social capital. Influences on parents' allocation of their responsibilities for care were explained by theories about social care (Fine, 2007) and social inclusion (Clapton, 2009). In brief, future planning sustains the trajectory of the life of a son or daughter with lifelong disabilities through the transition to post-parental care and beyond. Planning enables the appropriate distribution of parents' financial, cultural and social capital and the allocation of parents' responsibilities for the care and support of their son or daughter with lifelong disabilities. The next section describes the foundation of the framework, the life course perspective.

3.2 Life Course Perspective

The Life Course Perspective, represented in Figure 1 (Hutchison 2008), builds on life cycle models of human development. It acknowledges lives are shaped by interactions between characteristics of the person, the environment and time (Hutchison, 2008). Characteristics of the person such as biological, psychological, and/ or spiritual dimensions are only one influence on the life course of the person. Environmental factors such as the physical environment, culture, family, social movements, communities and formal organisations also influence the life course.
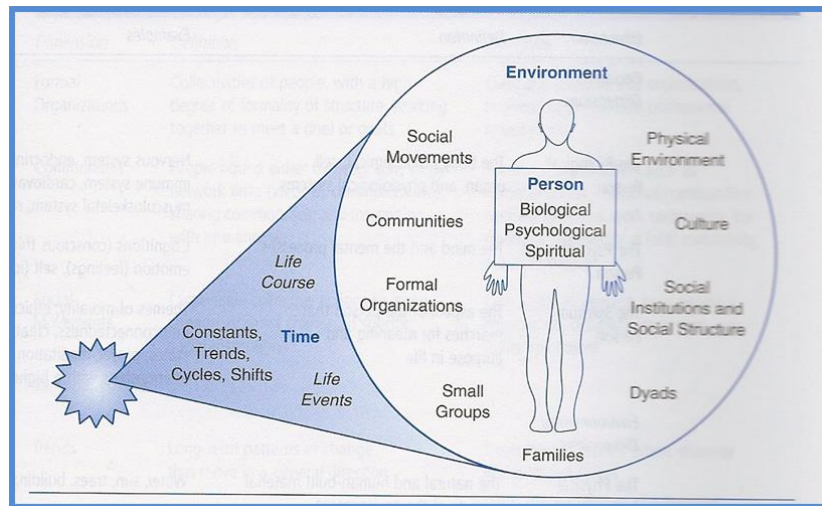
Figure 1: *The life course perspective (*from Hutchison 2008, p10)

Finally, 'time' related factors such as, chronological age, common life transitions, life events, and 'trends, cycles and shifts', also influences the life course. The life course perspective emerged from critiques of assumptions of "universal, fixed, sequential stages of individual and family development" (Germain 1994 in Hutchinson 2008, p. 10) in traditional life-cycle models of human development. This perspective recognises the influences of temporal and social contexts on stages of life-cycle development.

3.2.1 Cohorts, transitions, trajectories, life events and turning points

Several concepts emerge from considering human development within temporal and social contexts. Cohorts, transitions, trajectories, life events and turning points are staple concepts of the life course perspective. They describe influences on the course of a life over time. Key concepts from the life course perspective will be used throughout this chapter to explain the findings of previous research reported in Chapter 2. These are defined below.

- Cohorts refer to a "group of persons who were born at the same historical time and who experience particular social changes within a given culture in the same sequence and at the same age" (Hutchinson, 2008, p.11). As an example, sons and daughters with lifelong disabilities who are currently living with older parents were born into a social policy era which promoted institutional care of people with lifelong disabilities. As Llewellyn's (2003) parent carer biography described, these parents had increasingly protected their son or daughter with lifelong disabilities from the 'hostile' environments they, and their son or daughter, encountered.

- "Transitions" are "changes in roles and statuses that represent a distinct departure from prior roles and statuses" (Hutchinson 2008, p.12). They are associated with life stages such as the transition from late adulthood to the end of life (Bigby, 2000; Bigby, Ozanne & Gordon, 2002; Blacher, 2001; Grant, 1993; Quails, 1997; Seltzer, Krauss, Hong & Orsmond, 2001; Ytterhus, Wendelborg, & Lundeby, 2008). Stages of late and very late adulthood are associated with the loss of social roles through retirement, death of a partner, accepting the care of adult children, institutionalisation, the search for personal meaning often through reminiscence, and the allocation of assets and responsibilities to others (Hutchison 2008). Future planning research outlined in the previous chapter, addresses the latter of these. When older parents prepare for the end of their lives they usually have two abiding concerns: leaving a fair will and resolving problematic relationships, either between themselves and a child or between children (Victor, 2005). As such, future planning, that is, making provisions for home, care, financial and legal responsibilities for sons and daughters with lifelong disabilities can be seen as parents' preparation for the transition to the end of their lives.

- "Trajectories" refer to "long-term patterns of stability and change, which usually involve multiple transitions". Trajectories are the course of a person's life or the course of a particular aspect of a persons' life, such as parenting. From this perspective, the 'good life' that future planning initiatives encourage parents to describe for their son or daughter with lifelong disabilities is the life trajectory parents' want for their sons and daughters (Etmanski, 2000; Reinders, 2002).

- A "life event" is described as a "significant occurrence involving a relatively abrupt change that may produce serious or long lasting effects." (Hutchinson 2008, p.15) While life events are inevitable, careful management helps to maintain lives on preferred trajectories (Hubert-Williams & Hastings, 2008). The 'crisis resettlement' that resulted from the unanticipated illness or death of a parent that was described in the media article in Chapter One is an example of a life event (Corrigan, 2009; Prosser & Moss, 1996).

- A "turning point" is described as a "life event that produces a lasting shift in the life course trajectory" (Hutchinson 2008, p.18). Life events that have served as turning points close or open opportunities; make lasting change on the person's environment and/ or change the person's self-concept, beliefs or expectations (Rutter, 2008). Llewellyn's (2003) older parent-carer biography identified several turning points in parenting trajectories. These included "finding out" a son or daughter had a lifelong disability; "declaring parental responsibility"; "seeking help", which involved public acknowledgement; "developing expertise" in parenting and negotiating "life challenges" (Llewellyn, 2003).

3.2.2 Future planning – a stage in parents' lives

Future planning is associated with late adulthood. It involves parents distributing their assets and allocating their responsibilities. The plans that have been described, that is the naming of a 'key successor' and/ or residential arrangements, identify the people to whom parents intend allocating responsibilities for the care of their sons and daughters with lifelong disabilities (Bigby, 2000). Consistent with a transition, research has described future planning as a process of change that occurs over time (Bigby, 1996; Bowey & McGlaughlin, 2007; Joffres, 2001; Prosser & Moss, 1996; Smith, Tobin & Fullmer, 1995; Taggart et al, 2012). Even the repeated confrontation with parents' reluctance to plan might be understood as consistent with a process of transition.

From a life course perspective, parents hold the trajectories of the lives of their sons and daughters with lifelong disabilities on a course for as long as possible. Once they have established a trajectory, such as living together successfully, that trajectory is held unless a life event such as parents' ill health or an impending transition triggers a change. Examples of this include previous involvement with services leading to a residential plan (Bigby, 1996) or the avoidance of residential plans due to a history of difficult relationships with service providers (Joffres, 2001; Mansell & Wilson, 2010). Similarly, siblings who enjoyed a close relationship throughout their lives are more likely to be included in plans for the future. Reluctance to signal change by placing a son's or daughter's name on waiting lists or even suggestions of the need for future planning, could also be interpreted as older parents protecting the life trajectory of their sons and daughters with lifelong disabilities, as well as their own.

Does the "tone of frustration" about parents' reluctance to plan (Llewellyn, 2003, p.157) suggest disrespect for timing in the phases of parents lives? Research recognised future planning traversed difficult emotional terrain. However, with their failure to plan parents were commonly blamed in the

literature for thwarting the lives of sons and daughters with lifelong disabilities. Gilbert, Lankshead & Petersen (2007), for example, questioned the fairness of expecting adults with lifelong disabilities to negotiate a shift that the authors described as a move toward adulthood, in accordance with the timing of their parents' lives rather than their own. In doing so, Gilbert et al (2007) prescribed an adult life as one which is not lived in the same household as parents. They also failed to acknowledge the influences of the contexts which may have resulted in sons and daughters with lifelong disabilities living with parents throughout their lives (Gilbert et al, 2007). Planning for holding a trajectory on course was confused with a different stage of family life.

Future planning for parents of sons and daughters with lifelong disabilities is a stage in parents' lives that is rendered more complex by the nature of the responsibilities these parents were planning to allocate.   Rather than negotiating the transition of a son or daughter with lifelong disabilities into adulthood, as might be implied by the articulation of a 'good life', the networks that parents foster will more readily ensure the trajectory of a son's or daughter's life will stay on course through the transition to post-parental care.

3.3 Networks – keeping a life on course.

Social network theory explains how social support networks are able to keep the trajectories of lives on course (d'Abbs, 1982; Wellman & Berkowitz, 1997). It emerged out of social network analysis. Social network analysis is the study of social structure (d'Abbs, 1982; Borgatti, 2009; Wellman & Berkowitz, 1997). It aims to understand how social structures facilitate and constrain opportunities, behaviours and cognitions. Analyses have described the size, density, clustering and reachability of networks. This theory has developed its own language.

Social structure is said to be comprised of a set of actors (nodes) with relationships connecting pairs of actors. These relationships are referred to as ties. The ego is the person at the centre of some

networks and networks have holes (Borgatti, 2009; Burt, 1992; Goyal & Vega- Redondo, 2007). Holes refer to gaps in the networks. Bridging these holes provide opportunities into new networks and ideas.

3.3.1 What is a social support network?

A number of structures are referred to as social support networks. A social support network is said to be "that set of personal contacts through which the individual maintains his (or her) social identity and receives emotional support, material aid and services, information and new social contacts" (Walker et al, 1977). Networks may be in the form of a social convoy (Kahn & Antonucci, 1980; Kikabhai & Whittaker, 2005), that is, a core group of people within a social network who support the person at the centre of the convoy over time, indeed over a life time. The obvious group to fulfil this function is immediate family, but membership is not necessarily confined to family. The group may comprise friends and/ or community members such as school teachers, support workers or neighbours. The social convoy acts as both a buffer and connection to broader networks. The term "personal communities" (Chua et al, 2009) has also been used to refer to multilayered networks that have an inner, densely knit and multiplex core and an outer layer that is sparse and segmented. This inner core is described as more stable when people know one another as well as knowing the person at the centre. Networks might also refer to "naturally occurring forms of social support in the everyday life of ordinary citizens" (Gottlieb, 1981, p.31). The Seebohm report (1968), one of the first that referred to harnessing the support of a community, said "the notion of a community implies the existence of a network of reciprocal social relations, which among other things ensure mutual aid and give those who experience it a sense of well-being" (p.147). Therefore, this concept is not limited to any particular form. As identified in the previous chapter, for the purposes of this study I have adopted Walker et al's (1977) definition. I chose this definition for its inclusiveness. It does not prescribe any particular structure. Instead it focuses on what these relationships provide.

3.3.2   Keeping trajectories on course

By maintaining social identity, providing emotional support, material aid and services, information and new social contacts, support networks can potentially keep the trajectories of lives on course (Walker et al, 1977). The social convoy in particular maintains the trajectory (Kahn & Antonucci, 1980). Networks that are small, dense, culturally homogenous, lowly dispersed and have strong ties reinforce the social identities of their members. People in networks configured in this way are less likely to encourage change. The "homophily principle" indicates people cluster around people of similar race, ethnicity, age, religion, education, occupation and gender (McPherson, Smith-Lovin & Cook, 2001). People choose to relate to people with whom they share social characteristics and this reinforces their social identity (White, Godart & Coron, 2007). Resources such as material aid, information and new contacts are accessed through trusted sources. Trust refers to the level of confidence that people have that others will act as they say or are expected to act, or that what they say is reliable (Buskens, 2002). Trust increases through 'network embeddedness', that is, being known to people through other people, but it also increases with 'temporal embeddedness', that is, repeated transactions between people over time (Buskens, 2002). Links to other networks, such as links across network "holes" (Burt, 1992), increase access to resources. Thus more diffuse networks offer more pathways to resources (Granovetter, 1973). While they may not necessarily be supportive, networks reinforce the trajectory of member's lives.

3.3.3   Potential influences of the networks that support people with lifelong disabilities on the trajectories of their lives.

Being supported by networks that are "family-dependent, self-sufficient, and rarely extending beyond immediate family" and the "distinct social space" of people associated with the disability sector of human services, means son's and daughter's social identities are prescribed by family and disability (Clement & Bigby, 2009; Lippold & Burns, 2009; Power, 2008; Robertson et al, 2001; Todd et al, 1990).

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Apart from fleeting contacts with other members of the community, access to emotional support, material aid and new contacts is mediated by family and/ or people associated with the disability sector. In networks of these configurations, parents influence the trajectories of the lives of this sons and daughters.

In addition to the membership, the size of the networks that support people with lifelong disability also render these sons and daughters vulnerable to the declining capacity of their parents. Small and dense social convoys reinforce social identity, are emotionally supportive and foster trust. However, the loss of network members threatens the sustainability of the network. Conversely, future planning initiatives promote the fostering of as many relationships as possible (Etmanski, 2000). These initiatives encourage members of the social convoy to provide opportunities for sons and daughters with lifelong disabilities to mix with the broader community. These connections negotiate paths through hostile environments to people and networks who welcome a son or daughter with lifelong disabilities. As well as reinforcing the sustainability of the network, encouraging relationships with more and diverse people clearly enables access to further resources.

The structure of the social convoy and its relationship to the broader network has not been fully examined. Mothers hold a pivotal position within the social convoys of their sons and daughters with lifelong disabilities. Being supported by services associated with the disability sector may necessitate service involvement in the social convoy. The struggles that have been described may indeed emerge from ongoing service involvement in this intimate space (Stehlik, 2000). It is not clear if the 'sites of struggle' within the networks represent struggle between members of the social convoy, that is, between domains within the social convoy, as well as between the social convoy and the broader network (Stehlik, 2000).However, the extended caring role of mothers does refer to mothers' advocacy in wider networks (Panitich, 2003; Reiger, 2000; Traustadottir, 1991).

Parent's plans for a 'key successor' to assume responsibilities of parents within the networks that support their sons and daughters with lifelong disabilities, is indicative of the significance of this role. These plans ensure parents' responsibilities in these networks will be fulfilled into the future. However, these plans do not introduce changes to structures that necessitate a pivotal oversighting position in the network.

Future planning initiatives encourage parents to revise the structure of the networks that support their son or daughter with lifelong disabilities. By fostering of a circle of support (Barrett, 2007; Hole, 2007; Klees, 2007; Richards, 2007), relationships with the 'tribe' (Etmanski, 2000) and neighbourhood relationships (Hole, 2007; Klees, 1996), larger social convoys with greater diversity of membership might emerge. Larger social convoys could compromise network density. However future planning initiatives manage this risk by repeatedly encouraging strong ties between members. Homophily is reinforced, potentially minimising sites of struggle, as new members are invited by parents on the basis of parents' judgement about members' trustworthiness. Familiarising more members of the social convoy with parents' ideas about the preferred life trajectory of a son or daughter informs the social convoy of the trajectory they might aspire to support. Such strategies might relieve parents of their pivotal role.

In summary, while it is understood that small, dense networks protect the trajectory of the lives of sons and daughters with lifelong disabilities, the loss of a member of a small network, such as a parent, leaves a significant gap. Future planning initiatives encourage larger networks. Yet they warn against compromising the protection of density. Parentals plans appear to retain the integrity of the structure of the networks that support sons and daughters with lifelong disabilities. However, future planning initiatives encourage significant changes to the social convoy. Overall, while features of the social convoy have been identified, interactions between key people, the social convoy and/ or broader network have not been fully investigated.

3.4   Social care

When parents worry over who will care for their child and the way they might do so their worries

mirror questions raised more broadly about social care (Daly & Lewis, 2000; Harper, 2006). 'Care' is a

slippery term. On the one hand, care has been understood as a form of meaningful work, as social

solidarity, as an expression of interpersonal relationships and as a source of personal meaning. On the

other hand it has been reduced to a set of household duties for women, recast as a form of custodial

protection or fashioned as a product to be packaged and sold for corporate profit (Fine, 2007). Care

has been defined as both a positive concern for another and the performance of tender acts of

kindness and on the other hand, worry, control and self-sacrifice (Fine, 2007).

Care has come to be portrayed as a pejorative term. When care is associated with control, it is

associated with being in the subordinate position of being the cared for. Being cared for denies

subjectivity and reinforces the agency of the carer. One is done to rather than with. Renaming 'care'

to 'help' or 'personal support' provided by friends or in the context of freely given relationships is said

to emphasise interdependency in caring relationships. While this has proven popular, for Fine and

Glendinning (2009) such a simple linguistic shift does not, and cannot, address the real concerns of

power imbalances embedded in caring.

Responsibility for care provision has shifted over time. Hoschhild (2003) described four domains of

care provision. The 'traditional' model of care is that of unpaid care provided by women. The

'postmodern' ideal of care is that of the image of a 'super mum' in which ideal women are seamlessly,

proficient in multiple domains in their lives and over time. In both cases, much of this work by women

is rendered invisible within the family and community. Feminist debates have pushed for the

acknowledgement, and validation, of the significant 'caring' contributions of women (Rutman, 1996;

Ryan & Runswick-Cole, 2008; Twigg & Atkin, 1994; Wickham-Searl, 1995). Sadly however, uncovering

the burden of care women hold, did not go as planned. People who were recipients of women's care

resented being referred to as a burden. They called for the acknowledgement of reciprocity in caring relationships and the recognition of the care people who are cared for contribute. The third domain, 'cold modern care', referred to formalised institutional care. In relation to this study, the residential services of the past as well as current group homes arrangements might be described as 'cold modern care'. The fourth domain, 'warm modern care', is more aligned with an 'ethic of care' (Knijn & Kremer, 1997; Sevenhuijsen et al, 2003). Under this model care is acknowledged as a social responsibility alongside justice and rights. It:

> seeks to sustain the ideal of egalitarianism, promoting shared caring between men and women, with formal services used when necessary to supplement and extend the capacity of the family to support those who need care (Sevenhuijsen et al, 2003, p.302).

Gendered divisions of care are said to be diminishing under 'warm modern care' as men are increasingly providing care, albeit in the context of personal relationships such as marriages and partnerships. Recognising social care as a social responsibility implies different but adequate resourcing. Concerns remain that in the absence of due recognition of the value of care through adequate resourcing, 'warm modern care' might further exploit the unpaid work of female family members. The social care context influences parents' ideas about networks that will support their sons and daughters with lifelong disabilities in several ways. These are discussed next.

3.4.1   Influences of social care context on the care that will be provided.

Parent's future plans, as identified to date, align with the domains in Hochschild's taxonomy (in Fine, 2007). "Key successor" plans, are similar to the 'traditional' model of unpaid care or the 'post-modern' model in that they rely on a person who is often the sister of the son or daughter with lifelong disabilities. The timing of planning to accommodate the midlife responsibilities of siblings suggests that these plans fit the 'post-modern' model. 'Crisis resettlement' and 'residential' plans fit 'cold modern

care'. Within this domain a form of institutional care, such as that provided in a group home, will care for sons and daughters with lifelong disabilities into the future. While this might appear to shift the responsibility from family, Seltzer et al (1997) confirmed care-giving transcends residential placement. The 'networks of support' that are proposed by both Dillenburger and McKerr (2010) and future planning initiatives, equate with 'warm modern care'.

Care provision is gendered and while gender differences in parenting as well as the gendered nature of 'key successor' plans have been identified, the expertise and experience that these women bring to this work has not necessarily been acknowledged. Deliberately subtle approaches to the provision of care and support may in part contribute to the lack of acknowledgement of women's care work. Grant (1993) described how mothers deliberately conceal their care work to maintain the privacy and dignity of their son or daughter with lifelong disabilities. The focus of the processes employed in future planning initiatives, that is, the person-centredness of the approach, also blinkers the view of the work involved in fostering networks of support. Failure to acknowledge this work denies the expertise and amount of work involved.

Elements of the work of mothers in fostering the networks that support their sons and daughters with lifelong disabilities have been discerned. Mothers stand alongside their sons and daughters with lifelong disabilities (Read, 2000). Mothers mediate between their sons and daughters and their surrounding environment. In their extended caring role, mothers negotiate for broader social change. Influences on mothers' reluctance to plan and their advocacy at sites of struggle have also been described (Llewellyn, 2003; Stehlik, 2000). However, mothers' ideas about the networks that will support their sons and daughters with lifelong disabilities into the future and their experiences of the networks that support their sons and daughters that might have influenced their ideas for the future have not been explored.

3.5   Outcomes of care: social inclusion.

This study referred to the perspective of social inclusion to conceptualise care outcomes (Abrams, Hogg & Marques, 2005; Bates & Davis, 2004; Clapton, 2009; Daly & Silver, 2008; Northway, 1997). Clapton's (2009) 'metaphorical quilt' lays out four perspectives on the inclusion of people with disabilities. The quilt captures meta-discourses about disability. Each perspective has been, and continues to be, influential in the contexts in which parents plan for the future. This section lays out the pieces of this 'metaphorical quilt' before reflecting on future planning from the perspective of pieces of this quilt. The pieces of the quilt include profound exclusion; technical inclusion; legislative inclusion and ethical inclusion.

- **Profound exclusion** describes a view that embraces the undesirability of people with lifelong disability. The intention is to exclude them from society. Disability is perceived as a tragedy and associated with burden and uselessness. People with disabilities are considered dispensable. This view promotes prohibition and prevention. Thus debates about sterilisation and eugenics, aligned with this view, consider the sacrifice of people with disabilities for the greater good. This view is aligned with institutional care.

- **Technical Inclusion** focuses on needs and the least restrictive alternative. It promotes people living in the community. Philosophies of Normalisation and Social Role Valorisation are embedded in this perspective (Wolfensberger, 1992). The focus is on technologies to facilitate community living. This perspective results in human service workers being needed in all facets of the lives of people with lifelong disabilities and in doing so it locks both workers and service user into roles associated with human services of 'them' and 'us'. While people with lifelong disabilities are present in the community, they remain segregated.

- **Legislative Inclusion** adopts the discourse of human rights and citizenship. Independence and autonomy are prized over dependence; 'support' over 'care'. This is a movement to address social oppression and instil socio-political change. Claiming to have the same rights as others,

people with disabilities find themselves in the paradoxical situation of seeking equality by highlighting difference. Legislative inclusion assumes moral agency, rationality and autonomy whereas people with lifelong disability may indeed require or prefer interdependent relationships. Because of this, people with lifelong disability are potentially disqualified from legislative inclusion.

- **Ethical inclusion** refers to an ideal. It is readily observed in the private arena of relationships of acceptance. The emphasis here is not on independence but interdependence, mutuality, flexibility and possibly chaos as diversity and complexity are privileged over 'normal'. This view accommodates difference and redefines moral personhood.

Reflecting on future planning from the perspective of the pieces of this quilt reveals the diversity of experiences of inclusion in the networks that support sons and daughters with lifelong disabilities. Stehlik (2000) described how mothers struggled to hold the profound exclusion of their sons and daughters with lifelong disabilities at bay. The "distinct social space" (Cummins & Lau, 2003; Todd et al, 1990) people with lifelong disabilities are described as occupying is consistent with technical inclusion. Kittay (1999) described mothers concurring with technical inclusion as they socialised their son or daughter with lifelong disabilities into their surroundings in order to help them fit in. Yet in their extended caring role, mothers advocated ethical inclusion. They anticipate their sons and daughters with lifelong disabilities will be recognised as citizens.

The variety of perspectives about social inclusion represented in these networks and the potential for struggle about meta-discourses about disability have been identified (Stehlik, 2000). However how struggles about social inclusion will be negotiated in the networks that support sons and daughters with lifelong disabilities into the future has not been explored. This and the previous section explored the influence of the contexts of care and inclusion. The final section of the framework, explores the social capital that parents might bequeath to their son or daughter with lifelong disabilities.

3.6   Assets parents' plan to bequeath to their sons and daughters

Bourdieu's (1986) analysis of capital reveals the assets that parent's might plan to bequeath to their

sons and daughters. Bourdieu (1986) unravelled the capital families bequeathed to future generations.

He described three forms of capital: economic capital, cultural capital and social capital (Bourdieu,

1986). Economic capital refers to financial capital. Cultural capital refers to personal presentation and

ideas, the appreciation of culturally valued goods such as pictures or books and institutionalised forms

of recognition such as educational qualifications. Social capital refers to social obligations or

connections. Social capital has been investigated as both a personal and a community asset

(Chenoweth & Stehlik, 2004; Daly & Silver, 2008; Field, 2008; Hogan & Owen, 2000; Portes & Landolt,

1996; Putnam, 2000; Widmer et al, 2008; Winter, 2000). I am focusing here on social capital as a

personal asset. Social capital refers to the accumulation of social contacts that enable access to

information and decision makers. These assets are as significant as cultural and economic capital in

maintaining individuals' social position (Bourdieu, 1986). This would suggest that in addition to

planning for the allocation of financial and cultural assets, parents plan for the distribution of their

accrued social capital.

Social capital is accrued through investment in relationships. A return can be expected from the

relationships in which one invests. These assets are "a resource to action" (Winter, 2000, p.9). They

are not necessarily tangible resources that are swapped between people. The return may come from

someone other than the person with whom the specific relationship has developed. It may come from

a known mutual acquaintance or a distant colleague. In some instances family members reciprocate on

behalf of those who are unable to. For this investment to be realised as capital, relationships must

involve 'durable obligations subjectively felt' (Bourdieu, 1986). They must be able to be called upon in

the longer term. Some future planning initiatives involved several families of people with disabilities

working together (Botsford & Rule, 2004; Carer's Queensland, (n.d.); CENTRIS, 2006; Etmanski, 2000;

Hole, 2007; Klees, 1996; "Pathways to Leadership", 2004). They referred to the commitment they had

made to one another to look out for sons and daughters with lifelong disabilities into the future. In referring to the "tribe", Etmanski (2000) was suggesting that parents' investment in the Planned Life Advocacy Network organisation would be realised into the future when the tribe would look out for their son or daughter with lifelong disabilities.

Social capital is particularly valued for what it can achieve. It acts as a resource to be actioned when needed. Well-connected individuals are more likely to be "hired, housed, healthy and happy" (Woolcock, 1998, p.154) than those with few social connections. Social capital enhances the capacities of individuals to use social systems and enhances the life chances of individuals (Field, 2003). Social capital is not randomly distributed across populations. It exhibits a clear demographic profile along a variety of socio-demographic axes (Hogan and Owen, 2000). It has proven difficult to develop a precise picture of determinants of social capital. It may be that social capital relies on complex feedback mechanisms of 'virtuous circles'. "For example ... education appears to be an important factor in individuals' access to social capital. At the same time, good access to social capital may enhance individuals' educational prospects" (Australian Productivity Commission, 2003 p.12). Like other forms of capital, this asset can be built through investment.

The idea that social capital is a personal resource that can be developed through investment is contested. Coleman (in Field, 2003, p.200) believed social capital is not purposefully built. He saw it as a by-product of other endeavours such as, membership of a church or geographical communities. He saw the family as an 'archetypal cradle' of social capital. Similarly Fukuyama (1995 in Field, 2003) saw it as a resource of such long standing that it would be difficult to be influenced by an individual. Accordingly, parents' investment in relationships that might be realised by their son or daughter with lifelong disabilities into the future is an unrealisable ambition from this perspective.

The 'dark side' of social capital is that it is unequally distributed and by privileging the wealthier, perpetuates further social inequality. The most affluent and well educated are generally the ones with

largest number of connections and there are qualitative differences in the nature of people's networks (Portes & Landolt, 1996). Bourdieu's (1986) research identified social capital ensured the French upper classes maintained their social positions regardless of their economic circumstances. People in disadvantaged groups have only limited access to new resources as their networks are with people in similar circumstances to themselves. In a crisis close tight networks of likeminded people may bring comfort, but will not necessarily bring resources (Portes in Field, 2003, p.80).

The assets that parents plan to bequeath to their sons and daughters with lifelong disabilities are rarely referred to in future planning research and future planning initiatives. The positive association between planning for the future and higher family income and higher levels of social support may indicate that parents who planned did so because they had assets they wanted their sons and daughters to inherit. Could oblique references to the 'tribe' in future planning initiatives, represent an investment in social capital with the expectation of return on investment into the future? The focus on the person at the centre of future planning initiatives, that is, the son or daughter with lifelong disabilities, not only obscures the work involved in fostering networks, it also obscures the view of parents' investment. Parents are asked to make a plan, let go, actively welcome other people into the lives of their sons and daughters with lifelong disabilities, strive to have their son or daughter living in a home they own and find contributions their son or daughter might make. Yet what parents invest to achieve this remains unclear. If the investment was obscured might the 'dark side' of future planning initiatives be that they, like social capital, perpetuate inequality?

3.7 Considering the networks that will support sons and daughters with lifelong disabilities when their parents are no longer able to from the perspective of this theoretical framework.

When parents plan for the future support of their son or daughter with lifelong disabilities they are fulfilling responsibilities associated with late adulthood. Planning for these parents does not only entail the distribution of their assets and the allocation of their responsibilities. It also involves

sustaining the trajectory of the life of a son or daughter with lifelong disabilities through the transition to post-parental care. Many aspects of parents' plans for the future have been described in the literature (Bigby, 1996; Prosser, 1997). However, the networks that parents envisage supporting their son or daughter with lifelong disabilities into the future have not been fully explored.

The structure of the actual networks which parents envisage supporting their sons and daughters with lifelong disabilities when they are no longer able to might be conceptualised in terms of a social convoy (Kahn & Antonucci, 1980). Circles of support, for example, might be akin to a social convoy (Etmanski, 2000; Hole, 2007; Klees, 1997). However, replacing a small, dense, family-dependent social convoy with a circle of support with few links to broader community networks will not necessarily address the vulnerability of sons and daughters with lifelong disabilities to the declining capacities of members of their social convoy. Future planning initiatives encourage the reconfiguration of both the social convoy and the broader networks that support sons and daughters with lifelong disabilities. They encourage the fostering of a densely connected social convoy that has multiple links to other people and networks (Bigby, 1997; Etmanski, 2000; Hole, 2007; Klees, 1997). Into the future, a key person and/ or people associated with a residential service might be integral to the social convoy (Bigby, 2000). However, it is not clear if parents' anticipate the integrity of the existing network structure being maintained into the future or if they anticipate the structure of the network substantially changing.

It might be anticipated that networks that will support sons and daughters with lifelong disabilities into the future will hold the trajectories of sons' and daughters' lives on course through the transition to post-parental care. Understanding how parents intend to allocate their responsibilities for caring for their son or daughter with lifelong disabilities has occupied much of the research effort described in Chapter Two. Research into parental plans has identified specific aspects of their son's or daughter's support that parents have planned for (Bigby, 1997; Prosser, 1997, Dillenburger & McKerr, 2010). Their

plans include arrangements for a 'key successor', finances and residence However, the functions that parents look to these networks to fulfil into the future have not been fully explored.

The influences of the social and temporal contexts on the course of lives, the networks that support lives and, the negotiation of life stages, are integral to this theoretical framework. Previous research has revealed the influence of social and temporal contexts on parents' propensity to plan for the future support of their sons and daughters with lifelong disabilities (Bowey & McGlaughlin, 2006; Grant, 1993; Haley & Perkins, 2004; Joffres, 2001; Mansell & Wilson, 2010; Prosser, 1997; Weeks et al, 2009; Walker & Walker, 1998). Research into future planning has also identified the influence of these temporal and social contexts on particular aspects of the plan (Bigby, 1996; Chou, 2009; Heller et al, 2007; Prosser, 1997). Considered from this framework, the networks that will support the lives of sons and daughters with lifelong disabilities, and parents future planning, will be influenced by attitudes to, and ideas about, social inclusion (Clapton, 2009), social care (Fine, 2007) and social capital (Bourdieu, 1986). However the influence of social and temporal contexts on the actual network that parents' envisage supporting their son or daughter with lifelong disabilities through the transition to post-parental care has not been fully explored.

Finally, despite progress towards shared care, care provision remains gendered. Mothers are pivotal to the social convoy of their sons and daughters with lifelong disabilities. Mothers stand alongside them and mediate between their sons and daughters and their surrounding environment (Kittay, 1999; Read, 2000). In their extended caring role, mothers negotiate for broader social change (Goodley, 2007; McKeever & Miller, 2004; Panitich, 2003; Reiger, 2000). Stehlik (2000) and Llewellyn (2000) described conflict about meta-discourses of social inclusion within the networks that support sons and daughters with lifelong disabilities. Mothers engaged in these struggles about meta-discourses (Stehlik, 2000). Sisters anticipate assuming responsibilities as key people into the future (Bigby, 1997, Burke et al, 2012; Davys, Mitchell & Haigh, 2010; Grant, 1998; Greenberg et al., 1999; Heller & Arnold, 2010; Heller & Factor, 1991; Heller & Kramer, 2009; Krauss & Seltzer's, 1993). However, despite their

integral position, mothers' conceptualisations of the networks they envisage supporting their sons and daughters with lifelong disabilities into the future and the influence of their considerable experience in the networks that support their sons and daughters on their ideas about these networks, have not been fully explored.

This study explored the networks that are fostered to support sons and daughters with lifelong disabilities when their parents are no longer able to and the influences of the social and temporal contexts on these networks. Mothers hold a pivotal position in these networks. They mediate the interaction between their sons and daughters with lifelong disabilities and the community. By standing alongside their sons and daughters they advocate for and coordinate the care and support of their son or daughter (Fine, 2009; Read, 2000). Privileging mothers' views acknowledges the gendered nature of care provision. Further, as older parents are mostly mothers, it will be mothers who will mostly be making future plans. Therefore this study explored the networks that will support sons and daughters with lifelong disabilities into the future from the perspective of the mothers of the sons and daughters with lifelong disabilities.

3.8   Conclusions

By reflecting on the research into future planning and future planning initiatives described in the previous chapter, this chapter formulated a view that provided the research questions for this study. Fostering networks for the future support of sons and daughters with lifelong disabilities enables the distribution of parents' assets, the allocation of their care responsibilities and will potentially hold the trajectory of the life of a son or daughter with lifelong disabilities on a desirable course through the transition to post-parental care. However, the social convoys envisaged by parents for these purposes have not been fully explored. Despite moves towards 'warm modern care', care provision remains gendered and mothers hold a pivotal position in the networks that support their sons and daughters

with lifelong disabilities (Hochschild, 2003). Mothers are well positioned to act as informants about networks that will support their sons and daughters with lifelong disabilities into the future. The next chapter describes the research methodology I used to tap into mothers' experiences and ideas.

Chapter Four

Investigating mothers' ideas about the networks that will support their sons and daughters with lifelong disabilities when they, and the father of their son or daughter, are no longer able to.

Consistent with qualitative approaches, decisions about the research design used in this study were not made in advance. They were dependent on the context and the setting (Denzin & Lincoln, 2008; Miles & Huberman, 1984; Silverman, 2005). Therefore, the methodology was influenced by the research project brief and project data. This chapter describes the research design. It identifies the research questions, the research framework and the steps in the research process. It opens with a brief description of the emergence of mothers as key informants in this study.

4.1   The emergence of mothers as key informants

Preliminary analyses of the broad project data revealed the mother of the person at the centre of each network in this study was integral to her son's or daughter's network. Mothers became the research teams' contact point into the network. Mothers were given authority by other network members to sanction their involvement in the research. They had an historical perspective of network development and a view of the overall network. They were familiar with specific details, such as names of support workers, weekly routines and gaps or shortfalls in the network. Mothers' unsolicited descriptions of sources of their son's or daughter's future support showed they had considered the future and had made plans. Some had embarked upon very elaborate networks. In brief, mothers made ideal informants about the networks that support their son or daughter with lifelong disabilities. It was the mothers' narratives of their experiences in the networks that supported their son or daughter with

lifelong disabilities that alerted me to the gap in the literature, described in Chapter Two, that this study addressed.

4.2 Purpose of the Study

As revealed in Chapter Two, previous studies identified theoretical perspectives of networks of support (Dillenburger & McKerr, 2010) and described idealised views of possible network structures (Etmanski, 2000). This study examined mothers' views about the actual networks that they envisaged supporting their sons and daughters with lifelong disabilities when they and the father of their son or daughter, are no longer able to. Mothers', rather than parents', views and experiences were examined in this study because, as described above, the mothers in the networks in this study presented as ideal informants. The mothers in this study occupied similarly pivotal positions in these networks to those described in the literature in the previous chapter (Grant, 1993; Read, 2000). Uncovering the perspectives of these mothers avoided perpetuating the invisibility of the expertise of women in care work (Fine, 2007). The mothers in this study identified features and functions of the networks that they envisaged supporting their sons and daughters into the future. They offered a view of these networks that had not been fully explored in the literature. Mothers described the influence of their experiences in the networks that supported their sons and daughters with lifelong disabilities on the networks that they envisaged for the future. These descriptions revealed the influence of social and temporal contexts on the networks that supported sons and daughters with lifelong disabilities.

4.3 Research questions

This study addressed the following questions:

- What were the features and functions of the networks that mothers envisaged supporting their son or daughter with lifelong disabilities when they, and the father of their son or daughter, were no longer able to?

- How did mother's experiences in the networks that supported their son or daughter influence their ideas about the networks that they envisaged supporting their son or daughter with lifelong disabilities into the future?

4.4   Research Framework

As summarised in Table Two, the study addressed the research questions from a phenomenological perspective. This perspective was informed by a social constructionist view. This section provides a summary of each aspect of the research framework and indicates why this framework suits the purposes of this study.

Table 2:

Research Framework

Epistemology	Methodology	Methods
Social Constructionism	Phenomenology	Open ended Interviews
		Member checking
		Narrative analysis

4.4.1   Epistemological position

A social constructionist view, the epistemological position that underpins this framework, assumes that the idea of, and meanings associated with, support networks are constructed within the contexts in which they occur (Denzin & Lincoln, 2008, Silverman, 2005). Social constructionism is the view that,

> … all knowledge, and therefore all meaningful reality as such, is contingent upon human
>
> practices, being constructed in and out of interactions between human beings and their world,
>
> and developed and transmitted within an essentially social context (Crotty, 1998, p.42).

From this perspective phenomena, such as support networks, exist and influence the meanings

inscribed upon them. Meanings are inscribed upon them by the social contexts in which they exist.

Meanings are inscribed through the relationship between the phenomena and people, in this case,

mothers and, through them, the researcher.

> Meanings are constructed by human beings as they engage with the world they are
>
> interpreting. We do not create. We construct meaning. We have something to work with.
>
> What we have to work with is the world and objects in the world (Crotty, 1998, p.43).

There are no fixed interpretations of meaning; however there can be more useful or liberating

interpretations.

This study investigated the phenomena of networks that serve the specific purpose of supporting sons

and daughters with lifelong disabilities into the future. Social support networks are commonly referred

to and recognised as social phenomena. Social network theory has emerged from the analysis of social

structure (d'Abbs, 1982; Borgatti, Mehra, Brass, & Labianca, 2009; Wellman & Berkowitz, 1997). Social

support networks have been described and analysed. However, what the term or concept actually

refers to, and the meaning associated with it, is contested. A network is considered a "set of personal

contacts" (Walker et al 1977, p.35). Does a set refer to one relationship? Alternatively how personal

might the contacts be if the set refers to one hundred relationships? Through these contacts "the

individual maintains his (or her) social identity and receives emotional support, material aid and

services, information and new social contacts" (Walker et al, 1977, p.35). Are these contacts only

included in the support network while they serve these functions? Alternatively, including every

personal contact because of the potential for contacts to be supportive would render the network

limitless. These examples reveal the ambiguity of the term. However, there is clearly such a thing as a set of relationships through which an "individual maintains his (or her) social identity and receives emotional support, material aid and services, information and new social contacts" (Walker et al, 1977, p.35). They are not naturally occurring entities, the nature of which is waiting to be discovered. Ideas about them have been constructed by, and within, the social context within which they occur.

A social constructionist perspective was also important to this study because it acknowledged the influence of the social and temporal contexts on the meanings associated with phenomena. Meanings and ideas about them have been constructed and these constructions influenced the phenomena. Support networks exist and the nature of their existence is influenced by the cultural context in which they occur. Ideas about them have been constructed by the interaction of multiple forces such as people with disabilities, their families, people they know, popular media, literature and social policy. This study aimed to unveil social and temporal influences on these networks.

4.4.2 Methodology

Phenomenology was originally conceptualised by Husserl (Hammond et al, 1991; Crotty, 1996; Holstein & Gubrium, 2009) in reaction to positivist methods. Phenomenology encourages the laying aside of "the prevailing understanding of phenomena ... revisit(ing) the immediate experience of them" to enable "possibilities for new meaning (to) emerge" (Crotty, 1996; Crotty, 1998, p.78). Human beings reach out to and make meaning out of the things around them. Intentionality, this process of making meaning out of things, is the idea that,

> ... every thought is a thought *of something*, every desire is a desire *of something*, and every judgement is an acceptance or rejection *of something.* Consciousness is always and essentially related to objects. In short there is an insoluble union between object and subject (Crotty, 1996, p.39).

Therefore more can be understood about phenomena by investigating people's experiences of them and the meanings people ascribe to them. Phenomenology looks to achieve this by "bracketing" the researcher's "natural attitude" (Husserl, 1970b in Crotty, 1996, p.59).

"Bracketing" refers to temporarily setting aside the "natural attitude" (Husserl, 1970b in Crotty, 1996, p.59). The "natural attitude" refers the taken for granted ideas that the life world exists before members of it are present. Often bracketing is considered the sincere endeavour to disallow one's beliefs and assumptions to influence the meanings imposed by the researcher on the understandings and constructions of phenomena however Husserl was actually referring to the suspension of the "natural attitude" (Husserl, 1970b in Crotty, 1996, p.59) in total.

A phenomenological methodology was selected for this study in order to focus on and delve into mothers' subjective experiences of the networks that support their son or daughter with lifelong disabilities. The pivotal position of mothers in these networks made them excellent informants. However, as women's care work has been subtle and unacknowledged mothers' ideas and experiences have been obscured. A phenomenological approach addressed this lack of recognition. Fundamentally a phenomenological approach meant holding to one side my ideas, paying careful attention to the transcripts of the interviews with mothers. Further, I chose to be guided by Husserl's description of phenomenology as his perspective gave the researcher the responsibility for holding the focus on the rich subjective experience of the participants in this study, the mothers (Husserl, 1970b in Crotty, 1996). This methodology meant that this study focused on unveiling mothers' ideas about support networks and the meanings they constructed about them. It witnessed mothers reaching out and interacting with these support networks, influencing them and being influenced by them. Therefore it revealed a wealth of insight that had previously been obscured by the feminisation of social care (Fine, 2007).

4.4.3 Open ended interviews

As the interviews that were conducted for the purposes of collecting data for the overall research project were open ended and relatively unstructured, the transcripts of the interviews with the mothers leant themselves to narrative analysis. These interviews took the form of conversations (Fontana & Frey, 2005; Spradley, 1979). Further, consistent with a phenomenological approach, the interviewers minimised their influence over the interview process, encouraging the mothers to express their views and direct the interview towards topics of their choosing. The details of this data collection are described later in this chapter.

4.4.4 Member checking

Member checking was conducted to ensure that my analyses of mothers' narratives adequately represented their rich experiences in, and ideas about, these networks. Consistent with the phenomenological approach member checking held the focus on mothers' subjective experiences by returning to the mothers throughout the study to discuss each aspect of the emerging themes and the representation of their experiences in draft research reports, presentations and articles (Doyle, 2007; Stacey in Gluck & Patai, 1991).

4.4.5 Narrative analysis

Narrative analysis was selected for this study because it offered a method for accessing and examining mothers' rich descriptions of the complex influences of their experiences in the networks that supported their son or daughter with lifelong disabilities on the networks that they envisaged supporting their son or daughter into the future (Clandinin, 2007; Czarniawska, 2004; Elliott, 2005; Grbich, 2007; Gubrium & Holstein, 2009). Narrative analysis made these descriptions accessible by keeping the participants' stories intact (Riessman, 2008). Stories, one type of narrative, offer windows into phenomena, in this case, networks that will support sons and daughters with lifelong disabilities into the future. Acts of creating and telling narratives involve multiple layers of representation of

phenomena and the experiences of them (Riessman, 1993). By keeping their stories intact, I was able to identify nuances to the features and functions of the networks that mothers envisaged for the future. Theorising from the case rather than from component themes across cases, preserved the sequence and the wealth of detail (Elliott, 2005). In particular, I was also able to appreciate the influence of social and temporal contexts on their ideas about these networks and their direct experience if bringing the networks into being. The context of the time and place of narration, historising the narrative account, drawing on the references the mothers made to context in their stories is an important component of narrative analysis (Riessman, 2008). Thus conducting a narrative analysis provided a thorough and considered appreciation of mothers' conceptualisations of these networks and the meanings that they associated with them.

The mothers were articulate and described their experiences using stories. They had messages they wanted the team to understand and they linked it their experience. To dislocate these from each other through coding would be doing the mothers a disservice. Thus the transcripts provided an opportunity to take a narrative approach. By paying attention to how the events in the narrative were assembled and sequenced, this analytic process provided insight into the points that mothers wanted to make to the research team. In their stories they emphasised aspects of their experiences and ideas. These emphases were able to be discerned by analysing their narratives. Using this analytic process meant that the mothers influenced the research design through their narratives. Narrative analysis offered a method for 'bracketing' my influence over the analytic process. Thus mothers constructions of their narratives indicated what they wanted the project team to know about, and the meanings they made of, these networks. Finally by encouraging the collation of their meanings and experiences into a collective story, this analytic process reinforced the explanatory power of the analysis.

Polkinghorne (1998) distinguished between narrative analysis and the analysis of narratives. The first can be seen as a form of qualitative research in which narratives are analysed into themes and categories. The second described the narrative explanation, the grand narrative. In a narrative the

final result is presented as a story (Clandinen, 2007). The narrative research report recreates history with various episodes, actions and actors. It does not develop generalisable laws. It is a retrospective gathering of events that makes sense of the ending. It identifies "constant antecedents" to events that occur that make the ending plausible (Polkinghorne, 1998). In this study, mothers' narratives explained their ideas about the networks that she anticipated supporting her son or daughter into the future in terms of influence of her experiences in the networks in the past. The collective story of their experiences revealed key influences of the social and temporal contexts on these networks. The next section describes the research process, that is, the application of this framework to this study.

4.5   Investigating mothers' ideas about the networks that will support sons and daughters with disabilities into the future.

This study investigated mothers' ideas about the networks that will support their son or daughter with lifelong disabilities by analysing a subset of the projects' data, the transcripts of interviews with the mothers of the person at the centre of the network, using a narrative analysis. This section describes the analytic process. Firstly, however, the source of the data is discussed.

4.5.1 Source of the transcripts of interviews with mothers

This section describes recruitment to the project and the interviews that were conducted for the purposes of the project before turning to the selection of the transcripts for analysis within this study. The interviews that were conducted for the purposes of checking with the authenticity of the findings with the mothers are also described in this section. In addition to ensuring the rigour of the analysis, which is considered in more detail at the end of this chapter, the transcripts of some of these interviews were also a source of data.

4.5.1.1 Recruitment to the Project

Following approval from the University of Sydney Human Research Ethics Committee (Appendix 1) families who were interested in and actively pursuing the establishment and further development of networks of support for their adult son or daughter with disabilities were invited to participate in the research project[3]. These invitations were issued through the social networks of the research project team. Recruitment was carefully contained through personal invitations in order to avoid misunderstandings by participants that they would be assisted in the establishment of support networks. Purposive recruitment ensured that people with a diversity of support needs, care arrangements and family circumstances were included (Denzin & Lincoln, 2005; Silverman, 2005). Network members were invited to participate with the agreement of family members and the person with a lifelong disability and through their facilitation of the invitation.

Nine (9) networks were recruited to the research project. The people with a disability at the centre of each network ranged in age from early 20s to mid-40s; lived at home with family or were supported to live in their own home and varied in support needs. Initially seven people lived in Sydney, Australia. Of these, three lived with parents and four in shared housing. Two people lived in Brisbane, Australia; one in his own home and the other with parents. One family relocated from Sydney to Queensland during the study. Support networks included the parents of the person with a lifelong disability; their brothers and sisters; neighbours; peers of the person with disability, people from leisure and interest groups, employment and recreation programs, health professionals and support workers. The people at the centre of the network were involved with accommodation support services, employment support, day programs, leisure groups and allied health services.

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[3] The research project refers to "Moving beyond crisis management: Creating futures for people with disabilities living with ageing parents" project funded by the Australian Research Council.

The parents were aged from their 40s to their 80s. In four of the families, the parents of the person with a disability were married to one another and lived together. In one family the father was deceased. Two fathers died in the course of the research. The parents in two of the families were divorced. Mothers of the person with disabilities were the primary contact for the research team in eight of the families. While some mothers were in full-time paid employment, most had retired or were working part-time. The next section describes the interviews that were conducted with the mothers.

4.5.1.2 Interviews

Interviews were conducted by four members of the research team. Individual networks were assigned to a member of the research team. I collected data in three of the nine networks. Prior to being interviewed mothers were given an information sheet about the project and consent form. The information sheet was entitled "Networks of Support" and stated:

> This research will look at personal networks of a group of people with disabilities and their families. We are interested to know about how people developed their personal networks and what they mean to the people involved both now and in the future.

A copy of the information sheet is included as Appendix 2. The interviews were unstructured, however there was a shared agreement between the interviewers that the opening statement for the first interview would be "tell us about (name of the person with lifelong disability)". This was supposed to be introduced after the description of the project and the signing of the consent form. This opening line was not always used. In some cases having discussed or read the information sheet and signed the consent form, mothers launched into the interviews. Little invitation was needed before mothers offered their ideas about the support networks of the son or daughter and described their experiences in those support networks very generously.

The open format of the interview allowed mothers to begin with whatever information they chose and move into the areas they thought were relevant to the research. The interviews were interactive and the mothers and the interviewer took active parts in changing the topic or returning to topics of interest (Fontana & Frey, 2005; Spradley, 1979). Few prompts were offered, or indeed needed, as the interviews progressed. Accounts of personal experiences were acknowledged with minimal reassurances such as "mm' or "oh dear" from the interviewers. Interviewers sought clarification on particular points such as "How old is she?" When mothers paused after having explored a particular topic, the interviewers filled silences with a question that would prompt further information about the support networks of the person with lifelong disability. An example of this was "and what does she do in the daytime?" In some interviews the mothers commented the conversation had digressed and they changed to their chosen subject.

At times interviews took the form of an exploratory conversation about a particular aspect of the support network. For example, in one interview, the varying aspects of a circle of support were explored through a conversation between the mother and the interviewer. The mother had presented her ideas about a circle of support and then the interviewer asked about the role of the person with lifelong disability to the circle. The mother had not mentioned her son's input in the circle prior to this. In summary, the mothers were invited to speak about their son or daughter within the context of a project entitled "networks of support" and the interviewers specifically elicited information about the everyday life and current support of the person with a lifelong disability. Apart from situations in which there were time limitations, interviews drew to a natural conclusion, often after up to 2 1/2 hours, at the instigation of participants.

Subsequent to the first interviews, both the team and mothers instigated further interviews. Mothers contacted the team with updates about the networks. The team interviewed mothers to elicit

feedback about a range of topics that constituted the findings of the overall research project. The interviews that elicited feedback for the purposes of the study involved: the interviewers providing a summary of the proposed findings to seek feedback; discussions about the appropriateness of selected interview transcript quotations to ensure they accurately represented the experiences of participants; gaining permission to use specific quotes and; confirming mothers' preferences for the manner in which participants were referred to in these quotations. For example, when feedback was sought about a grand narrative, mothers were offered a draft of the journal article that had been stripped of all other quotes apart from the quotations of the mother being interviewed. This enabled the mother to comment on the context in which her quote was being used and to comment on the overall concept as it was portrayed in the article. The completed draft was also shared with mothers for their feedback. During the course of these interviews mothers provided updates on developments in the networks. Thus mothers were interviewed intermittently over 5 years from 2007 to 2012.

Interviews were recorded and transcribed. Both recordings and transcriptions were stored on a dedicated password protected drive at the University of Sydney. All identifying information was removed from the transcript and each participant was referred to using coded terms and in accordance with their relationship to the person at the centre of the network, such as Edward's mother, where Edward was a pseudonym chosen by his mother. Names, contact details of participant and codes were stored separately to protect privacy and ensure confidentiality.

4.5.1.3 Selection of interview transcripts

The interviews in which the voices of the mothers had been recorded and transcribed were analysed. The transcripts of interviews and members checks with 8 mothers were analysed. The recording of the initial interviews with the mother in the ninth network had failed and therefore in the absence of a transcript of actual words and ideas, the ninth network was not included. The sources of data are summarised in Table 3. Transcripts included:

- the initial interviews in which mothers volunteered a range of information;

- subsequent interviews in which mothers had updated the team on developments in the support networks;

- member checks with mothers related to a range of topics that emerged from the findings within the research project and;

- member checks with mothers for this study.

Table 3

Data Analysis

Year	Analysis	Data source – Transcripts (+indicates an interview; *indicates a member check)							
		Hamish's mother	Claire's mother	Betty's mother	Edward's mother	Greg's mother	Emily's mother	Maree's mother	Mary's mother
2007	**Phase 1**			+ +	+				
2008	I wanted to find out 'what do they want us to know?'. I located the stories in the transcripts; identified the plots in these stories and; consolidated the plots into a grand narrative entitled "You're the bottom line I guess".	+	+*	+ *	+	+	+	+	++
2009	**Phase 2** I conducted a thematic narrative analysis of the transcripts to date. I located stories in the transcripts and identified themes in the stories of each mother.	**	*	*	**	*	*	*+++	*
2010	**Phase 3** Mined the set of available transcripts for information about the networks, the 'thing itself'; the features and functions of the networks.		*		+	+		+	
2011									
2012		*	*	*	*	*		*	*

4.5.2   Analysis of the transcripts of interviews with the mothers

The transcripts were analysed in three phases. In the first phase, I analysed mothers' performance of their narratives (Riessman, 2008) to identify what they wanted us, the research team, to know about their experiences of the networks that support their sons and daughters with lifelong disabilities. A grand narrative emerged in this phase of analysis. In the second phase, themes across mothers' stories were identified using a thematic narrative analysis (Riessman, 2008). This analysis revealed mothers' stories of their experiences in the networks that supported their sons and daughters with disabilities provided the rationale for the networks that they envisaged for the future. In the third and final phase, the narratives of each mother were again mined for information about the networks mothers envisaged supporting their son or daughter into the future, the 'thing itself'. This analysis revealed the layering of networks over time. An excerpt from one the transcripts is included in Appendix 3. Table 3 summarises the phases of the data analysis. This excerpt provides examples of each of the three phases of the analysis. Each phase of analysis is discussed in more detail in the following sections of the thesis.

4.5.2.1 Phase 1 – Towards a grand narrative – mothers' experiences in the support networks of their sons and daughters with lifelong disabilities.

Phase 1 viewed mother's narratives as a performance and looked for signals in their performance of what they wanted to draw their audience's attention to. The question in my mind was: what do they want us to know? The opening stories of mothers and the stories they returned to, perhaps against the flow of conversation with the interviewer, were identified. Some stories were told almost in spite of the interviewers' questions and queries. For example, several mothers did not wait for the interviewers to pose questions; they volunteered information in the form of a story. I presumed the information mothers volunteered was that which they thought was pertinent to the study. In other

situations, mothers made qualifying statements that signalled they wanted to make an important point. Examples of these include 'but I wanted to tell you …'.

The whole transcript of each of the initial interview was considered including answers to interviewers' questions as well as discrete stories. The "narrative" was the account provided by mothers in conversation with the researcher. These accounts took the form of evolving dialogues within one interview and over several interviews, as facets of their experience were explored for further developments, clarification and elaboration. In the first phase of the analysis stories were identified within the transcripts by locating the stories amongst other forms of interaction in the interview (e.g., question and answer exchanges) by paying close attention to 'entrance' and 'exit' talk that marked the beginning or end of a narrative segment in the conversation. The stories were identifiable by a plot linking events to one another. The plot made a point.

The plots of these stories described discovering the abilities, and disabilities, of their son or daughter. They talked about finding people to support their son or daughter in managing their disability and nurturing their abilities. Often at the instigation of the interviewer, they imparted information about the weekly routine of their son or daughter. The stories they went on to tell about the weekly routine were reflections about what they were pleased or displeased about with the weekly routine and/ or the challenges they had faced to get this routine established and maintained. They talked about the networks of support they envisaged and were currently creating. There were stories about discovering like-minded people that brought great hope and stories about the isolation of not discovering such people. They talked about the challenges they faced in supporting their son or daughter towards independence while ensuring their son's or daughter's safety and happiness. Some of them highlighted stories about things that had gone wrong and how they were now consistently alert to the need for protection, monitoring the quality and safety of the support their sons and daughters received and, taking action. They talked about their families and how they shared the care of the son or daughter with his or her father and the involvement of other siblings and the extended family.

Across these stories they conveyed a sense of being "the bottom line". When all else failed, they would be there.

The plots were collated and clustered into four themes that formed the sketch of a grand narrative. These themes were discussed with the mothers for their feedback. The themes and the quotes that had been lifted from that mother's transcript as evidence of the theme were discussed with each mother. This feedback was incorporated into a conference presentation and a draft journal article entitled "You're the bottom line I guess". The draft journal article was also shared with the mothers for their feedback and comment. Their response to the article was very positive. One mothers said "I feel acknowledged – thank you". For those whose experience differed, they commented on what they knew of other mothers for whom this description would be accurate. This confirmed the commonality of the story. It also reinforced their position as informants for this study. The next phase of analysis, with the benefit of more transcripts from these member checks and member checks that were conducted for the purposes of other studies within the project, aimed to unpack and refine the unique dimensions of the experience of each mother.

4.5.2.2 Phase 2 – Influences of mothers' experiences in the support networks of their sons and daughters with lifelong disabilities on their conceptualisations of the networks that will support their son or daughter into the future.

In the second phase of the analysis I returned to mothers' stories of significant events in the support networks of their sons and daughters with disabilities. Phase 1 confirmed that these mothers had repeatedly assessed and intervened in the networks of their sons and daughters throughout their sons' and daughters' lives. Phase 2 identified shifts in mothers' thinking that remained significant to the networks of the future.

This phase used thematic narrative analysis to identify the mothers' experiences of the support networks of their son or daughter with disabilities. This phase was undertaken in three stages:

explication, explanation and exploration (Czarniawska-Joerges, 2004). In the first stage, the transcripts were again reviewed to locate all the stories and identify the breadth of topics and the plots of each of the mothers. The focus was on representing and summarising the stories of each mother. The analysis focused on explicating the content of the stories within the transcript. The narrative included a mixture of historical information and stories about their experience and hopes for the future.

Some attention was given to the ways the stories were delivered. How the stories were delivered often provided further insights to the mothers' experiences of the support network of their son or daughter. For example, one mother opened the first interview with a story of discovering other like-minded people by happening upon a radio program. This story of a particular day in her life encapsulated what she hoped for in the network of support for her son. A particular moment in time had initiated profound change in her life. In contrast, another mother told the stories as a series of onslaughts to be battled and recovered from. She did not convey quite the same hope. The second stage of this phase of data analysis was explanatory. It aimed to construct a narrative explaining why something had happened.

In the second stage of this phase of the analysis links were made between the stories each mother told about their experience of the support networks of their son or daughter and the support they envisaged for their son or daughter into the future. All of the stories each mother told were reviewed for a theme or themes. What became apparent was there was often a theme that the mothers returned to in various stories or that they emphasised in the telling of the story. One example of this is one mother's repeated use of the word "traumatised". She, her son and her son's father had indeed been traumatised when her son was abused. Her stories included various examples of the experience of being traumatised, the impact of the trauma and what they were doing to avoid being traumatised in the future. The networks of support she was establishing for her son were characterised by their attention to protection and safety. Further, this theme had arisen from a traumatic experience that became a turning point in her son's life and in his network of support. As indicated above, another

mother developed the theme of the hopefulness of finding people who had a certain way of thinking. Again she recounted a story that signalled a turning point in her son's life or rather her experience of her son's life. The themes explained the network of support they were developing or proposing to develop and informed the understanding of how they conceptualised the network.

The third stage of this phase of analysis revealed the commonality of mothers' experiences in the support networks of their sons and daughters with lifelong disabilities and its concurrence with the life course perspective. This analysis revealed that across all of the stories mothers' experiences of transitions and turning points within the networks of their sons and daughters with disabilities influenced the networks. For example, mothers who were older and had lived through the social policy era in which they were offered a residential placement for their son or daughter looked to the network of support to advocate for their son or daughter with disabilities. Further, the pattern of the lived experiences revealed mothers supported sons and daughters to maintain life trajectories through transitions and to redirect life trajectories in response to turning points. Some shared experiences of key turning points and transitions. Finally, mothers highlighted links between maintaining these life trajectories and the networks of support they envisaged for the future. The narratives were then mined for information about the form of the networks that will support sons and daughter into the future.

4.5.2.3 Phase 3 – Networks that will support sons and daughters with lifelong disabilities into the future.

Phase 3 identified the network each mother envisaged supporting her son or daughter with disabilities into the future. This phase returned to the 'thing itself'. When mothers described the networks of support they envisaged for their sons and daughters with disabilities, they described how support would be provided after their life time. Mothers described fostering the independence of their son or daughter with disabilities and, they identified who would assume responsibilities when they and the

father of their sons and daughters with disabilities were no longer able to. Further, while future planning was not always prominent, it was interwoven into a life time of building the independence of, and/ or preparing, their sons and daughters and the networks that supported them for the *changeover*. Mothers in their 40s and 50s as well as older mothers referred to their own mortality. Therefore while these networks were not exclusively designed for future planning, they were conceptualised with future planning in mind and are informative about influences on future planning.

In this phase, mothers' narratives were re-examined to identify their conceptualisations of networks that would support sons and daughters into the future. Comparing mothers' descriptions of network structures revealed the layering of networks over time. For example, geographically based networks supported sons and daughters with disabilities moving out of the parental home and establishing their own adult life style. Families and/ or circles monitored, and when needed advocated with, the networks that supported these adult lifestyles.

Mothers' conceptualisations of networks that will support sons and daughters with lifelong disabilities into the future were clustered according to the functions mothers associated with the support networks. These functions arose out of the second phase of the analysis. Mothers envisaged networks would *bring enquiry*; support adult lifestyles; offer protection through *checks and balances*; and assist parents in *preparing* for *moving on*. Another cluster of networks had stalled due to acrimony between parents. These functions addressed mothers' experiences of turning points and transitions in the lives of sons and daughters with disabilities. Mothers' experiences of the turning points and transitions and the networks mothers envisaged would support sons and daughters such that these functions were addressed were clustered under each of these functions.

These summaries were checked with mothers in 2012, for some this was almost 5 years after their first contact with the project team. In 2008/9, the analysis of phase 1 was checked by the team member allocated to the network. I chose to check the findings from this study with the mothers so that I could

spontaneously explore these features and functions with them if the opportunity arose. An outline of the findings, my summary of each mother's story of her experiences in her son's or daughter's support networks, the functions I understood she hoped the network would fulfil, the influences of her experiences in her son's or daughter's support networks on her ideas about the need for these functions and the network features, were provided. All the mothers were contacted. However despite several attempts to set an appointment time, one is yet to provide feedback. Those who were able to be contacted also updated me on new developments in the networks. There were significant changes in one mother's ideas about what constituted the support network of her son from what I, and other research team members, had understood from the transcripts. Mostly however mothers provided further examples of the ways in which networks were needed to fulfil the functions they had envisaged. In addition to their direct feedback, I interpreted these additional examples as further evidence of confirmation of the significance of these functions to their ideas about the network. The findings reported in each of the chapters that follow remain in the same format as those checked with the mothers. They have been revised in accordance with the mothers' feedback.

4.6   Rigour and trustworthiness

Attention was given to the rigour and trustworthiness of this study at each stage of the research process (Denzin & Lincoln, 1994; Silverman, 2005). Informed consent was obtained from mothers before their inclusion in the project.

These networks were ideally suited to the investigation of the research questions. The participants who were recruited to the project were involved in networks that were committed to actively developing a positive, meaningful future of an adult family member with lifelong disabilities. All of the mothers referred to a plan for the future and the networks covered experiences of mothering an adult

son or daughter with disabilities from transition to adulthood to the death of a parent. The study fitted well with the written brief that was provided to participants about the rationale and scope of the project.

The rigour of the data collection was reinforced by ongoing audit, review and discussion through weekly data meetings involving at least three team members. Processes used for data collection and the data that had been obtained were discussed at these meetings. As the project research team members were experienced researchers, they were able to foresee possible pitfalls in data collection and guard against them. Regular discussions ensured interviews were open-ended and unstructured. As discussed earlier, the confidentiality was protected by de-identification of interview data during transcription and storage in password-protected computer files.

The rigour of the analytic process was also reinforced by several strategies. I chose to use narrative analysis because the analytic technique allowed mothers perspectives to shape the analytic process. The performative analysis (Riessman 2008) supported 'bracketing'. I focused on the issues their narratives indicated that they wanted to emphasise. The member checking process of the emerging grand narrative and the themes within it, collated in the draft journal article, provided opportunities for the mothers to comment on the usefulness of my interpretations (Doyle, 2007; Polkinghorne, 1998). Their responses indicated these early drafts offered 'liberating' (Crotty, 2008, p48) interpretations. Their influence over the use of names and quotations reinforced the integrity of written work. Providing mothers with my précis of their stories, as they appear at the beginning of each of the chapters of findings that follow, meant they were able to check the accuracy of my account. Discussion of my interpretations of their narratives, as presented in the chapters that follow, helped to refine my ideas about the networks.

The interviews and emerging themes in the data were discussed at weekly interviewers' meetings. During these discussions the interviewers offered their perceptions of the interviews as they related to

the themes that emerged in particular transcripts. The value of the contribution of this specific research became more obvious in this process. Team members who were very familiar with the data found it challenging to separate out their perceptions of the support networks in total from the perception of the experience of the mothers, leading to robust discussions. This showed how easily voices could be silenced in the context of other voices and as such reiterated the importance of the contribution of this project to the broader research endeavour. However, these discussions promoted greater clarity about the presentation of mothers' perspectives.

Prolonged engagement with the transcripts, over 5 years, allowed time for mothers' ideas to permeate. Discussions toward the end of the study included their reflections on the *journey* of each networks development. Thus the findings have also stood the test of time. Repeated analyses over the three phases of the study enabled me to capture the wealth of mothers' information and experiences. Reading for points of emphasis in the narrative uncovered different information and interpretations to reading the transcripts for themes about the networks mothers envisaged for the future. As I read and reread the transcripts, I pondered on, and refined and clarified my interpretations of their experiences and ideas, consistent with the phenomenological approach. These repeated analyses encouraged more nuanced and detailed interpretations. Personally checking the findings with the mothers toward the end of the study, rather than relying on the generosity of other team members to conduct these interviews on my behalf, meant I could clarify the nuances of my understandings with the mothers. This proved fruitful. After carefully reading the transcript of one mother over a 5 year period, it was through one of these discussions that I further understood the context of the circle she described as the network of support. Thus my interpretations evolved throughout the 5 year period.

Peer review and my discussions with the mothers about the overall study and its findings reinforced the integrity of the overall research process. Mothers were provided a summary of the findings should they, like other peers, like to comment them. The project research team, with whom this study was

discussed intermittently, are very experienced in the field of disability research. Their intermittent comments on the research design and early drafts of chapters for this thesis reinforced the integrity of the research process. The relevance of the research to the field and the congruity of the research design with the topic were reinforced by peer review of a draft journal article, discussions at the Research and Higher Degree conference at the University of Sydney and at the International Association for the Scientific Study of Lifelong Disability conferences. A paper entitled, "You're the Bottom Line, I guess", was presented to the International Association for the Scientific Study of Lifelong Disability conference in June 2009.

4.7   Mother's ideas about networks that will support their son or daughter with lifelong disabilities when they, and the father of their son or daughter, are no longer able to.

The next five chapters identify and examine the features and functions of the networks mothers envisaged supporting their sons and daughters with lifelong disabilities into the future. The influences on these networks are also examined. Table 4 provides pen portraits of the situation of each of the mothers. This section outlines the format for these chapters of findings.

Table 4:

Pen Portraits

Hamish's mother
Over the course of the study Hamish's mother initiated and established a *circle* for Hamish as she *is not getting any younger*. She has university qualifications and has been actively involved in advocating for people with disabilities. Hamish's is in his 40's and shares his home with four other people with disabilities in a suburb neighbouring his mother's home. He and his flatmates are supported 24 hours. Hamish's father is deceased and the circle will support his two sisters in *bringing enquiry* to decisions about Hamish's life.

Claire's mother

Claire is in her 40s and has lived away from home since childhood. Claire shares a flat with a friend she has known since school. They have been supported by the same service since childhood. Claire is actively involved in her local community. Her mother, who has a Masters degree in Disability Studies and is now in her 80s, has steadfastly advocated with the service on Claire's behalf throughout Claire's life. Her father is deceased. Claire has 3 sisters. Her mother describes her daughter's network of support as the *family*. Into the future, they will support Claire, as their mother has before them.

Betty's mother

Betty is in her 20s. Her mother has a Masters degree and works in the disability sector. Betty moved from her parents' home into her own flat during the course of the study. While a support package has recently been approved, her parents were integral to establishing Betty in her flat. Betty has 2 younger siblings. This family espouses a value of individual self reliance and this permeates the approach they have taken with their children.

Edward's mother

Edward is in his 20's. His mother has a university degree and continues to pursue a successful career in her profession. Edward's parents are in their 60s. His father died during the course of the study. His sister and brother are integral to his life. Edward actively participates is his community and lives in a share house with two housemates. He requires consistent support and returns to his parent's home on the weekends when his housemates are not available to provide this support. The house is supported by a "circle". The addition of an intentional community to the current arrangements will ensure that Edward is adequately supported into the future.

Greg's mother

Greg's parents have been integral to the establishment of the complex multi-layered network that has evolved over 10 years to support Greg. Greg is in his 40s. His parents are in their 70s. His mother initiated the networks after she retired from her professional career. His father died during the course of the study. Greg is supported by *a service, a circle* and *his social network* to live in his own home. He shares his home with lifestyle support facilitators 24 hours a day. His brother and sister are involved in the network.

Emily's mother

Emily is in her 20s. Her mother has a Masters degree and continues to successfully pursue her professional career. Emily's parents separated when she was 10. She now lives with her father and

his partner and stays with her mother. She has a brother and sister whom she sees regularly. Her nuclear family lives in separate households in neighbouring suburbs. Emily is employed and pursues several interests. Emily's mother would like to develop a network of support to engage the younger members of the extended family in a relationship with Emily and think creatively about her lifestyle. Her parents do not agree on the necessity of this.

Maree's mother

Maree is in her 20's. Her parents separated when she was young. Their relationship continues to be acrimonious. Her mother is a sole parent and has worked part-time. Maree has lived between households. She moved from her mother's home into her own flat during the course of the study. She shares her life with her fiancée and has many friends at the sheltered workshop where she is employed.

Mary's mother

Mary's parents are in their 80s. Her mother has chosen not to pursue paid work. Over the course of the study, they were involved in establishing a circle that supported Mary to move out of her parents' home into her own flat. Mary had lived with her parents most of her life and had pursued a 20 year career in retail. She is one of six siblings. They were all very supportive of Mary. Mary now lives alone. However, the circle provides a venue for the coordination of the support that enables her to do so.

The networks mothers envisaged supporting sons and daughters with disabilities into the future were influenced by mothers' experiences in their sons' and daughters' networks in the past and those anticipated into the future. The chapters are sequenced to evoke the life course perspective. The first chapter of findings, titled '*... bringing enquiry'*, describes the influences of mothers' experiences of seeking out support when their sons and daughters with disabilities were children. The next, '*moving into a truly adult phase of life'*, looks at the influence of their experiences of fostering networks that support the adult lives of sons and daughters with disabilities. The third chapter of findings, '*checks and balances'*, describes the influence of concerns for safety. The fourth chapter, '*I'll do it one day'*, reveals how ongoing acrimony between parents impacts on networks throughout the lives of sons and daughters with disabilities. The fifth and final chapter of findings, *'... backing off ... and the*

changeover', considers networks for preparing for parents' transition at the end of their lives. Thus each chapter addresses a stage of transition or a turning point.

Each chapter considers the influences of experiences of a particular transition or turning point on the networks mothers envisaged supporting their sons and daughters with disabilities into the future. Each mother's experience in the networks that have supported their sons and daughters with disabilities influenced her ideas about networks for the future. These are presented in a storied format in a text box that opens each chapter of findings. The chapters then explore what these stories revealed about the meanings (Husserl, 1970b in Crotty, 1996) mothers looked to networks to capture; the features of the networks that will support sons and daughters with disabilities into the future and the influences of these experiences on mothers' ideas about these features. Thus the chapters address the research questions in relation to particular transitions and turning points. In essence, mothers envisaged networks would embody respectful *ways of thinking*; *bring enquiry* to their sons' and daughters' life choices; support adult lifestyles; provide *protection* through *checks and balances* and; assist families in *preparin*g for parents *moving on.*

Inadvertently, mothers' stories revealed their own agency in the support networks of their sons and daughters with disabilities. Examples of mothers' agency are woven across these chapters. Mothers sought out alternatives for their children when support was offered through large residential units. They prepared their sons and daughters for their adulthood. They acted when sons and daughters were traumatised. They prepared for the futures of their sons and daughters in which they and the father of their son or daughter had died. Further, this study revealed they did so because they needed to. There was no one else to do so. Paradoxically mothers were increasingly engaging the support networks of their sons and daughters with disabilities such that they might be confident others will be involved when they ultimately disengage. Mothers' agency is highlighted through the chapters.

Several conventions have been adopted in the style of writing in these chapters. Firstly, while the study is indebted to mothers' generous reflections on their ideas about, and experiences of, their sons' and daughters' support networks, this study did not investigate mothering. It is their experience as a mother that was investigated. Therefore mothers are named as a person's mother rather than given their own pseudonym. This reinforces the idea that the focus is on the experience of someone in this role. It depersonalises them. It is intended to be a deliberate, if unfortunate, reminder of the disembodiment of these representations of their experiences. Mothers agreed when I checked with them that this convention reflected their role in this study. Secondly, quotes from mothers' narratives are presented in *italics*. Thirdly, during the final stage of the member checking my discussions with one of the mothers revealed her discomfort with the label of lifelong disability that had been given to her son. She questioned the extent to which this description fitted her son. As such I have referred to the sons and daughters at the centre of these networks as having lifelong disabilities rather than intellectual disabilities.

These chapters do not provide a comprehensive account of the narratives of each mother in the support networks of their sons and daughters with lifelong disabilities. Rather it is intended that the reader will arrive at the end of each chapter with an appreciation of something of the experiences of the mothers whose stories are featured in that chapter. The reader should arrive at the end of the findings chapters with a sense of what mothers wanted in the networks that would support their sons and daughters when they were no longer able to.

6.5   Conclusion

The study investigated the features and functions of the networks that mothers envisaged supporting their son or daughter with lifelong disabilities into the future and the influences of mothers' experiences in their son's or daughter's networks on the networks that they envisaged for the future. This chapter described the research methodology and research process. The social constructionist view

acknowledged the influences of the contexts in which networks were constructed on ideas and meanings associated with them. The phenomenological approach held the focus on the intricate and rich views and experiences of mothers and the narrative analysis provided an analytic process to do so. The following chapters describe the network features and functions that were unveiled and the influences on the networks that mothers envisaged supporting their sons and daughters with lifelong disabilities into the future.

The Middle

Chapter Five

Scenario One *... bringing enquiry*

In the first scenario mothers anticipated the *family* or a *circle* will *bring enquiry,* will *monitor and advocate* with the services that support Hamish and Claire, when their mothers, like Claire's and Hamish's fathers, are *no longer here*. Hamish's and Claire's mothers, the narratives of whom are featured in this chapter, discovered th*ere was not much on the ground* when they sought support for Hamish and Claire. They found themselves agreeing to their children moving into residential settings. Hamish and Claire are now supported by *services* to live in houses they share with friends with disabilities. These early experiences in what will become the networks that will support Hamish and Claire into the future, marked the networks.

T*he beginning of it all* for Hamish's and Claire's mothers, the *beginning* of their ideas about who will support Hamish and Claire into the future, were experiences that revealed differences in *ways of thinking* about people with disabilities. Hamish's mother heard a parent of a son with lifelong disabilities speaking on a radio program. His mother upheld her son's *value as a person and his right to be treated in the same way as everybody else.* Claire's mother recounted a disagreement with Claire's father at Claire's birth. Claire's father wanted to *place* their baby in a residential service and her mother was *horrified*. Hamish and Claire were not *treated the same way as everybody else*. Their mothers brought *ways of thinking* about the value of people with disabilities to the networks that supported Hamish and Claire. They envisaged *the family* or *the circle* will ensure *enquiry,* and therefore these *ways of thinking,* will continue to influence Hamish's and Claire's lives into the future.

The chapter explores the networks Hamish's and Claire's mothers' envisaged supporting Hamish and Claire when they, like Hamish's and Claire's fathers, are *no longer here.* It also explores the influences on their ideas about the future. The text boxes contain a precis of Hamish's and Claire's mothers' stories of their experiences in the Hamish' and Claire's networks. Their future plans, that is, t*he family* or *the circle,* are described before the chapter reflects on what influenced Claire's and Hamish's mothers' selection of *the family* and *the circle.* Finally, the chapter compares Claire's and Hamish's mother's future plans, and the future planning process in which they are engaged, with previously documented descriptions of future plans and future planning processes described in Chapter Two.

Textbox 1 - Hamish's mother's experiences

Hamish was born in the early 1960s *when there was not much on the ground*. His mother searched for and eventually found a non-government school that could cater to his educational needs. Despite the school's specialised focus she was subsequently asked to *take him away because he wasn't keeping up with their program*. A large residential unit was the only alternative she could find. He was 11 years old and he moved to live 3 hours drive away. His mother visited him weekly. After he moved into the large residential unit he was regarded as aggressive by the *service* and was given increasing dosages of medication to calm him. Around this time Hamish's mother recalled hearing the mother of another person with lifelong disability on a radio program.

> "She was *speaking, so strongly and so comprehensively about (her child)'s value as a person and his right to be treated in the same way as everybody else. ... I captured that. ... I knew that was the right thing to do.*"

Hamish' mother sought out that woman and joined a social group related to the rights of people with disabilities. She volunteered during strike action by staff in the large residential unit where her son lived. She *could see all the problems* associated with living in residential facilities and her *whole vision for Hamish changed*. She volunteered on a committee and planned Hamish's move to a cottage. When changes in government policy threatened his move, she pursued connections she had made to reinstate him. Finally, through her advocacy and initiative, 10 years after moving to the large residential unit, Hamish moved to a group home in his mother's neighbourhood. The move to the cottage was wonderful for her son. *We went to the house and the staff were already there. ... and he just walked into the house and he walked right through the house without any problem ... and he just seemed to feel well I know this is right*. He lives in the same house 20 years later.

This is the lived experience of the emergence of new ideas out of and in response to the old. *The policy and political changes* provided the context for Hamish's mother's advocacy. She *was either protesting about what the government was doing or supporting initiatives that the government was taking. … So it was within that kind of ... political and social framework*. She would like her daughters to have access to these ideas and has invited them to join her in establishing a circle of support which can continue her vision for a satisfying life for Hamish.

The family socialise together each week over afternoon tea. *Hamish's two sisters live not far away ... and both of them are now married. And (*name of sister*), the youngest one, has two children... we meet every Sunday. Hamish is home every Sunday. And we either go to a park where the children have their bicycles or we go up to (*sister's) house or they come here for afternoon tea. It's a ritual… The kids love it*. Hamish' mother suggested extending these social occasions into a venue for the circle. Her daughters are busy with young children and it is not yet clear *what they want to do, why they want to do it and who they want to have involved in the circle*. Hamish' mother has *monitored carefully what's happening with Hamish* in relation to the support the service provides him *with some success and with a lot of frustration*. She expects that her daughters will continue to do so into the future and she would like them to be supported by two or three people who know Hamish. If *situations arise where they need to think about what is best for* [him] ... *then they would have other people who are looking at Hamish's needs as well*. This is her way of both *protecting* Hamish's interests in the future and supporting her daughters.

Hamish's mother identified a circle was needed because she was *not getting any younger* and *the circle ... would … bring more enquiry into Hamish's life* and support her daughters. Nevertheless it *is also a matter of getting the vision and the enthusiasm and the engagement of family members to begin ... that's quite a lot of work*.

Textbox 2 - Claire's mother's experiences

Claire's mother marked her actions to protect Claire soon after her birth, as *the beginning of it all*. When her daughter was born, Claire's father investigated the support that was available to their daughter. He and the nursing staff of the hospital followed the recommended wisdom of the time, the 1970s, and suggested placement in a residential setting. H*e (Claire's father) said "you can place her. I can take her to (*name of a capital city*)". Well, I was horrified; I mean I'll never forget that anguish. I think I just about killed her, I held her so tight, and said "no one's going to take her away from me" and that was the beginning of it all*.

Claire's mother wanted her daughter to be with her, not in a residential setting. She had a *strong gut reaction* that was reinforced by a friend's advice to "*take her home and love her*". Claire's mother recalled paving the way for her new baby to be welcomed into the family. She introduced Claire to her 3 sisters in the grounds of the hospital. Children were not allowed in hospital wards at that time. She *wanted them to know that Claire was a normal little baby. She did have certain little characteristics but, she was going to be fun, and lovely*. These were the first of many actions of challenging assumptions and protecting her daughters' interests from current standards of practice.

When Claire was 10 years old her mother finally surrendered to the tide of opinion and followed the advice of Claire's father. Claire *went into residential care.* When she recalls this time, she says it *makes me cringe when I think of it, but, family circumstances. I couldn't withstand the barrage … continuing from my husband at the time. … And, so, I placed her. Everyone* supported it. She cringed again when she re-read this account in the member checking process. It made her *realise how alone I felt about it at the time.* Claire went to live with a non-government organization, her mother called a *boarding school*. The students were expected to live in full-time and have no contact with their family for the first 3 months to allow them to settle. Claire's mother challenged these rules. She said *"I'll be bringing her home every weekend"* and consequently the sisters developed *normal and natural* relationships with one another. She was repeatedly discouraged by the superintendent. *… They'd make me wait outside his (*superintendent's*) door every time I came to pick her up.* Even though she felt she was treated like an errant child she was not deterred. She was not saying the school was regressive, indeed she said *the staff were wonderful ...the school was excellent.* Rather she was marking the different domains of the network because of the intolerance for the different course she wanted for Claire's life.

The school and the organisation of which it is part, changed over the years that followed. Claire and as such, her mother have been involved with the organisation since Claire was 10. The school initially adopted a *medical model* and when they revised their approach, Claire moved into a group home. With further policy changes Claire was supported to move into the community. *They had a group home model… very early on in the seventies and eighties, seventies maybe. So when it came to moving out into the community, … to devolve the whole institution, they already had the group home.* Further, *they had the idea that everyone who had had the decent education and schooling should have the opportunity to go out in open employment.* Claire's mother lived these changes through the experiences of her daughter. She has consistently monitored developments and advocated on Claire's behalf to instigate change or as change has arisen.

Claire's mother is now in her late 70s and has recently suffered with health problems. One of her daughters recognised that their mother was *really struggling.* As Claire's mother said, "*She told me to back off and really I just felt I was really struggling at that point and she recognised that and told me to pull my head in."* This was a few years ago and Claire has now adjusted. (Claire) *comes over here and we do a bit of shopping and then she'll say well you can take me home now … and that's only just happened in the past 6 months (2012) when she's quite strong about saying no we'll go now*.

In the future when Claire's mother is no *longer here … there'll be lots of input and family support.* Claire will continue to be supported by a *service* to live in the flat she shares with her friend and pursue her interests. Her sisters will take up the role of *monitoring* their sister's life. When she talks about the future, Claire's mother is delighted that her daughters will support one another and is confident of their capacity to do so. Until then, she continues to be as actively involved in monitoring the support of her daughter as she can be.

5.1 *The family* **or** *the circle*

In the future Claire and Hamish will be supported by *the family,* actually her sisters*,* or *the circle.* They will *monitor and advocate* with the service and *bring enquiry* based in respectful *ways of thinking* to Claire's and Hamish's lives. Claire *has three sisters who are all involved with her … She's always been part of the family*. *The family* support one another and will do so into the future. The *circle* will reinforce Hamish's sisters' capacity *… to bring more enquiry into Hamish's life*. As his mother says "*I've got learned experience gained over time, but Hamish's sisters don't so the support of a circle could be valuable."* Hamish's mother envisaged people with *learned experience* would join the circle such that they might advise Hamish's sisters into the future. Like Mary's mother, described in Scenario Five, Hamish's and Claire's mothers' ideas were triggered by their anticipation of the family's adjustment to their own decline and passing away.

The future which Hamish's and Claire's mothers are planning for is imminent. Hamish's mother is *not getting any younger* and Claire's mother is thinking about when she is *no longer here.* Claire's mother was *struggling* with her own health concerns when she agreed to her daughters' suggestion to *back off*. The siblings in both families are involved in one another's adult lives and will continue to be so when their parents *no longer here*. As summarised in Table 3, the next section reflects on their mothers' experiences in the networks that supported Hamish and Claire.

5.2 **Influences of their experiences in Claire's and Hamish's support networks on the Claire's and Hamish's mothers ideas about** *the family* **and** *the circle***.**

Claire's and Hamish's mothers' experiences of *what was on the ground*, *ways of thinking* about disability and the demand for their agency influenced their plans for the future. These mothers had *entered into the public structures of society to advocate* for the rights of people with disabilities. They had invested years of their lives in improving *what was on the ground*. Because of this experience they anticipated *monitoring and advocating* with the *service* and *enquiry* based in their preferred *ways of*

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thinking would be needed into the future. They envisaged several people, *the family* (3 sisters and a niece) or *the circle* (of which 2 sisters are members) will support one another to do so. They wanted to ensure their daughters were supported in these negotiations as mothers' experiences of negotiating Hamish's and Claire's support had been traumatic.

Table 5:

Plans for supporting Hamish and Claire when their mothers are *no longer here.*

Past *When there was not much on the ground*	Present *not getting any younger* *She told me to back off ... I was really struggling at that point.*	Future	
Transition / Turning Point	**Network of Support**	**Features**	**Functions**
I captured that .... ways of thinking *She was speaking so strongly ... about (*her child's*) value as a person*	*the cottage & the service* *getting the vision and the enthusiasm and the engagement of family member to begin* *they would have other people who are looking at Hamish's needs as well*	*the circle*	*Ways of thinking* *learned experience*
You can place her ... I was horrified ... no one is going to take her away from me...	the flat, her flatmate, support coordinator, work, church, art, soccer & *the service* *... comes over here ... and then she'll say well you can take me home now*	*the family*	*... bringing enquiry*

5.2.1 When there was not much on the ground

Witnessing the segregation of a son or daughter with disabilities influenced Hamish's and Claire's mothers' ideas about networks for the future. When Hamish and Claire were children*, there was not much on the ground* to support them. These mothers found few *services* for their children. Consistent with the wisdom of the 1960s and 1970s (Clapton, 2009), the support their mothers were offered for their children was segregated and based in the *medical model*. Fruitless searches for suitable alternatives for Hamish and the *barrage* of pressure from Claire's father resulted in Hamish and Claire living in residential settings in their childhood. In the residential unit Hamish was perceived as

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aggressive and medicated. Claire's mother was discouraged from visiting Claire. Medication and

segregation were indicative of the way in which support was provided. While s*ervice*s and ideas

developed as their children became adults, and these mothers participated in the changes to the

political and social framework, they knew that segregation and the *medical model* continued to

influence the disability sector. These stories of segregation and being treated as ill were painful to

recall and despite recognising they had little choice, Claire's and Hamish's mothers remained

distressed by the thought of having to make the choices they had.

5.2.2 *You can place her/ I captured that*

 These mothers identified events that would be turning points in their sons' and daughters' lives, the

emotion of which remained years later, in which they recognised different *ways of thinking* about

disability. Claire's mother remembered the anguish of the confrontation with her husband and the

nursing staff of the hospital when they suggested she *could place her*. More than thirty years later,

Claire's mothers still *cringe*s when she thinks about it. Her gut reaction told her to resist. Recalling "i*t*

makes me realise how alone I felt... there were no advocates coming and telling me ... it was just

normal procedure to go into institutional care from birth." At that moment in time, it was she and her

daughter against *normal procedure*. Similarly Hamish's mother recalled the moment when she heard a

radio program in which the views outside the *normal procedure* Claire's mother had referred to were

expressed. When she said "*I captured that*", she signalled a moment in time in which ideas were

expressed in the public domain that reflected her own. While one recalled a moment of resistance, the

other, recalled a moment of recognition. Both acknowledged what was important was, unlike the

normal procedure, hopeful *ways of thinking*. Further they wanted to ensure these turning points in the

lives of their son and daughter with disabilities would be sustained into the future.

5.2.3 *Ways of thinking*

Claire's and Hamish's mothers were distressed by the choices they had made, however they did not acquiesce to the *ways of thinking* that living in residential units represented. They influenced services towards their own *ways of thinking* by *bringing enquiry*. Hamish's mother referred to rights, *the right to be treated in the same as everybody else,* whereas Claire's mother referred to the *normal patterns of life*. Hamish's mother wanted there to be *total respect for the person*. As such she encouraged support workers to step back and see how Hamish responded rather than *take on a caring role.*

> *They want to do the best they can but, and especially for people like Hamish who can't say "don't do that" or "I don't like that", it's sometimes difficult for people to see that they have to stand off a bit to see what his responses are.*

Claire's mother's *gut reaction* guided her. Claire's mother addressed signifiers of Claire's segregation. For example as she said: "*Claire sometimes arrives here and her clothes, she looks as though she's just walked out of a St Vinnie's bin and I'm appalled. And sometimes the clothes are dirty, but most of the time they're just sort of crumpled".* Her mother intervenes. She washes and irons Claire's clothes. For her, inconsistency with community standards reinforces difference and signifies disrespect for her daughter. She says the support worker said *"oh she'll be the best dressed"... I thought well people look at her because she's different. ... her clothes as well, I mean that doesn't help her.* Her mother fostered Claire's acceptance by the broader community. In saying *she'll be the best dressed,* her support workers compared her with her immediate social group. *"Oh, it's their choice"* does not justify reinforcing disrespect. They are perpetuating her disability by not supporting Claire to dress in socially acceptable ways. Similarly Claire's mother compared Claire's time in a group home with her granddaughter's time sharing a house with fellow university students. It wa*s normal late teens early 20's.* These living arrangements were stepping stones from which relationships will be developed that

enable access to networks beyond segregated *services*. Claire's mother reiterated her point with a recent example.

> *In the last 6 months ...I was asked to come and see Claire in a dance competition ... It was held in a local school hall. I arrived there and I realised that all of the local services who were supporting people with disabilities were there and there were other parents as well but it was all disability. Claire had a lovely time. She met up with friends and so on and I had mothers, young mothers coming up to me and saying oh isn't it enlivening it's so wonderful for them. .. I was groaning inside thinking this is not for Claire, Claire has been in the community for 20 years and she shouldn't be tagged into disability stuff.*

In summary where one mother wanted people to stand back and take their lead from sons and daughters with disabilities, the other wanted people to intervene and ensure their sons and daughters with disabilities were given opportunities to be like anyone else in the community. Both scenarios signified to*tal respect* for sons and daughter with disabilities. They signify different forms of social inclusion (Clapton, 2009). Appropriate *ways of thinking* were not ingrained in the *services* Claire and Hamish were supported by. Advocating for *ways of thinking* enabled these mothers to bring about changes for their sons and daughters and they looked to the *family* or the *circle* to continue to do so in the future.

5.2.4 learned experience

T*he circle* provided a vehicle through which Hamish's mother's *learned experience*, her social capital, might be shared with, and passed onto, her daughters. Whereas Claire's mother was confident that between her three daughters and a niece Claire will be well supported. These mothers knew *it's … easy to be sucked into the service system and to do what they think is right.* Hamish's mother does not want her daughters to find themselves unsupported. She was reassured by knowing that she was not alone in the *way of thinking* and pursued connections with other like-minded people. This *learned*

experience involved social capital of connections and skills she had accrued through her involvement in lobbying for change in the disability sector on Hamish's behalf. *The circle* would be a vehicle through which she would pass on this *learned experience,* this "social capital" that she had accrued, to her daughters (Bourdieu, 1986). Claire's sisters have been involved in *monitoring and advocating with the service* alongside their mother. Finally, these stories revealed mothers' agency in the networks that supported their sons and daughters with disabilities.

5.2.5 Initiative has to be taken

Initiative ha(d) to taken for plans for the plan for future support to be realised. Claire's mother might not have been thinking about a future in which she had passed away when she was *bringing* Claire *home every weekend* and holding the *normal and natural* relationships between sisters. Nevertheless her initiative, against the advice of the school, has indeed paid off. More recently her daughter's initiative, which Claire's mother heeded, enabled her to *back off*. Hamish's mother suggested the idea of the circle to her family. They subsequently gathered for afternoon tea and talked about other family projects but no one returned to the subject of the circle.

> *It's not a topic of conversation at afternoon tea or at lunchtime that we have naturally … we can ask how (Niece's name) is getting on at her pre-school or how (nephew's name) is going with his soccer … nobody raises the question "how are we going with the circle".*

She needed to *take the initiative.* When she *says "well this is going to happen" then they certainly step forward.* Her daughters will join in and help however it will not progress spontaneously. It was not only that they took the initiative had to be taken but that the timing of it was negotiated between mothers and daughters.

5.2.6 An exercise in strategy and planning

Claire's and Hamish's mothers had *enter(ed) into the public structures of society* to advocate for the kind of society they envisaged supporting Claire and Hamish. Claire's and Hamish's mothers acted to address the limitations of the *services* that brought them such distress. They participated in the tide of social change associated with deinstitutionalisation. They were involved with advocacy initiatives, informed advisory committees, members of community based management committees, lobbied government ministers and networked with senior government staff. These were exercises in *strategy and planning.* They *enter(ed) into the public structures of society in taking on that role of responsibility.* They had *to know how society works... i*n order ... *to try to achieve something.* Claire's mother, for example, was the second woman to be elected to the board of Claire's school. At that time, it was mostly fathers who were members of boards. She took a bottle of scotch to the first meeting and *plonked it on the table and said I don't make tea*, signalling with humour her intention to challenge preconceived ideas and promote improvements for the students. They had invested substantially in the networks that currently surrounded Hamish and Claire. *The family* and *the circle* foster will hopefully sustain and/ or capture their complex *learned experience* into the future.

5.3 *the family, the circle and bringing enquiry*

When Hamish's and Claire's parents are *no longer here* Hamish and Claire will be supported by networks that encompass two distinct domains. On the one hand there will be the *family* or *other people with learned experience* in the *circle.* On the other hand support will be provided by s*ervices*. This second domain is similar to a residential plan for the future. The first was needed because Hamish's or Claire's adult life was supported by *t*he second, that is, *services*. These domains related to one another dialectically; they were interdependent and opposing. A change in one influenced the other. A most striking feature of these stories was the emotional terrain they traversed. I hope I have managed to portray the depth of these emotions adequately. Future planning initiatives acknowledge

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'letting go' is difficult. But how much more difficult must it be with memories of the isolation and anguish of being asked to surrender a new baby into someone else's care, of being told that your child doesn't fit the school and not offered alternatives, or having to *wait like an errant child outside* the superintendent's *door?* Unlike parents who were deterred from planning by such treatment (Llewellyn 2003), experiences of advocating across these domains motivated these women to support their daughters into the future.

What might be seen to be a residential plan for the future had been nurtured over many years. Hamish has shared a house with a group of people with disabilities for 20 years. He lives in the same neighbourhood as his family. Each week he joins them for afternoon tea at his mother's house. His mother has monitored his support closely and carefully. She has encouraged support workers to step back and wait for Hamish to indicate what he wants. Having moved into a group home and worked in the city in open employment, Claire now shares a flat with a friend she has known since school. She has work, pursues several interests with community groups such as soccer and art. She is a member of the local church and is very familiar with the geographical area in which she lives. Hamish's and Claire's mothers had *monitored*, *advocated* and actively contributed to the disability sector to ensure Hamish and Claire enjoyed such rich lives. Nevertheless, their plans indicate that they did not anticipate a residential plan such as this was enough. It is beside these domains that *the circle* and *the family* will stand into the future.

In each case the second domain will *bring enquiry* however they differed in both the ways of thinking that informed the *enquiry* and in the nature of the network that would bring it. One used the recognisable structure of *a circle*, the other *the family.* Was it because of their experiences that these mothers anticipated 'sites of struggle' (Stehlik, 2000) into the future? Did they choose not to identify a particular daughter as a "key successor" opting instead for a group to avoid the pressure that might be brought to bear on one person? The domains within each network were marked out by differences in *ways of thinking,* however the *ways of thinking* Claire's and Hamish's mothers described differed.

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While both mothers described positions akin to social inclusion, their interpretations of inclusion varied. Hamish's mother's references to rights resembled "legislative inclusion" (Clapton, 2009, p.219) and Claire's mother ideas about the *normal patterns of life* corresponded with "technical inclusion" (Clapton, 2009, p.212). In addition to this, Hamish's mother planned to realise a return on the social capital she had accrued through her involvement in advocating for the rights of people with disabilities.

5.7   Conclusion

This scenario suggests a residential plan for the future may not be enough (Bigby, 1996). When a residential plan includes substantial *service* involvement, a second domain is needed to harness the *learned experience* that mothers had accrued and *bring enquiry*. The second domain might be *the family* and siblings supported by a *circle*. Clearly however, mothers were concerned that a solitary "key successor" would find it difficult to negotiate on their own (Bigby, 1996). The next chapter explores the networks envisaged by mothers who associated the beginning of their ideas with their sons' and daughters' transition into a *truly adult phase of life.*

Chapter Six

Scenario Two … *Moving into a truly adult phase of her life*

In this second scenario Betty's and Edward's mothers fostered networks that supported Betty's and Edward's *adult... life*. The networks described in the previous chapter were influenced by decisions made in childhood about support networks. The networks described in this chapter supported the transition of sons and daughters with disabilities into adulthood. The mothers in the previous scenario anticipated a time when they *were no longer here,* whereas the mothers in this scenario anticipated not being *a full-time carer*. For Betty and Edward, their mothers *made* their *… independence … happen* and the networks their mothers envisaged reinforced *independence*.

This chapter highlights how networks bolster *independence*. The chapter describes mothers' agency in *grooming* or *pushing for independence.* Betty's and Edward's mothers repeated, at times paradoxically, negotiation was integral to the fostering of these networks. Yet future planning initiatives failed to acknowledge the significance of mothers' agency. The similarities between the networks described by Betty's and Edward's mothers and those described by future planning initiatives are then highlighted. Betty's and Edward's mothers' ideas about, and experiences of, the networks they envisaged supporting Betty's and Edward's independence and *adult ... lives* are presented in the text boxes that follow.

6.1   **Networks that maximised the *independence* of sons and daughters with disabilities in their *adult*... life.**

The networks that supported Betty's and Edward's *adult … life* were web like and geographically based. They featured Betty and Edward living *independent*ly in their own *places,* fulfilling *valued social roles* and having *other people to have a life with.* Edward's network also included a circle on which he

could call *in a crisis*. By accounting for direct support; health; friends; having *someone... there to do something in a crisis; ferrying around;* going *to whatever social activities she (or he) likes* and; getting *away* from mothers *every week,* these networks supported Betty's and Edward's rich *adult ... lives* and ensured these lives were not contingent on mothers' support. Their influence was *all right, ... balanced*. In essence as summarised in Table 4, these networks signified the unique expression of Betty's and Edward's *adult ... life.*

Textbox 3

Betty's mother's experiences - *next big hurdle … moving into … a truly adult phase of her life*

When her mother talked about Betty's network of support she referred to Betty's *own place* that she, Betty's father and Betty envisaged for their *next big hurdle … moving into … a truly adult phase of her life*.

Betty *started having seizures just before her first birthday … She went through so many years of people not being able to understand her.* Her mother *became her interpreter.* Betty and her mother talked about Betty's adult life over many years*.*

> *Sometimes we see houses for sale and so we talk about, "do you think that would be a good place to live?" .. She wants to be right in the, not the city, (name of outer suburb), so she can walk to the (shopping centre) and walk to the things she knows.*

Her mother says:

> *I would see her … living in her own apartment or townhouse … in preference with one or two others of her friends of her choosing. … In her own place, close to public transport, close to a shopping centre where she could just go across every day and collect … food for dinner, come back cook food, be able to get to the movies, get to whatever social activities she'd like.*

Betty's parents bought a townhouse for her within close proximity of their home and Betty moved into her home. She shared with a flat mate. She still goes to the family doctor. *I've been with this doctor since before she was born, so all her life she's been going to this doctor.*

Her weekly routine is yet to be settled and without it, her enthusiasm for living in her *own place* waned. She preferred to be in her parents' home enjoying the company of her family. Betty shared her home with a flat mate for 12 months. Her flat mate shared in the shopping, cooked meals together with Betty and problem solved in emergencies in lieu of rent. Betty's mother anticipated these flatting arrangements may not be permanent and as such the turnover would need to be managed. A support package has been secured to fund the management of the flat mate and subsidise the rent.

Betty's mother doesn't *want to limit Betty.* She also doesn't *want to be a … full time carer for the rest of (*her) *life.*

> *I want to have that freedom of being able to do what I want … but also I see the logical side of it, I'm not always going to be available to be that carer.*

Betty's mother has indeed stood closely alongside Betty. She has been her interpreter. Betty has learnt from her mother. Betty and her mother imagined Betty's adult life over many years and her mother helped put the networks in place to make it happen. Betty's mother's stories of these experiences reveal the incremental evolution of networks through repeated revisions. In essence, her mother is looking to create a living arrangement with which Betty was sufficiently familiar that she could live quite independently.

Textbox 4

Edward's mother's experiences – *he was a support worker and we talked and talked*

Edward's adult lifestyle emerged as his parents and a support worker *talked and talked. It didn't start with us, it started with (*name of support worker*).* The support worker had known Edward for many years and became a friend of the family. Edward has diabetes and therefore needs support 24 hour per day. Edward's network of support is embedded in a neighbourhood with which he and his family are familiar. It comprises his housemates, his family, a support coordinator, friends with whom he shares the activities of his days and pursues his interests, a circle of support and the potential friends of a *good village* in which Edward will live in the future.

Edward lives in what was a rental property of his paternal grandmother in a suburb neighbouring his parents. During the week he catches the bus to a community participation program, attends a drama class and visits the local pub for a weekly karaoke session with his housemates. On the weekends, he returns to his parents' home, for a *great social whirl*, where his parents *ferry him around* various social activities.

Edward shares his home with 2 housemates who ensure he has company 24 hours per day, 5 days per week and manage his diabetes in lieu of rent. The housemates ensure that Edward stays *alive and healthy*. The housemates are managed through a non-government organisation with which his parents have an established partnership. The support coordinator supports Edward and manages the housemates. The support coordinator's direct support role is increasingly expanding as Edward's mother shares some of her responsibilities with him. He now goes clothes shopping with Edward and accompanies him to hair and podiatry appointments. His mother continues to oversight medical decisions, his money and his social calendar.

There is a circle of support ... around the house. ...

> The circle started with (his mother) asking (people) and creating a circle but it's proving to be much more dynamic than that. ... We have sort of layers of it. We have circle members who don't really come to meetings, they support in a different sort of way... it's again not an institution...It's a much more organic structure.

The original members were Edwards' parents, the support worker who initiated the idea of Edward moving out, Edward's sister, a friend of his mothers' and three other people who have previously supported Edward in paid capacities. Current housemates and paid support workers were not included. More recently an ex-housemate has joined and a friend of hers *that was nothing to do with the house ... She said "I was going to miss Edward going out to dinner"* because (housemate) had left the house. *... She's one of the most active members now*. The circle meet bi-monthly for dinner at a local pub. Edward does not attend. His mother facilitates the meeting and circulates minutes via email. In this way Edward's sister, who lives overseas keeps up to date with the circle. Initially his mother described how circles *take away the stress from the person, the sole carer ... someone to talk to and ... know in a crisis someone's there to do something*. More recently she has said *it's a support for* (Edwards' sister) *really... she found it very good and it still is*. Nevertheless, while they can respond to a crisis, the circle is not a position to provide the weekend support. The intentional community, which was akin to living in an English village, *a good village*, where his mother grew up, discussed in Scenario 3, will fill this gap. This complex multilayered network of support has grown organically over many years and will continue to change as opportunities arise.

6.2   *Grooming ...* sons and daughters with disabilities *... for independence*.

The momentum for networks that supported *adult... lives* was sustained by Betty's mother's *grooming*

Betty *for independence* and Edward's mother's *push*ing for his independence. Betty's and Edward's

transition to a *truly adult life* was anticipated and planned for. Mothers *groomed* their sons and

daughters with disabilities for *independence,* at times withstanding their sons' and daughters'

reluctance.

6.2.1 You have to be much more active in facilitating … independence

Mothers anticipated their sons' and daughters' with disabilities transition towards adulthood and they,

rather than their sons and daughters, *pushed* for independence. Unlike his brother and sister, Edward

did not *push* to move out of home and claim his own lifestyle.

> *Gradually with children who aren't disabled in any way, they gradually take that on for*
>
> *themselves. Like, they start to buy their lunch from the canteen at school and you don't make it*
>
> *at home and then they get holiday jobs and pay for their clothes ...Then they start to want*
>
> *privacy, so they go to the doctor on their own and so on. Gradually, they are taking over. That*
>
> *doesn't happen with a person with a disability so much that you have to let it go, rather than it*
>
> *being naturally taken over… Well you have to be more active, like you have to make it*
>
> *happen... Edward would be happy with me bathing him and spooning food into his mouth I*
>
> *think, if I let him. … So you have to be much more active in facilitating his independence.*

Betty's brother and sister *insist(*ed*) on breaking away* as they grew older, *whereas Betty still feels that*

*the ultimate decision is (her mother's). (*This*) puts a lot of pressure as a parent because you are*

maintaining that responsibility. Paradoxically Betty's and Edward's mothers exercised *responsibility* by

enabling Betty and Edward to take responsibility for their own lives. They took initiative to *make …*

independence … happen. Examples of their experiences of *grooming* or *pushing for independence,*

which revealed mothers' agency, follow.

6.2.2 look I've got to go. I'm going to be late

Betty's and Edward's mothers gradually stepped back, increasingly supporting Betty and Edward to come to their own decisions by talking through options and keeping them on track towards *independence.* Betty's mother recounted a daily scene for example, where she increasingly left Betty to wait for the bus in the company of others. Betty enjoyed having her mother wait with her however her mother withdrew saying, *'look I've got to go. I'm going to be late'.* Betty protested about being left alone until she became accustomed to waiting for the bus without her mother. As another example, Betty contacted her mother throughout the day to talk over her decisions. Betty's mother increasingly ignored Betty's telephone calls. This was not easy, having ignored the call, she worried something might be wrong. She tried to g*ive Betty more options and teach her to ask herself is this really urgent* to enable her to call less frequently. Her mother also explained the *difference between discussing something … and actually getting permission.* She was happy to offer her opinion to Betty, but it was up to Betty to decide. Nevertheless *… she keeps me involved ... so it's not just me jumping in.* As another example, each week Edward moved between homes. He was reluctant to leave his parent's home on Sunday afternoons yet when he arrived at his own home he was very pleased to be there. His mother *makes* this *happen e*very week. This sustained negotiation of *independence* relied on the agency, and thus investment, of mothers. Betty's and Edward's mothers assumed responsibility for gradually *push*ing their Betty and Edward toward recognizing they could assume responsibilities for themselves. Thus g*rooming for independence* included mothers consistently and gradually withdrawing and enabling sons and daughters to make their own decisions. Mothers also enabled *independence* by supporting their sons and daughters with disabilities in relating with others.

6.2.3 If you're going to go places with him you know he'll probably bring it up. You either accept that and be prepared to say that every time... or you choose not to go with him.

Mothers stood alongside their sons and daughters with disabilities and helped to negotiate their relationships with people with whom they shared their lives. Betty met her friends at school, her transition to work program, her technical college class and her social group. H*er friends all have disabilities.* Their disabilities complicated communication,

> *for example one of her friends is forever asking her to be his girlfriend. ... And she is very definite that she doesn't want to be his girlfriend. ... I sat down and said "Well Betty you make a choice, if you're going to go places with him you know he'll probably bring it up. You either accept that and be prepared to say that every time "well no I don't want to be your girlfriend", or you choose not to go with him."*

By explaining interactions, suggesting ways of communicating, encouraging perseverance and urging Betty to pursue a range of social situations, Betty's mother enabled Betty to sustain relationships with a range of people.

6.2.4 What I lead with

Paradoxically, mothers lead their sons and daughters with disabilities towards *independence*. Betty's mother hoped to support Betty to pursue the independent lifestyle of her own choosing, yet Betty *pick (*ed*) up very much on what (her mother) led her with*. Betty's and Edward's mothers were conscious of their influence over Betty and Edward and accounted for the paradoxical position in which they found themselves. Betty's mother was *very aware* she had *power over* Betty and regularly reflected on *"why am I doing that?" How much power does she have not to agree to it?* Alternatively, Edward's mother welcomed Edward's relationships with other people to *balance* her influence over Edward. She reacted differently to Edward at different times depending on how tired she was and described a continuum

between o*ver protection on the one hand and giving independence on the other.* Her actions moved up and down this continuum. The following stories illustrate these differences.

Betty's mother acknowledged she subtly influenced Betty much of the time. While she fostered Betty's independence her mother also set the parameters in which Betty exercised it. Paradoxically, her mother used her influence over Betty to enable Betty to build a lifestyle that reflected Betty's preferences and choices. As Betty's mother responded to Betty's interests, Betty refined her preferences and became increasingly confident of expressing them. As an example, Betty and her mother have been negotiating about Betty getting her driver's license. Betty's sister recently secured her drivers' license and as Betty was impressed by the independence a drivers' license afforded her sister, she would like to have her own license. Betty's mother was concerned for Betty's safety. As Betty's mother was *very aware that … * she had *… that power over her* she supported Betty and left the final decision to licensing bodies. Nevertheless she acknowledged she asked herself if she is *putting (*her own*) judgments on what's the best place for Betty to be.* Edward's mother also managed her influence over Edward by encouraging others to be involved.

Edward's mother enabled Edward to develop his own lifestyle and this increased her tolerance of her own embarrassment or fears about Edward's life choices. She laughed a little uncomfortably, for example, when she mentioned Edward's karaoke nights at the local pub. She was delighted by his pleasure in performing and the friends he shared the karaoke nights with. However, she was uncertain of how comfortable she would be witnessing his performance. As she said, s*ome people like to keep a tight rein so that they're kids with disabilities don't do anything embarrassing ... You've got to be able to allow your child, like any other child to do things that you mightn't like really... and that's not easy for some people.* Having other people with whom they shared their lives meant sons and daughters with disabilities could explore interests their mothers might not necessarily want to pursue with them. The influence of their mothers was *balance*d by the influence of others.

6.2.5 *you've got to be careful not to get caught up in the moment*

Fostering *independence* demanded mothers maintained their effort and resolve. Edward *is so in the moment… you've got to be careful not to get caught up in the moment yourself.* Edward and his parents *talked and talked* with his support worker to set up his home arrangement and this arrangement continued to evolve. Betty and her mother have been talking about Betty moving into her own home for many years and when we initially talked about it, she anticipated it would happen in five years time. Thus over time and in particular moments in time mothers remained *clear that this was the right thing to do. .. If you waiver on it then you might be tempted to say "well it's all too hard".* They also acknowledged how tempting it was to lose resolve. I*t is very easy for it to happen and when you are tired and stressed it's just easy to give up being push-push.* Nevertheless mothers were rewarded by their efforts.

6.2.6 *… it's amazing how different she is when I'm not there*

Mothers were reassured that in their absence sons and daughters were *quite capable.* Betty watched and learnt from her mother and when her mother was absent Betty comfortably assumed her mother's place. *My husband said it's amazing how different she is when I'm not there… She takes on, I suppose my role… She'll take it on and she can do it.* Conversely, when her mother returned, they resumed their respective roles. *When I am with her she tends to go back into very reliant sort of behaviours, wanting me to do things for her which she's quite capable of doing and spending a lot of time actually trying to get me to do things for her that she can do.* Paradoxically while her relationship with her mother facilitated Betty's independence, her mother's presence also limited it. Betty emulated her and looked to her for direction. Despite her mother's best intentions and insightfulness, their relationship both supported and thwarted Betty's independence. Betty's mother's presence robbed Betty of the opportunity to act in her role yet witnessing her mother allowed her to develop

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skills for the role. While Edward did not emulate his mother, relationships with other people enabled him to explore other ways of relating. Edward's living arrangement meant *Edward goes away every week. So it is all right, balanced.* He connects with many people with whom he relates differently to the ways in which he relates to his mother. Further in the future i*t will be even better when he doesn't have to come home every single weekend* because he will be supported in the *good village.* His mother linked the familiarity of the family home to patterns in their relationship. His extended network of support interrupted this pattern because he has *other people that he can have a life with* and he acted differently with them. Mothers were aware however, of other parents of adults with disabilities judgement and acknowledged they might be seen as *negligent*.

6.2.7 Cop *criticism*

Mothers were aware of the *criticism* they might *cop* from other parents. Betty had benefited from her involvement with both mainstream and disability focused organisations. Betty *was in mainstream schooling until year 6 of high school … They weren't meeting her needs academically but more importantly she was really struggling socially. … She was getting very stressed and sort of having panic attacks.* Her mother responded to Betty's growing distress and she changed schools. *So we withdrew her and put her into a special school.... which was probably the best thing because she grew a lot of confidence ... and also a lot of friendships which she still keeps today. ... She really enjoyed her last 4 years of school.* Betty's mother confirmed and protected this life path for Betty; however she was ostracized by a family support organisation that judged her selection of a special school over a mainstream school as unacceptable. *It's alright to have ideals but when those ideals are creating too much stress it's not fair on the person. (One) shouldn't push a child through a system just because you should be able to.* Edward's mother revealed that other parents *see it as almost negligent to push a child out into a situation where there's dangers and risks.* In this she is referring to managing Edward's diabetes. A*lthough some of the mothers of Edward's peers would be accessing services like the (*social club*) at the (*non-government organisation for people with disabilities*) … they wouldn't be pushing for*

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independent living. In fact they'd be resisting it. So they can be wanting networks up to a point and then they don't want it. Both she and Betty's mother have *cop*ped *criticism* from other parents and they have courageously stood up to challenges to their approaches to independence.

6.2.8 Mothers' agency in *grooming* and *pushing* for their sons' and daughters' *independence*

Experiences of *grooming and/* or *pushing for independence* revealed mothers' complex agency in fostering the networks that supported the transition of their sons and daughters with disabilities into adulthood. Betty's and Edward's mothers assumed that with the right networks, the details of which are explored next, Betty and Edward could enjoy their independence and pursue *truly adult* lives. Their mothers recognized, however that Betty and Edward would not pursue their independence and hence their adult lives without their mothers making Betty's and Edward's' *independence happen*. Further Betty's and Edward's independence was a crucial foundation to the networks that would support Betty and Edward into the future. Therefore, their mothers *push*ed for independence by stepping back, increasing parameters within which Betty and Edward made their own decisions, supporting them in their relationships, helping them to imagine possibilities for their adult lives and keeping these adult lives on course over time.

When mothers enabled their sons and daughters with disabilities to pursue their independence, shifting the *ultimate decision* towards Betty and/ or witnessing Edward*, like any other child do things you mightn't really like,* they potentially encroached upon *independence*. Paradoxically, their ongoing influence over Betty and Edward was exercised by ensuring Betty's and Edward's wishes were taken into account. At times this meant overriding sons' and daughters' short term choices to maintain desired longer term life courses. Despite his reluctance, Edward's mother ensured Edward returned to his own home each weekend. Mothers were aware of their influence and grappled with the power they exercised.

Mothers' agency in *grooming* sons and daughters with disabilities towards *independence* was addressed briefly in the Planned Life Advocacy Network process (Etmanski, 2000). Etmanski (2000) anticipated the paradox would resolve. He acknowledged the "tug of war" of differentiation from parents did not occur as frequently with sons and daughters with disabilities and that therefore "parent/child separation ... may need a boost" from parents.   What was required, according to Etmanski was parents' "gentle firm pushing hands for momentum and guidance. And for catching. Just in case" (2000, p.63). Betty's and Edward's mothers' stories revealed their "pushing hands' were more than a "boost". They described their recurring commitment year in, year out, to encouraging, enabling and keeping the *adult ... lives* of their sons' and daughters' with disabilities on track. Further, while Etmanski thought the 'paradox of parenting', that is, needing to let go but not wanting to, would 'dissolve' with time (2000, p.61), the complex, paradoxical positions in which these mothers found themselves did not dissolve. They continued to manage their influence over Betty's and Edward's lives over many years. The next section reflects on features of the networks that reinforced independence and compares them with future planning processes.

Table 6:

Networks that reinforced *independence* of sons and daughters with disabilities.

Past	Present *I want to have the freedom to do what I want … but also … I'm not always going to be here.*
Transition / Turning Point	**Network of Support**
Moving into a truly adult phase	His/ her *own place* … house and flat mates *I've been to this doctor before she was born … all her life she's been going to this doctor*
– he was a support worker and we talked and talked	*… other people… (to) … have a life with*
You have to be much more active in facilitating his independence *Look I've got to go, I'm going to be late*	*having a role rather than being amused* *I am calling Edward a (football club) fan … and it becomes quite different … it is a different way of looking at it*
	Someone is there to do something in a crisis *We have circle members who don't really come to meetings, they support in a different way, it's again not an institution . .. it's a much more organic structure*

6.3   Networks that supported sons and daughters with disabilities in *truly adult*... lives and future planning processes.

Networks that sustained the independent *adult … life* of a son or daughter with disabilities and in turn enabled parents to revise their *full-time carer* responsibilities featured son's and daughter's with disabilities having:

- their *own place* and in particular uniquely tailored living arrangement in locations that provided ready access to familiar neighbours and facilities;

- people *to have a life with* including *house* or *flat mates;*

- valued social roles, and;

- *a circle* that meant *someone was there to do something* in a crisis*.*

Like future planning processes, these networks were uniquely tailored to play to the strengths of the person at the centre of the network (Etmanski, 2000; Klees, 1996). Comparing these features, and Betty's and Edward's mothers' experiences, with the networks described in future planning programs confirmed networks that will support sons and daughters with disabilities into the future incorporated "natural supports" (Klees, 1996) of geographically based webs, clusters associated with the pursuit of interests and structured circles (Etmanski, 2000). It revealed however that mothers' agency and family assets underpinned these structures.

6.3.1   His/ her *own place*

Living in their *own places* in locations that reinforced their *independence* signified Betty's and Edward's *adult… lives* and established arrangements that prepared for their parents *moving on*. By purchasing Betty's and Edward's *places*, their parents were able to choose uniquely tailored locations. Convenience of location reduced the demand for *ferrying around.* The *places* in which Betty and

Edward lived utilised Betty's and Edward's familiarity with the geographical location to maximise their independence. Betty's and Edward's familiarity with services and public utilities boosted their confidence in using facilities and therefore boosted their independence. Betty's mother, for example, has *been with the doctor since before (*Betty*) was born.* Edward was the third generation in his family to live in his neighbourhood. He enjoyed striking up conversations with neighbours and they with him and this had proven to be protective when he was feeling unwell. Thus, the foundation of these networks was a geographically based web of familiar relationships with neighbours and public facilities that reinforced Betty's and Edward's independence. The influence of such familiar geographically based webs of relationships on sons' and daughter's safety (Etmanski 2000) and independence was acknowledged in future planning literature. Etmanski privileged home ownership for the "stability, permanence, predictability, control, choice and status" it offers (Etmanski 2000 p 112). The second feature of the networks mothers described was the more intimate web of relationships with housemates and *other people... (*with whom to*) ... have a life.*

6.3.2   *… other people… (*to*) … have a life with*

Betty's and Edward's mothers repeatedly encouraged and enabled Betty and Edward to have *other people … to … have a life with.* In addition to independent access to a familiar web of neighbours and public facilities, the company of friends and the right housemates or flat mates were crucial to the networks that would support sons and daughters with disabilities when parents had *moved on*. Betty's and Edward's "fellowship" with people of shared interests or histories featured in the networks Betty's and Edward's mothers envisaged (Etmanski, 2000, p62). These relationships were embedded in valued social roles. The network structures that hold these relationships are discussed in the next section. This section focuses on the house or flat mates that were crucial to the life Betty and Edward enjoyed in their own *places*. Edward's housemates made sure he *stayed alive and healthy*. In the absence of Betty's flatmate, Betty was tempted to abandon her adult lifestyle and return to her parents' home to

enjoy the company of her family. While future planning programs recognised house or flat mates might be needed, they did not necessarily recognise the network structures that held them.

Edward's and Betty's parents have contracted arrangements with non-government organisations for the management of the house and/or flat mates. His support coordinator and housemates were recruited through a non-government organisation. The funding secured for the subsidisation of Betty's place was also channelled through a non-government organisation. A detailed analysis of the organisational structures that managed the recruitment and support of housemates and/ or arrangements for self-managed support packages, although clearly important to the viability of the networks, are beyond the scope of this research. Of note here however was the right housemates were vital to the networks and house or flatmate turnover was high as the nature of the arrangements attracted itinerant people. While Betty's and Edward's mothers had secured arrangements with non-government organisations, they remained integrally involved in the management of house or flat mates. Their experience in the disability sector had informed them in the negotiation of such arrangements. Thus, the right house or flatmates reinforced independence and therefore featured in these networks, however their management remained somewhat contingent on mothers' agency.

6.3.3 … having a role rather than being amused

Another feature of the networks that Betty's and Edward's mothers fostered to support Betty's and Edward's *adult … lives* that anticipated the future was the garnering of "natural supports" (Klees, 1996, p. 57) that offered Betty and Edward valued social roles. Rather than "making a contribution" (Etmanski 2000) per se, it was valued social roles that reinforced relationships and made moving into their own *places* attractive. Valued social roles were located within a cluster of relationships and their involvement with these clusters supported Betty's and Edward's independence. Edward being a member of the local drama group and Betty being a member of her social group, for example, meant Betty and Edward were able to pursue relationships with long standing friends who were also group

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members. Edward's mother did not view Edward's membership of this group or pursuit of his interests as Edward *being amused.* Rather, pursuit of his interests offered him valued social roles. She referred to football to exemplify thinking about *Edward as a football fan, not Edward filling in his time by watching football. I am calling Edward a (*name of a football club*)' fan, because* name of a football club*' fans buy magazines, they look at pictures and they find out when the games are on, they go to game matches, they talk to their friends about the scores and it becomes quite different ...It's just a linguistic shift but it is a different way of looking at it. T*his membership, be it actual or experienced, to a group of people of similar interests meant these networks involved clusters of relationships based around the pursuit of similar interests. These relationships were both long standing friendships, such as Betty's social group friends with whom she went to school, and incidental, such as Edward's shared experience with other football fans. Betty's and Edward's mothers also illustrated the roles in which they wanted Betty and Edward to be embedded within the networks by contrasting them with experiences they hoped to avoid in the future.

Both Betty and Edward had experienced situations that undermined their *independence.* When Betty recently went to a camp at the beach with her social group for example, she was required to have someone watch her when she showered. These precautions were imposed because t*here had been a few deaths of people having seizures in baths who were under the care of (*state government department*) staff.* Betty's epilepsy was well controlled with medication. Nevertheless, her mother was unable to convince the organisation that this directive was not relevant to her daughter. Her mother described the *psychological* effect *of her being told now that she is not capable of having a shower independently or it's not safe to.* It *must have some effect on someone's ability to feel confident in themselves.* This is *actually a barrier to that independence.* Betty enjoys the friendships and interests she pursues with her social group and she and her friends are unable to organise these activities without support yet the support reinforced their dependence. Edwards' mother had similar concerns

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about how Edward spends his days. Edward had struggled to secure suitable valued social role(s) during the day. Edward had a *great placement at a café in central railway. .. But as soon as he learnt the tasks … the support person would pull back. He would do it for 10 minutes then he'd get over it and go have a chat with someone or wander off.* Current *supported employment* programs do not provide the support that Edward needs. He tried a more structured workshop environment but he *didn't like it, it was boring and he hated it and he told them so.* His mother sees these as two ends of what should be a continuum in supporting people in work situations. *That edge didn't work and that edge didn't work, there's something in the middle.* In contrast, Edward has struck upon a "natural support" (Klees, 1996) that may indeed offer an interesting valued social role.

Edward recently befriended the people in the café near his day program and his coordinator from the day program helped him to negotiate with the café owner for afternoon work. This is exactly what his mother had hoped for. Working with (name of the café*) for a couple of hours … he wouldn't need paid support, he'd be being mentored by the owner of the café who'd be quite happy to do it, not because he was asked but because he chose to.* Edward's mother, like Klees (1996), welcomes this opportunity for Edward to pursue *natural activity* the opportunity for which arose from relationships developed through familiarity in geographically based networks. Finally, the *adult… lives* of sons and daughters with disabilities would be protected both now and into the future by having *someone … there to do something in a crisis*.

6.3.4 *Someone is there to do something in a crisis*

While Betty's mother had not seen the necessity for a circle in Betty's network, Edward's circle supported the *house* and ensured that in addition to his mother *someone was there to do something in a crisis.* His circle offered the protection that is discussed in more detail in the next chapter. It is included here because his mother included it in her description of Edward's *house and his housemates*.

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Thus, in addition to living his own *place*, in a neighbourhood that offered a web of familiar relationships, housemates, seeing his friends regularly by belonging to networks of people who shared similar interests and contributing in valued social roles, Edward's *house and his housemates* was underpinned by a circle who could be mobilised *to do something in a crisis*. Initially Edward's circle *started with (his mother) asking (people) and creating a circle.* It has evolved into a layered network of people. *We have circle members who don't really come to meetings, they support in a different sort of way... it's again not an institution...It's a much more organic structure.* Edward's mother's response to Edward's unexpected rendezvous at the football was an example of how she mobilised Edward's circle.

> *There was a particular game last year on a Monday night…. What he did was ring (Name) who is an ex-housemate on the circle. (name) thought lots of people were going so he said sure I'll go and I'll meet you there. Edward just got there by himself and no one knew. The house mates had no idea where he was. We didn't know where he was. Luckily he now answers his mobile phone so one of the housemates rang and he said oh I'm at the game and I'm with (*name of circle member*).Father: *But, but the real worry is Edward having a hypo...* Mother: *So what we had to do then was ferry the insulin ... because I arranged for our other son to take him and pick him up so (*Son's name*) still did that, but he dropped off the insulin then he went to pick him up.*

His mother was delighted with Edward organising his own outing. She was pleased with his initiative and welcomed and coordinated other people's involvement. While there was a breakdown in communication about who would go with him, there was sufficient rapport between the housemates and his mother to work out together how to solve the problem of getting Edward's insulin to him. There were enough people linked to his circle, housemates, ex-housemates and family, that no one was left alone to work out where Edward might be. Nevertheless, while circle actively engaged in creative problem solving, his mother understood the detail and orchestrated others.

6.5   Conclusion

The family and/ or *the circle* described in the previous chapter will *bring enquiry* based in preferred *ways of thinking* to the support of sons and daughters with disabilities who have been supported by services throughout their lives. When sons and daughters with disabilities had lived with their parents in their childhood, networks that were fostered to support an *adult... life* reinforced sons' and daughters' *independence.* These networks featured *their own place* the location of which offered ready access to familiar neighbours and facilities, house or flat mates, clusters of people pursuing similar interests including friends with whom sons and daughters with disabilities might *have a life* and, a *circle* or family who *could do something in a crisis*. These networks were not dissimilar to those described in future planning initiatives. The experiences of the mothers in this scenario revealed however, that these networks emerged and were sustained through mothers' persistent and repeated agency in *grooming* or *pushing* sons and daughters with disabilities towards *independence* and the investment of financial capital in purchasing houses and social capital accrued through both generations of residence and work in the disability sector. Betty's mother hopes that the networks that support Betty's *truly adult life* will be sufficient to support Betty when she and Betty's father are no longer here. Where there were further concerns for safety, such as Edward's health, additional layers were added to the networks. Multi-layered networks are the subject of the next chapter.

Chapter Seven

Scenario Three … *Checks and balances*.

Additional layers were introduced to the networks in this third scenario to protect the *adult… life* of a son with disabilities*.* This chapter focuses on the experiences of Greg's and Edward's mothers. Layers were added to the networks that supported Greg and Edward to address fears for Greg's and Edward's safety. Greg's and Edward's health was at risk because of Greg being traumatised by abuse and Edward's diabetes. The networks that supported Greg's and Edward's *adult... life* were revised to incorporate *checks and balances* and thereby reduce risk and improve safety.

This chapter explores the layering of networks, the *checks and balances* that will protect *the adult… life* of a son or daughter with disabilities when their parents die. Initially the chapter reflects on the network structures. The *service*, a *good village* and/ or the *social network* provide a protective milieu in which the networks that supported Greg's or Edward's uniquely tailored *adult… life* nestled. In addition to this, the interconnections, the *checks and balances* between these layers, reinforced *adult… lives*. Having considered these structures, the chapter identifies influences on the networks their mothers' envisaged protecting Greg's or Edward's *adult… life.* The chapter then highlights the similarities between the protective features of these networks and the safety features of the networks described in future planning initiatives. In addition to these similarities, the experiences of these mothers revealed that careful attention to risk prevention was important, but not enough. Networks needed to act and they looked to mothers to signal for them to do so. The stories of the emergence of Greg's and Edward's networks are recounted in the textboxes that follow.

Textbox 5

Greg's mother's experiences - *We thought he was safe*

Greg's parents revised the networks that were supporting Greg's adult lifestyle when they witnessed the consequences of his abuse. Greg was assaulted and the alleged perpetrators of his assault were staff of the group home where he lived. Despite several investigations no charges were made as the reliability of Greg's version of the events was questioned. Greg was traumatised by the abuse and could only bare limited contact with people. More than 10 years later, following his parents intervention, Greg was welcoming people into his home and looking forward to a birthday party he asked for. Greg's parents have created a network of support around Greg that enables him to feel safe and mitigates the recurrence of abuse. Greg's mother is on a *quest to* sustain a network of support that protects her son. His network of support is *the service, the circle and … his social network.*

Greg's abuse precipitated a crisis for both Greg and his parents. *He didn't know who you were or he would just attack anyone.* His parents moved him into their home to secure his safety and weathered his trauma with him. *We really thought we may die in the situation we were in. Because we didn't think there was anyone who would support us. ….We used to lock ourselves in our bedroom and call out reassurances for him. … or we'd abandon the house.* When they tried to get help they were met with waiting lists. *I said "is there anyone to support us in anyway" and they said "oh, oh we'll put your name on the list in so many months' time someone might come out to see you." I said "I doubt if we'll be around in a few months' time."*

 They were liberated by a parent of an adult with lifelong disabilities who offered both support and introductions to other people. *We were very fortunate in that one lady... rang one day and she said "I'm coming over for a cuppa and I'm bringing a couple of people I've met".* These people had *the right philosophies* and supported them to set up the network of support. Hearing this I was reminded of Hamish's mother's description of resonating with the words of another parent. Again, in contrast to the group home and the services they had contacted for help, these people knew the *right philosophies*.

Greg, now in his 40s, was initially diagnosed with autism in childhood. Like Claire and Hamish, Greg moved into a group home on the tide of institutional reform and it was in the group home that he was abused. Greg's parents were actively involved with the group home. His mother was a member of the management committee of the house in which he lived. Greg remains house bound with agoraphobia consequent to the assault.

Greg's parents developed a multilayered network around him. The layers are interconnected. It includes *lifestyle facilitators*, a circle of friends and friends. His parents bought a house in a suburb neighbouring their home and through their support and government funding for his *lifestyle facilitators*, administered through a community based organization they helped establish, he lives alone. The community based organization employed lifestyle facilitators *who are prepared to use the philosophies (*his parents*) believe in, not this punitive model.* They are on ground ... and *they are guided, supervised and everything is modeled for them … they are supervised daily*. The circle of friends was established *because just having a service is certainly not enough protection, not enough in a person's life.* The circle meets monthly and share meals with Greg. He refers to them as his *trusted friends*. Previous *lifestyle facilitators* have become friends and visit him regularly. Other friendships are fostered through social events and correspondence his mother organises. The team leader, a staff member who has supported Greg for many years, and his mother are *across* the network. They know all of the layers. There is a *roast night every month …* where everyone in the network share a meal. This network is *evolving all of the time* under Greg's mother's watchful guidance.

Greg's mother's experiences - *We thought he was safe (continued)*

Greg's protection is fostered by the philosophy of the people in the network and the interconnections between the various layers. As the new network arose out of flaws in the previous network, the new network isn't what the last one was, it is *not controlling and containing*. It is not a shared group home, where p*eople were all just plonked in* and *… the only things they had in common was that they were all regarded as …"challenging … extremely challenging".* His *lifestyle facilitators* are not government employees. The people with whom Greg is in contact recognise his *personhood*. His mother looks beyond people who

> *espouse … theories but deep down they are really considering themselves superior … and they are either patronising or discriminating and it shows in the little things … making choices for (him)… speaking louder… things like that ..actions which constitute disrespect… it's a breach of courtesy or manners … No matter what organisation you set up … it's the actual practice, the delivery at every level that is going to impact and of course that comes from the top and right down throughout.*

 The embodiment of this philosophy within the network is sustained by relationships between *lifestyle facilitators*, family, circle members and friends and, by his mother's and team leader's involvement across the layers.

Greg's future safety, will be protected by the team leader, his siblings and the circle. Greg's parents' estate will *meet the shortfall* between government funding and the support hours Greg needs the voluntary efforts of his parents currently address. Sadly, the viability of Greg's support network was tested when Greg's father died in 2010. His *lifestyle facilitators* supported Greg at this time however while circle members were steadfast in their support of his mother they delayed their condolences to Greg, awaiting his mothers' prompts. Greg's siblings have been more involved in his network since their father's death and as their responsibilities to their own families allow.

Greg's complex network of support which embraced *the service, the circle and … his social network* was triggered by trauma and developed incrementally over many years to prevent the recurrence of abuse. Embodiment of the *right philosophies* and layers of *checks and balances* protect Greg. Greg's parents have knitted the web of people together such that those who know Greg will protect him from being re-traumatised in the future because of the *checks and balances* built into the network.

Textbox 6

Edward's mother's experiences *… he stays alive and healthy*

As described in Scenario 2, Edward is established in his own home in a suburb neighbouring his parents. He shares his house with 2 housemates. They ensure *Edward stays alive and healthy* 5 days per week by helping him to manage his diabetes. Edward returns to his parents' home in the weekends. As Edwards' parents prepare for their impending retirement and older age, they do not want *to dump the care of our son with a disability on our other children or to leave him stranded if anything happened to us,* and therefore they are creating a community, a *good village*, in which Edward will be supported on the weekends.

Edward's parents are working together on *artificially creating a good village*. The building will comprise 50 to 60 apartments housing a mixed population of people of which 15% would be people with disabilities. People who live there will make a commitment *to be good neighbours … help each other out*. Edward will contribute by shopping for people or playing with children. *He's caring and kind, so he could get things for people.* He's gregarious and sociable so he loves neighbours. The *village* will be … *in an area where* (Edward's) *grown up and where* (he's) *comfortable.* Edward's current housing arrangements, described in the previous scenario will be transferred to the *village*. The village will *ground him* as Edward's weekends at his parents have done. There would be *formal support coming to the people with disabilities and … the informal* (support) *from the residents*. The inclusion of the people with disabilities into the broader community will be fostered by a paid role. T*he community coordinator will link … the other residents with the people with disability. … It's the linking role in making the community happen.* The finances of the community will be managed by a trust and the community ethos will be maintained by the board.

The idea for the *good village* was born when Edward's mother went to a public presentation and heard Janet Klees speak of about Deohaeko Support Network (Klees 1996). The ideas *resonated* with her and she decided to set up a committee to introduce the model to an Australian setting. The committee conducted a feasibility study and developed a business plan with the assistance of a state government grant and the pro-bono support of many people. The group have identified a suitable site and are working to secure investment partners. Edward's mother describes herself as the *driver*. She has involved many people, shared the process with them and worked collaboratively.

While it is exciting and stimulating to be part of this venture, *it's a huge amount of work.* Over time his mother's perspective has changed in relation to her and his fathers' role in driving this initiative. Initially she questioned why parents should be doing it. She compared Australia unfavorably with the UK for example, where they would be *proactively approached by social services to encourage them to support their son or daughter with a disability to live as independently as possible.* They would do so by being able to offer a range of desirable living arrangements for people with lifelong disabilities. Offering a range of options would be a government responsibility. More recently she has been encouraged by her experience of working collaboratively. She recognises the government is looking for alternative solutions to the support of people with lifelong disabilities because

> *they've got this huge problem of aging baby boomer parents and longer living healthier people with disabilities that they won't know what to do with soon.* Their model *is one option for them. Group homes nobody wants or well even if they do there's not enough of them and they're not in your area where you live. They're now wanting to build on community and keep people in the communities where they've got built in support. … So that's good, it's a different way of thinking.*

In summary, it's both exciting and exhausting. *Some days it feels a good idea and other days it feels crazy*.

7.1 Networks that will protect Greg and Edward should *something happen* to their parents.

Greg's and Edward's mothers described complex multi-layered networks that evolved out of concerns for safety. Greg's personal safety and emotional health were protected by layers: *the family and the circle* modelling and planning for the support the lifestyle facilitators' *delivered*. Edward's health was protected by the attentiveness of his housemates, having circle members to ring *in a crisis* and being known to members of the *good village* who will remind him to eat regularly and notice and respond to behaviour that might be indicative of the mismanagement of his diabetes. As summarised in Table 5, the networks these mothers envisaged for the future protected Greg's and Edward's *adult ... life* by providing social milieux that reinforced their safety. Living in their *own places* which were located in familiar neighbourhoods; house mates, flatmates and/ or *lifestyle facilitators*; clusters of people with shared interests and; circles, provided the foundation. Edward's *house* would be set in the context of a *good village* and Greg's *lifestyle facilitators* were influenced by his *family*, *circle, service* and *social network*. There will be *checks and balances* between network layers. This section explores the protection these layers offered.

Table 7:

Networks that will protect Edward and Greg should *something happen* to their parents

Past	Present *Group homes nobody wants or well even if they do there's not enough of them and they're not in your area where you live*	Future	
Transition / Turning Point	**Network of Support**	**Features**	**Functions**
We thought he was safe	*The house and his lifestyle facilitators/ not ... plonked in, trusted friend, his* social network.	ever widening circles	*They're wonderful people but they're not really making decisions about his everyday life. They're supporting within the bounds of the philosophies.* Protection ... *checks and balances...*

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			the right philosophies … mutual respect … balancing out of each other's strengths and weaknesses … not controlling, not containing. *Meeting the shortfall* *If you're not watching… easily things could deteriorate.*
… he stays alive and healthy	*the house and his housemates, someone there to do something in a crisis*	*A good village*	*Whole lifestyle … social glue, social capital*

7.1.1 the house and his housemates/ not … *plonked in*

Greg's and Edward's *adult... life* was protected by living in *places* of their *own* which were located in familiar neighbourhoods and webs of relationships. In addition to reinforcing sons' and daughters' independence, explored in the previous chapter, the *places* in which Edward and Greg lived were carefully selected to reinforce their safety. Greg lived alone in his own home. The house Greg's parents bought him, in a suburb neighbouring their own home, was in a quiet tree lined suburban street that provided Greg a peaceful, sanctuary. The location of his home mitigated the anxiety he lived with subsequent to the abuse. In contrast to the group home in which his housemates were chosen for their similarly challenging behavior, Greg's home offered him solitude and a peaceful work environment for his lifestyle support facilitators. Reducing the household stress reinforced his safety. In contrast, Edward enjoyed company and a *village* would mean he would not only have the company of his housemates and his familiar neighbourhood, his *village* neighbours would share an implicit agreement of being known to one another. Some will know Edward well enough to recognise signs of his ill health and respond. The *house and his housemates* will be transposed into the *good village* located in the same geographical area.

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As *housemates* or *lifestyle facilitators* shared many unobserved hours with sons and daughters with disabilities, Greg and Edward were protected by ensuring housemates or lifestyle facilitators supported them appropriately. Greg's team leader or Edward's support coordinator ensured they were able to do so. Greg's lifestyle, and indeed life, was protected by the embodiment of the *right philosophies* by lifestyle facilitators*.* They honoured Greg's *personhood*. In contrast, while Edward's mother welcomed the relationships Edward and his housemates developed, she was as concerned that housemates were reliable in ensuring he *stayed alive and well*. Greg's and Edward's mothers had contracted their influence over the selection, recruitment and work practices of lifestyle facilitators and housemates. Greg's mother was on the management committee of the *service* and was the day to day manager of the *lifestyle facilitators*. Thus the nature of the support provided by *housemates* or *lifestyle facilitators* and *the team leader* or *support coordinator* and mothers contracted capacity to influence their support were central to protection. The influence their mothers exercised was reinforced by relationships with *trusted friends* and/ or circle members.

7.1.2 trusted friends

Edward and Greg were protected by *the circle* and *trusted friends.* They *checked* that all was well. Greg's *trusted friends*, his circle members called into his home throughout the week to observe how Greg and the *lifestyle facilitators* were getting on. Greg enjoyed these visits. They might involve the delivery of library books and a shared pot of tea. Should his *trusted friends* discover something was awry, such as when a *lifestyle facilitator* began locking the bathroom door designating parts of Greg's home out of bounds to him, they talked with Greg's mother. Similarly, Edward telephoned circle members when he was worried or needed help. Being a *trusted friend* to a son or daughter with disabilities meant being in a position to know when something was awry and, acting.

7.1.3 A good village / his social network

The wider social milieu of the *service* and *his social network* or the *good village*, provided a context that reinforced Greg's and Edward's protection. Edward will be a known neighbour in a *good village* and the *good village* will be located in the geographical area in which he and several generations of his family have lived. Consistent with the Deohaeko community (Klees, 1996), this familiarity with neighbours will provide a wider safety net. Someone would notice if Edward was behaving unusually and investigate. Firstly they would know him well enough to recognize unfamiliar behavior and secondly, the people who chose to live in the *village* would have done so because they wanted to look out for one another. Greg's funding for *lifestyle facilitators* was channeled through a small community based organisation which his parents had helped establish. The policies and procedures of organisation were a protective factor as they reflected the *right philosophies* his mother looked to the *lifestyle facilitators* to embody. Greg's broader social network was fostered by his pursuit of valued social roles. As he remained agoraphobic Greg's tolerance for joining community groups was limited. Instead he became known in his social network for his interest in art and writing. These roles were protective because they provided new avenues through which people were introduced into the *social network*.

7.1.4 ever widening circles

It was the interaction and interconnections between the layers that reinforced Greg's and Edward's protection. When Greg's mother described the layers of his network, she positioned her hands in ever widening circles. While she depicted the *service* as central, centrality was not meant to suggest predominance. Rather *lifestyles facilitators* were delivering the day to day support that was *modelled and planned by the family and the circle. ... They're wonderful people but they're not really making decisions about his everyday life, they are supporting him within the bounds of the philosophies (*his family and the circle*) espouse and under guidance.* It was the interconnections between these layers that would ensure the *right philosophies* were maintained throughout the network. *The family* and *the*

circle set the agenda and the lifestyle facilitators delivered. Similarly, Edward's housemates might come and go but their friendships stayed intact when they joined his circle. This extended the range of people he might ring should he want their company or their help.

7.2 Influences on mothers' ideas about the networks that will protect their sons and daughters with disabilities should *something happen* to their parents.

The networks their mothers envisaged played to Greg's and Edward's strengths, encouraged independence and protected Greg's and Edward's *adult … life*. Their mothers' ideas about the networks were influenced by the *places* they didn't want Greg and Edward to live in, that is, group homes; the *right philosophies*; their family's capacity to meet *the shortfall* in resources and; their own agency. Mothers were *the sheriff* or *project manager* and the networks evolved over many years with their *dogged determination*.

7.2.1. *Group homes nobody wants or well even if they do there's not enough of them and they're not in your area where you live*

Greg's and Edward's mothers actively sought out ideas about networks that might support Greg and Edward, because the options that were readily available were unacceptable. Greg and Edward needed 24 hour per day support and, apart from family, group homes were one of the few options that could provide it. Greg, however, was abused in a group home and as Edward's mother said "g*roup homes nobody wants or well even if they do there's not enough of them and they're not in your area where you live"*. Unfortunately, few alternatives were readily available. When Greg's parent's rescued him from the group home in which he suffered abuse and sought *anyone to support us in anyway, they* met waiting lists. Edward's mother recognized they were part of the *huge problem of aging baby boomer parents and longer living healthier people with disabilities* that social policy doesn't *know what to do about.* Edward would not be able to live in the geographical are with which he was familiar and Greg

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was *plonked in,* creating an unsafe situation. Therefore Greg's and Edward's mothers had to create their own. They envisaged networks that, like the future planning programs suggested, enacted the *right philosophies*.

7.2.2 the right philosophies

Networks that reflected the r*ight philosophies* or *ways of thinking* were fundamental to *protection*. Greg's and Edward's mothers fostered networks that located their sons in valued social roles (Wolfensberger, 1972). As an example, they invited *housemates* to share their sons' homes rather than assign their sons to the role of resident in someone else's house. Valued social roles were protective because the people who occupied them were afforded respect (Kendrick, 2009). Further when network members embodied the *right philosophies* they related to sons with disabilities with expectations of *mutual respect.* Having witnessed the profound consequences of the abuse Greg suffered, prevention was clearly very important to his mother. Further like Hamish's and Claire's mothers, Greg's mother's discovery of other people with the *right philosophies* was a turning point in Greg's network. Clearly, her ideas about Greg's networks were influenced by ensuring the hope associated with the *right philosophies* was embedded in his network. She vetted network members to ensure they had *empathy and understanding*. She preferred *lifestyle facilitators* with an *open minded philosophy … people with values that are a bit different from the norm.* She also resisted people who perpetuated *that institution type environment where there's his and ours* in his own home*.* Networks would offer a social milieu in which difference was viewed as a *balancing out of each other's strengths and weaknesses. Compatible contributions to life* would be valued. Greg would be enabled to offer his unique *contribution*. When she had entrusted his support to a service to which she brought enquiry, the consequences had been dire. Instead she wanted to ensure she could insist on the *right philosophies*. Edward's mother had not witnessed Edward's abuse. She assumed respect would be accorded to her son by the people with whom he associated and network she envisaged proceeded accordingly.

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7.2.3 We're meeting the shortfall at the moment

Greg's and Edward's mothers were also influenced by their family's capacity to meet the *shortfall* in public funding. Greg's and Edward's parents subsidised their sons' networks with their financial and social capital. Her pro-bono management of Greg's *lifestyle facilitators* subsidized the support hours funded in his package. Greg's mother was retired and her time and retirement funds were invested in Greg's network. As his father said, it is *practically a full-time job for (*Greg's mother's name*)*. As she says, *You couldn't work … you've got to be monitoring all the time and seeing where things are going wrong and you've got to be proactive. … if you're not watching … easily things could deteriorate.* Edward's mother worked in part-time paid employment to allow her time to devote to Edward's network. Like Betty's parents, Greg's and Edward's parents bought their sons' homes to enable them to have security of tenure and live close to family and familiar utilities and services.

Their mothers' social capital was invested in the networks they envisaged for Greg and Edward. Greg's mother met the woman who introduced her to others with the *right philosophies* by volunteering on a community based management committee through which Greg was supported. Edward's parents have been actively involved in non-government organizations in the disability sector for many years and had investigated future planning possibilities in Australia and abroad. His parents mobilised their own social capital such as their extensive personal and professional contacts they have from having lived in an inner city neigbourhood for 30 years and pursued professional careers. Edward's parents' contacts engaged in the development of *a good village* and the *village* will provide *a whole lifestyle ... social glue, social capital*.

While individualised funding was welcomed by Future Planning, PLAN clearly favored private financing programs (Klees, 1996; Etmanski, 2000). To them "every penny from government has a string attached" (Etmanski, 2000, p.277). Yet, as Edward's mother acknowledged, meeting the shortfall is not a prerogative of all families. As she says, it's *hopeless for people who have not got any language skills*

or … don't know the area or … Are poor or they haven't got any time or they are working full-time and are completely flat out or whatever the reasons might be. Greg's and Edward's parents mobilized financial and personal resources to establish tailored arrangements for Greg and Edward.

7.2.4 the sheriff/ project manager

These mothers were willing, capable and experienced at being the *sheriff* or *project manager*. While Etmanski (2000, p. 275) places families in the "lead role" as the "conductors of the symphony of caring, comfort and support" and Klees (1996) acknowledges networks emerged out of the vision and work of parents, they failed to detail the work involved. As the *sheriff*, Greg's mother keeps the network on track through her integral involvement in every aspect of it. For more than 12 years, she has participated in the management of the *service* through which Greg's funding is channeled, managed his paid support workers, filled gaps in the support worker roster, participated in the circle of friends, co-hosted barbeques with Greg's father, organised social events that bring people into Greg's life, such as exhibitions of his art and, supported him to maintain his friendships through correspondence. Greg's mother's hands on approach fostered the *right philosophies*, support that was *not controlling and containing*. Her relationship with Greg modelled how she wanted others to relate to him. As the *project manager* Edward's mother described a network with more of a life of its own. She steers it. She took responsibility for *pulling it together.* As the project manager, like Greg's mother, she was integrally involved in every aspect of the network. She however had not witnessed her son's abuse and *trusts in the process* and *outsources*.

Like Claire's and Hamish's mothers, Greg's and Edward's mothers were alert to personal support workers acting outside acceptable practices and proactively redirected them. While circle members were clearly alert to warning signs of a bathroom door being locked, Edward coming home late, or death in the family, Greg's and Edward's mothers led the circle's response. They acted and in doing so encouraged others to act. Greg's mother terminated the employment of the lifestyle facilitator who

was locking the bathroom door, as she recognised in this behavior an attitude she did not want in the network that supported her son. As discussed in the previous chapter, Edward's mother coordinated the response to Edward's unplanned attendance at a football game. Greg's mother called the circle and suggested how they might offer condolences to Greg. The circle members were clearly willing to act but they looked to mothers to guide their actions.

7.2.5 *the length of the journey*

Networks were laid down over time. These networks for example have been evolving over more than ten years. Daehokho also acknowledged *the length of the journey (*Klees, 1996). In the first instance, Greg and Edward found a home and the support that was needed to enable them to live in their homes. The right living arrangement harnessed familiarity in a geographical area and this familiarity fostered protection. Mothers' legitimised influence over recruitment and retention ensured people with the *right philosophies* would be selected as housemates and lifestyle facilitators and dismissed in a timely way if needed. Circles supported the combination of a home and lifestyle facilitators or housemates. Circles provided, amongst other things, people who shared in *monitoring* sons' and daughters' daily lives. While they were aware of the housemates and lifestyle facilitators, they were also interested in ensuring Edward's health problems did not deter him from staying at a football game or consoling Greg following his fathers' death when asked to. These layers however were not enough *protection,* the glue that connected the broader social network was needed. This was Edward's *good village* and Greg's barbecues and art exhibitions and people who moved between the layers. These broader networks know Edward and Greg in their valued social roles and would notice if something was awry. Thus, these networks were built incrementally from the foundation of a home. Reflecting on the study findings Greg's mother commented the member checking *made me relive it all again ... you see the length of the journey ... after all those year*s.

7.3   Networks that will *protect* sons and daughters with disabilities into the future and future planning programs.

Future planning programs advise networks protect sons and daughters with disabilities by preventing situations arising that induce harm. Future planning programs were grounded in the premise "relationships are key to well -being and safety" (Etmanski, 2000, p.278). Programs addressed safety in two ways. Firstly, they recognised risk was heightened by: being in devalued social roles; being portrayed negatively; segregation; limitations of autonomy, freedom, control, powerlessness, and/ or voicelessness; poverty; and denial by "official society" of the risk (Kendrick, 2010). Appropriate living arrangements which addressed these risks. Secondly, they identified people to assist with various types of decisions and in doing so promoted "supported decision making" (Etmanski, 2000, p.183). 'Supported decision making' drew on the personal network or circle; advocates; individualised funding and/ or microboards and; a documented supported decision-making agreement. The networks the mothers in this study described also fostered valued social roles, recognised skills and contributions and promoted inclusion and autonomy and; included circles and individualised funding. These mothers' stories revealed their agency was essential to reinforcing the networks' harm prevention and actions. Future planning programs failed to recognise the agency that was required to foster these conditions.

7.4 Conclusion

This chapter examined networks that will protect sons and daughter with disabilities when their parents have *moved on. Checks and balances* between a home selected to specifically meet the needs of a son or daughter with disabilities; housemates or lifestyle facilitators over whom mothers had contracted influence; *trusted friends*; and *a service, a good village* and/ or a *social network* prevented risk. The fostering of these networks relied on mothers as the *sheriff or project manager*. The extent of their investment, such as the mobilisation of their social capital, and therefore the potential influence

of differences between families, and the role of mothers in signalling network action, was

unacknowledged in future planning programs. The next chapter considers another barrier to the

fostering of networks, acrimony between parents.

Chapter Eight

Scenario Four - *I'll do it one day*

This chapter discusses a fourth scenario, the inability of parents to reach agreement following divorce hampering the development of networks that support, in these examples, their daughters with disabilities. In the second scenario mothers *pushed* for i*ndependence* and fostered networks that supported a uniquely tailored and *independen*t... *adult ... life* for their son or daughter with disabilities. S*plitting* with the fathers of their daughters with disabilities hampered Emily's and Maree's mother's influence over their daughter's *adult... life* and their daughters' networks. As Emily's mother said: *I would very much like to get something formalised but her father is not supportive of that view, so it sort of keeps going on the "I'll do it one day"* list*.* In essence, *this scenario* revealed networks for the future of sons and daughters with disabilities were contingent on parental cooperation.

This chapter explores the impact on the networks that will support sons and daughters with disabilities of their parents' inability to agree about their sons' and daughters' independence and ideas about the networks that support them. The chapter firstly identifies the networks their mothers' anticipate Emily and Maree will be supported by in the future*.* It then describes how *splitting* with Emily's and Maree's fathers has influenced their daughters' networks and has constrained their mothers' influence on their daughter's lives and networks. By contrasting Emily's and Maree's mothers' experiences of co-parenting with Emily's and Maree's father with those of other parents in the study, the chapter concludes that networks that span *households* and *rules* might support rich adult lifestyles but parental disagreement thwarts *grooming for independence* and the further layering of networks for the future. Emily's and Maree's mothers' experiences in, and ideas about, the networks that support their daughters are captured in the text boxes that follow.

Textbox 7

Emily's mother's experiences – *2 sets of households, 2 sets of rules*

When Emily's mother talks about the network of support she envisaged for Emily she referred to the *"Give Emily a Good Life"* company. Emily's parents divorced during Emily's childhood. Her mother works in a very demanding leadership position that necessitates regular travel nationally and internationally. Emily's mother is a practiced and competent negotiator however as her daughter's father won't agree on the company the network has stalled. *I would very much like to get something formalised but her father is not supportive of that view, so it sort of keeps going on the "I'll do it one day".* Emily's father doesn't see the necessity. He doesn't understand that it is not about *the desperate need stuff, it is the having a life stuff*. Also Emily's parents' relationship restricts her mothers' access to her father's side of the family. The network of support might be able to address this but she is unable to set up the network. Paradoxically the network of support she envisages for her daughter is constrained from progressing by the family circumstances that in part warrant it.

Emily has a rich life and diverse friends. She lives with her mother on weekends and her father during the week. She attends two work places: one mainstream, with her mother's family business, and one associated with the disability sector, plays tennis weekly, attends mainstream art classes and is a member of a social group with other people with Down' Syndrome. *Almost anywhere you go, Emily comes across someone she knows.... she's very busy. And she loves pretty much everything she does.* Her nuclear family lives across several households in neighbouring suburbs and a large extended family network. Emily has an interesting and fulfilling life, shared with many people. Nevertheless her mother can see room for improvement.

Emily's mother appreciates Emily's wide group of friends and experiences but expresses concern that few of these people *who would ring up to see what happened if she didn't turn up to something*. Emily's friends do not initiate contacts outside the scheduled routine. It is her nuclear family, particularly her parents and sister who initiate social engagements and opportunities to pursue her interests and develop her skills. Further, apart from her siblings, she is in regular contact with her parents' generation in the family rather than their children. She has *20 cousins who are younger and so they might all think someone else is already involved but they don't know Emily at all as a person and they don't understand disability.* They may take *the old charity attitude* (and*) that concerns me.* Emily's mother is concerned that the quality of Emily's life *is very, very reliant on (Emily's brother) and (Emily's sister) both being in the same city as Emily and being in a situation of being able to care.* Her mother is concerned that key members of Emily's network of support, herself, Emily's father and Emily's uncle are of a similar age and thus into the future, when they are no longer in a position to care, her siblings will be central. She would like to develop the network of support and involve the extended family now while she may be able to influence their thinking. Her father doesn't see the point. Should anything happen to him he thinks he has many brothers and sisters who would look after his daughter.

Emily lives across two homes. *Emily's father and I split when she was 8.* Emily has since lived between the households of her mother and father*.*

> So, one thing she's got going on in her life is two whole sets of ...rules and expectations and ... two lives… She has two sets of, or probably even three sets of, people in her life. There's the people she knows through her father and his partner; and there's the people she knows through me; and then there's the people she knows through her other activities.

While this offers Emily access to a diverse group of people, her parent's remain pivotal.

Emily's mother identified potential gaps in Emily's support networks in the future. T*he network needs to be a lot stronger than it currently is.* The *"Give Emily a Good Life"* company could provide a forum through which ideas about Emily's life might be shared. The company would make resources available to Emily to support her in achieving what she wanted in her life. Emily's father does not share her mother's view or concerns and as such the further refinement of her ideas has stalled.

Textbox 8

Maree's mother's experiences - *"Bring her home."*

Maree's mother has been *battling against the system or the world or somebody else. Maree … was diagnosed (*as*) developmentally delayed at 2 1/2.* Maree's parents separated more than 20 years ago when Maree was 4 years old. Maree and her younger sister lived with their father after her parent's separation and Maree's mother has persisted in keeping in contact with her daughters. *I'd ring probably once a week every week for years and years and they'd hang up and they'd hang up and I'd ring back and I'd ring back and they'd move.* Maree's mother has a son from a subsequent relationship with whom she lives. At times the 2 households have lived thousands of kilometers from one another. Maree's mother has battled to stay in Maree's life**.**

Maree's living situation changed significantly during the study. At the beginning of the study, following a crisis in Maree's support network, Maree moved in with her mother and step-brother. Maree was living with her step mother after she and Maree's father had separated. Maree's father discovered that Maree was being neglected by her step mother and he asked her mother if Maree could move in with her. Maree's mother had not anticipated his request. However she enthusiastically welcomed Maree into her home.

Maree's mother recalls the day Maree's father asked if Maree could come to live with her. *He said, "Well I need to find somewhere else for Maree to live" and I just said, "Bring her home." And within a week she was there, lock, stock and barrel*. The words "bring her home" convey the relief with which she welcomed her daughter into her home. Her mother, Maree's grandmother, was a member of the stolen generation. These words convey the emotional significance of returning to the fold. The home she welcomed her into was in the same capital city as her father, step mother and sister. Maree's social network could be accessible from her new home.

When Maree moved in, her mother set about redressing what she saw had been neglected. She addressed Maree's health issues and challenged her daughter to conform to the rules of her new home. She also reintroduced Maree to her side of the family and community elders. Maree's social network stretched across 4 households, friends at the sheltered workshop she attended 5 days per week and a paid support worker who visited their home weekly to attend to her health care. Maree met a young man at work and they are now engaged to be married. Negotiating so much change brought their own stressors into their relationship but the new situation was exciting for Maree. As her mother says *Maree told everybody she loved living with me*. Following ongoing frightening neighbourhood disputes the family of three moved interstate to be reunited with Maree's mother's family.

Establishing a new network of support for Maree in the new location was an arduous process for her mother. A similar work situation was not available in the new state. Services needed to be identified, Maree needed to face admission processes and there were limited vacancies. She pressed on *to find something for her to do*. Maree's fiancée visited and Maree and she and her brother got to know the local shopping mall. Maree struck up on-line friendships with people in the city they had left. The nature of these on-line discussions led to a dispute with her mother.

Unfortunately some months after the move interstate, Maree left her mothers' home in the thick of an argument. Her mother was deeply distressed when Maree left. She returned to the city in which her father lived. She now lives alone in her own flat and continues to share her life with her fiancée. She works 4 ½ days each week in supported employment and is supported with household tasks. *She's got her own life and she is independent*.

Maree's support network stretches across several households of family. Her network spans 800 kilometres. One cluster is based in a capital city and includes her boyfriend, father, uncle, sister and step mother. The other is her mother, brother, her grandmother and aunt. Like other mothers in the study, this mother has not been integrally involved in Maree's day to day support however she has tried to influence those who were.

8.1 Networks that will support Maree and Emily into the future

While their mothers have ideas about the people they would like to be involved in Emily's and Maree's lives in the future and the support they would like them to enjoy, their influence is limited. Features of the networks that will support Emily and Maree into the future are highlighted in Table 6 below. It is anticipated that her siblings will be t*he nucleus of Emily's network. From the time she was about 6 ... Emily's sister* anticipated *look(i*ng*) after* Emily. Emily may move into a *granny flat* attached to her sister's house. Emily's brother will also *be there* however their mother described his input differently. He would *be there when he remembered.* Maree's mother also anticipates Maree's sister *will take over and care for* Maree in the future. Maree's fiancée is becoming increasingly central to Maree's life. Maree shares her life with him. She lives in a garden flat in a familiar and convenient location. A support worker helps with shopping and household tasks for a few hours each week. Emily and Maree have many friends whom they see regularly at work or through their pursuit of interests. They have complex extended family networks that span several households. Emily and Maree enjoy rich *adult... lives* and know that they will be well supported by family into the future. Given the opportunity, however, their mothers would have encouraged particular aspects of their daughters' development and introduced additional dimensions to their daughters' networks.

When Maree moved in with her mother, her mother addressed Maree's health concerns and encouraged the development of her social skills. She introduced Maree to elders in the community. Given the opportunity, Maree's mother would secure these changes and contacts.

The "*Give Emily a Life" company* Emily's mother envisaged for the future comprised a core of trustees; Emily's siblings and one of her uncles, a solicitor. Her mother would be *the Managing Director ... and ... Emily will get to be a joint Managing Director. I don't ever see the government being on the Board.* Quarterly meetings would address w*hat she is going to want in her life.* I*t would be good to have a paid carer type involved in Emily's (*life*) ... a constant person in Emily's life who would come and go as*

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required, either at my place or at her father's place ... to undertake some of the tasks that need to be done. While this network was clearly conceptualised, it had not progressed as *her father is not supportive of that view.* Emily's father was confident that if anything should happen to Emily's parents his many brothers and sisters would look after his daughter and he wa*s not supportive* of any further planning. S*o it sort of keeps going on the "I'll do it one day" pile.* The "*Give Emily a Life Company*" would address Emily's mother's concern that Emily's *network needs to be a lot stronger than it currently is*. She is also concerned that supporting Emily may unduly compromise the lifestyles of Emily's siblings and as such she would like to f*ormalise* Emily's support into a company.

Table 8:

Influences on networks that will support Emily and Maree into the future.

Past	Present *… So it sort of keeps going on the "I'll do it one day".*	Future	
Transition / Turning Point	**Network of Support**	**Features**	**Functions**
Splitting with fathers of daughters with lifelong disabilities	Fiancée, several family households, numerous friends through work and interests.	*Sister... will take over*	
	Two sets of households, 2 sets of rules *…she's very busy. And she loves pretty much everything she does.*	*Brother and sister will be the nucleus. Sister will be central.* *"Give Emily of a Life" Company* *paid carer ... a constant person in Emily's life*	*… who would ring up to see what happened if she didn't turn up to something* *the having a life stuff*

8.2 Influences of *split*ting with the fathers of their daughters on the networks that will support Emily and Maree into the future.

Since Emily's and Maree's parents' divorce, Emily has moved between *two sets of households and two sets of rules* and Maree has lived across several households and no doubt several sets of *rules*. In one way, exercising choice between *rules,* by choosing the *household* in which they spent time, boosted Emily's and Maree's autonomy. On the other hand, however their mothers' efforts towards, what Betty's mother referred to as, '*grooming for independence'* were constrained. The introduction of further layers in anticipation of supporting Emily and Maree into the future was also constrained. Nevertheless, Emily and Maree enjoyed rich and interesting lives.

8.2.1 Two sets of households, two sets of rules

Emily and Maree have become adept at straddling the complex networks that supported them. They moved between at least "two *sets of households, two sets of rules*". By choosing *the household*, and therefore *rules* they preferred, they exercised choice and therefore boosted their autonomy, however they did not always choose the options their mothers might have preferred. Their mothers would have preferred they choose greater *independence* however … *Emily is going to fight you every inch of the way to not be independent and to not be autonomous.* Despite her mother's repeated encouragement of Emily's use of public transport to bolster her independence, for example, Emily preferred her father's offers of lifts. Without the, at least tacit, agreement of both parents, Emily's familiarity with public transport soon waned and her mother was forced to rethink her ideas about transport. Their daughters may have become more independent if household *rules* were agreed upon and applied consistently. Nevertheless, having *households* and *rules* to choose from, meant Emily and Maree could exercise choice. Emily could choose the transport she preferred and Maree was able to return to a more familiar environment when the move interstate proved too stressful for her. These were not the

only mothers in this study to identify how their opinions differed from the fathers of their sons and daughters with disabilities. Edward's mother, for example, reported Edward's father said she fussed over him too much and Betty's mother said Betty's father thought hiring a driver for Betty was more practical than supporting Betty to use public transport. These parents were however able to reach agreement about their sons' and daughters' *independence* and therefore were able to consistently encourage their sons and daughters with disabilities towards agreed upon lives. This is not to suggest that Emily and Maree did not pursue rich and interesting lives, they did.

8.2.2   *… she's very busy. And she loves pretty much everything she does.*

Despite their mothers' concerns, Emily and Maree have rich and interesting lives that are shared with many family and friends and with whom they pursue their interests. Until recently, whomever Maree or Emily were residing with stood alongside them in their networks. One of their parents would be the person who could be rung *… to see what happened if she didn't turn up to something.* More recently, *M*aree has moved into a flat of her own and shares her life with her fiancée. While Emily's mother appreciates Emily has many friends and interests and *she loves pretty much everything she does*, her mother discounts her *friends with lifelong disabilities* in the role she envisaged for the network in the future. *I am not really seeing (*her *friends with lifelong disabilities) being part of a network because they would not be able to initiate anything better than Emily herself could.* Like Betty's mother, Maree's mother is watching closely to see if the life Maree now shares with her fiancée will indeed sustain Maree sufficiently into the future. Whereas Emily's mother is already concerned that, in the absence of her parents, Emily will need to call on her sister to help with change. In summary, Maree and Emily have a lot of people in their lives. They have extended family networks and a wealth of friends. They pursue work and social interests. They participate in social groups that provide them ready access to long standing friends. Within this multitude of relationships, someone knows where they are at any given point in time and is able to assist with introducing change. In the absence of

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further developments, this responsibility will fall to Emily's sister and Maree's fiancée and/ or sister in the future.

8.2.3 I would very much like to get something formalised but her father is not supportive of that view.

The third feature of networks these experiences speak to is the more *formalised* structures such as *circles, services, a good village* and the interconnections of multilayered networks. Again Emily and Maree enjoy rich and interesting *adult… lives* and their mothers clearly value the relationships their daughters enjoy, nevertheless when Emily's mother says she wonders *who would ring up to see what happened if she didn't turn up to something,* she is suggesting the need for additional layers to the network in the future. Emily's parents protect her, one of them *rings up to see what happened*, and her father believes his extended family would look out for Emily should they need to. Further Emily's siblings, particularly her sister, will be *the nucleus* of her network when her parents are no longer able to. Nevertheless, her mother is not confident that the extended family is able to provide support and if they do, whether they may in fact adopt an *old charity attitude*. These uncertainties about the future, not unlike Hamish's mother's idea of introducing a circle to bolster support for her daughters, invite Emily's mother *to formalise* a structure, however she is unable to proceed without Emily's father's support. Thus in addition to the negotiation of independence from parents, the realisation of the more *formalised* network structures that are envisaged for the future also rely on parental agreement.

8.2.4 … so it sort of keeps going on the "I'll do it one day".

Finally Emily's mother does not say it will not proceed, rather she will wait until it is timely to proceed. Emily's mother is currently pursuing a busy career that involves complex negotiations. While she encouraged changes to Emily's support network, her time is limited and she prioritised her commitments. If Emily's father is not of a shared view, she may invest her energy, as she has in the past in supporting Emily to use public transport, to little avail. Like Greg's mother who in her

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retirement from paid work invested time and resources in Greg's network and Edward's mother who by working part-time had time to invest, Emily's mother is clearly able to negotiate differences of opinions and has clear ideas about how she could proceed, however it is not yet timely in Emily's mother's life to do so. So it sort of keeps going in the "I'll do it one day" pile.

8.3 The influence of parents' capacity to reach agreement.

Consistent with the life course perspective, networks emerged and evolved. The experiences of mothers in Chapter Six revealed the transition to adulthood triggered *pushing* or *grooming for independence* and the fostering of networks that reflected an *adult... life*. These networks provided the foundation onto which further layers, and the interconnections between them, reinforced safety and protection for the future. The layers in the scenarios described in Chapter Five included sisters who may or may not have been supported by circles to *monitor and advocate with services*. The layers might also include *a good village* and a broader *social network.* These were described in Chapter Seven. Therefore networks developed in layers based on the foundation of the network that supported an *adult... life.* In this scenario, parents were unable to agree on aspects of both the foundation and/ or the further layers. Emily's and Maree's independence and networks evolved. However, without their purposeful reconfiguration the networks that were emerging displayed features similar to those described in Chapter Two. These networks were family-dependent, in this case, centred on a fiancée and siblings into the future and occupied a distinct social space. They left people with disabilities vulnerable to the declining capacities of their parents because there were fewer people who might provide the support that is needed when their parents are no longer able to.

Their experiences revealed parental agreement about network layers was needed for them to proceed and comparing them with the experiences of other mothers in this study, networks require the investment of time, skill, money and social capital of both parents. In the networks that will support sons and daughters with disabilities when their parents have *moved on* that feature sons and

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daughters living in their own *places* with the support of *circles*, a *service* or a *good village,* mothers acknowledged the efforts of the father of their son or daughter with disabilities alongside them. Betty's parents for example, agreed Betty should be supported to move into her own home. Betty's mother supported Betty day to day. Betty's father:

> *... does the long hours. ... He's always there, but he's not an active hands-on role ... That puts us in the situation where we have more options from a financial point of view. ... He would see it as his role in setting things up. ... He comes from that traditional view that we have to care for her... I come more from an ideal that we support her so that she can get things for herself.*

Mary's parents, discussed in the next chapter, have worked together with the circle to establish Mary in her own home. Edward's parents are both active members of his network. His father sits on committees and drafts documents and in addition to this, his mother project manages. Greg's parents worked together in their retirement on Greg's network. Greg's mother was described as the *sheriff* and he as her *deputy.* Emily's mother looks to networks to *initiate*, *ring up to see what happened if (*Emily*) didn't turn up to something* and *work out ... the resources ... that need to make (*change*) happen.* She has struggled to influence change in the networks that support Emily. Thus, in addition to consent, the detail and complexity of what was involved in fostering networks that will support sons and daughters with disabilities when their parents have *moved on* required the resources of both parents. Emily's and Maree's mothers' experiences suggest support networks for the purposes of future planning stall if the agency of parents is expended in conflict with one another.

8.4   Conclusion

This chapter identified one factor in the network, the cooperative effort of parents, which may pose a barrier to the laying down of networks that will effectively prepare for parents *moving on*. Previous chapters revealed networks that will support sons and daughters with disabilities when their parents

have *moved on* emerged over a life time. A *circle*, a *service*, *a good village* and/ or a *social network* were uniquely configured to protect and reinforce networks that were uniquely tailored to support sons' and daughters' *adult... lives*. This chapter reveals that these networks were contingent on parental agreement and investment. Like other mothers in this study, without further network development, Emily's and Maree's mothers understood their daughters would be the *nucleus of the networks* that would support Emily and Maree into the future. Maree would also be supported by her fiancée. While the *day to day stuff* was working and Emily and Maree have rich *adult... lives,* how the network would plan for Emily *having a life* and respond *if* (Emily) *didn't turn up* into the future remains unclear. The next chapter examines the final scenario which explores mothers' experiences of the *changeover,* that is, stepping back due to increasing age and declining health.

Chapter Nine

Scenario Five ...*backing off* ... and *the changeover*

This final scenario examines a later stage of family life, parents' *preparing* for passing away and the

process of *the changeover.* Mary's mother's experiences of *preparing* with a *circle for* Mary's future

care inspired this chapter*.* Mary and her parents have enjoyed living together for almost 50 years.

However Mary will not be able to continue living in the home she shared with her parents following

her parent's death. Therefore her family embarked upon *preparing for ... moving on.* Mary and her

parents met regularly with a group of family and friends, the *circle*, to develop and implement a plan

that was not centred on Mary living in her parent's home. This family employed a process for

preparing for... moving on that was similar to those described by initiatives supporting families in

future planning (Etmanski, 2000). Mary's mother's richly detailed descriptions of her experiences

revealed the agency she and Mary's father exercised in fostering the revised network and the difficult

emotional terrain they traversed in the *changeove*r. Research and future planning initiatives

acknowledge planning raises fears about death and letting go (Etmanski, 2000). Mary's mother did not

fear death or letting go. However, witnessing others making decisions she disagreed with was initially

deeply distressing.

This chapter explores networks that supported *the changeover*. Mary's mother's experience of, and

ideas about, the process of *preparing* for ... *moving on* are summarised in Textbox Nine. The chapter

firstly describes the network that will support Mary into the future. It then highlights the influences on

Mary's mother's ideas about this network. Finally, the chapter reflects on planning processes

described and promoted by future planning initiatives (Etmanski, 2000).

Textbox 9

Mary's mother's experiences - *preparing for the care of your adult child because you're going to move on ultimately.*

*Well (*name of daughter*) started us off… I went with her to Parliament House. …He was an eighty year old and a father of a person with a very severe disability …*He was talking about *preparing for the care of your adult child because you're going to move on ultimately. ... He was very moving in what he told us, to get on with it. ... And after that experience I came home and said to (*Mary's father's name*) ... that really made me start thinking today.*

Mary's network of support was inspired by the ideas of another parent of a person with disabilities at a future planning seminar. Mary's sister had invited he parents to the seminar. Mary's mother captured the idea of a circle of support for *preparing for the care (of* Mary*) because you're ultimately going to move on*. Mary's mother referred to the circle as their network of support. However it was a vehicle for change that fostered Mary's new living arrangement.

Mary and her parents enjoyed living together for 48 years. Mary briefly moved into a group home in her 20s but she was neglected and s*he didn't want a bar of it* and she returned to the family home. *Mary's had such a community around her always, we've gone from a family of 8 and now we're three…. We love being with her because she's so lovely.* Mary has been a valued part-time employee in a department store for over 20 years. Nevertheless she has few friends outside the family. Mary has mostly socialised *with (*name of father*) and I …. It was always the three of us. … But (*Father's name*)'s 82 this year and I'm 76, so we've got to face reality*. Mary's parents foresaw change associated with their biological age.

Mary needed a living arrangement that would outlast her parents' lives. Past experiences of group homes ruled them out for the future. Mary's mother considered Mary moving into a retirement village. *Mary's heading for fifty and we've noticed over the years in her work situation that they are always older women that befriend Mary...* Mary would be *part of the community and older people are more generous.* Her siblings will *step in but ...* her mother would *... hate to see any of their marriages or families disintegrate because one of her sisters or one of her brothers says, well I'll look after Mary.* Also Mary's siblings didn't agree that a retirement village would be suitable. They wanted Mary to live in the manner of people of her own age rather than exclusively with older people.

The circle formed to engage in a process of negotiating and establishing a living arrangement that was agreed to by all. The circle supported Mary to move into her own flat and she now enjoys a lifestyle in which she is a member of the local gym and church choir and continues in her paid employment. At the time of writing she had been living alone in her flat for 18 months. Her mother remains concerned however that Mary does not have a companion. The process has not been an easy one for her mother.

Her mother weathered the *changeove*r as her sons and daughters assumed more responsibility for Mary's support. T*he changeover we're going through at the moment... It's really the two girls, her older sisters. They are the movers and the shakers.* They were moving and shaking in a number of areas simultaneously. Mary's sisters encouraged her to update her hairstyle and wardrobe. They insisted their mother phone Mary less frequently and encouraged Mary to attend mass independently from~~to~~ her parents. Some two years later connections with the local parish were not fruitful and Mary continued to attend mass with her parents. However by this stage her sisters were *pretty much covering everything ... they make sure the support workers* see Mary regularly. Mary's mother acknowledges there were "*things that I have had to let go of because people are trying to build up relationships to replace me ... I'm inclined to give in a bit because I think ... this is the thinking of her sisters and that's what's going to be when I'm not here. It is difficult"*. While they differ, she nevertheless has confidence in her family. *They're great people our* (children) *... a couple of them are very strong ... and I think oh she will be alright.*

9.1   Networks that will support Mary after *the changeover.*

Mary and her parents were supported through *the changeover* by *circle thinking.* When Mary's parents

have *moved on*, Mary will be supported by the networks that were established by this process. She will

continue pursuing the life that she and the *circle* have established. This section also examines the

network that will support Mary after *the changeover,* summarised in Table 7, and the process of *the*

changeover.

9.1.1 *Circle thinking*

The circle planned for and engaged in the process of *preparing* for Mary's future care. The circle

included Mary, her parents, her siblings and neighbours. The circle firstly provided a venue at which

agreement about Mary's future living arrangement was negotiated. They settled on the unit. The circle

then resourced Mary's move. Mary's parents coordinated the overall effort and at times covered

pretty much everything: ... attend Mass on Sunday well at the moment its mum and dad ... (and*) ... the*

follow up on the gym and singing. However others circle members pitched in. One sister, for example,

shared the unit with Mary for several months when she first moved into her new home. *Circle thinking*

resulted in the development of Mary's uniquely tailored network.

9.1.2   Living in the unit on her own

The network that was created with Mary was uniquely configured around the aspects of her adult life

that were already in place. Mary was familiar with household tasks and, public transport and public

utilities in a particular neighbourhood. She had pursued a career with the same company for more

than 20 years. Like the networks that supported an *adult... life* described in the previous chapters,

Mary moved from her parent's home into a unit that was chosen in part for the convenience of its

location. It was close to the public amenities Mary used. Mary shared the unit with her sister for 18

months and then chose to live on her own. Funding for support hours was secured by circle members

and Mary now sees and enjoys seeing people at her work, the gym, the local parish and the choir.

More intimate friendships are yet to develop from these contacts. Into the future, her sisters will continue to manage the support hours. They will *get the monthly calendar out* that they currently produce with their mother. Their father distributes the calendar to circle members. Mary's parents remain integral to Mary's life. While her mother is delighted when she reflects on *the growth in her independence,* she says she *know(s) it was the right decision,* she nevertheless laments a *good friend or some other person t*hat Mary doesn't have in her life. Additional layers, such as a *service* or a *good village* have not been necessary at the time of writing. Even though the circle had shared in planning, when Marys' mother referred to the future, it was Mary's sisters, who were circle members, who from Mary's mother's perspective would ensure Mary *was all right*.

9.1.3 the changeover

Mary's mother was confident Mary would be well cared for into the future. As she said, "*They're great people our (*children*) ... a couple of them are very strong ... and I think oh she (*that is Mary*) will be alright*." Nevertheless, her experience of the *changeover* wasn't easy.

Mary's mother trusts her family is well intended and feels *blessed* to have them. Yet she has struggled to *butt out*. Initially Mary's mother struggled with the paradox of *making ... independence ... happen* that Betty's and Edward's mothers described. Mary's mother recognises this process as a developmental stage she experienced with her other children but she says this time it is different. Her other children pushed for their own choices and she responded to their demands. *I've been caring for all of them, but Mary for a much longer time and when each of the other five moved out it was their choice, their wish, their plans.* But this move was not instigated by Mary or her parents. It was an initiative of her sisters. *(*Sister's name*) said to us a couple of years ago "far better we start making the changes now rather than when you or Dad have gone or about to go or it's all just too hard" and that was sensible, I recognised that.* She agreed that they should be *preparing* by developing Mary's

independence, however she had not expected that it would be as emotionally challenging as it has been.

The changeover (we)'re going through at the moment… It's really the two girls, her older sisters. They are the movers and the shakers. Mary's sisters are encouraging Mary to update her hairstyle and wardrobe, akin with the concept of "technical inclusion" (Clapton, 2009, p.212). Where Mary's mother had appreciated the familiarity Mary had developed with her hairdresser over many years, her sisters thought an age appropriate style was more important than this community connection. They are also insisting their mother phone Mary less frequently and support Mary to attend mass independently. Mary's mother is witnessing decisions being made that are being informed by a different perspective to her own. Mary's mother's ideas were similar to the concept of "ethical inclusion" (Clapton, 2009, p.244). It was not difficult to interpret this difference as criticism. At times she has wished she had never agreed to the change. *I had to say to her yesterday "would you mind if you waited until I dropped off, it would be a lot simpler".* Mary's parents have steadfastly supported one another throughout this time. Thus while Mary's sisters were prepared to assume responsibilities their parents once had, watching other people make decisions differently was not easy. Mary's mother was weathering *the changeover* like Claire's mother, the experiences of whom opened these chapters, who was *backing off.* Mary's mother was confident Mary *will be all right* because Mary's sisters will *be (*here*) when (*their mother*) is not.* Claire's mother was *backing off* with the encouragement and support of her daughters. The next section describes the influences on Mary's mother's ideas about the networks that will support Mary into the future.

Table 9:

Preparing for... moving on.

Past	Present	Future	
	... the changeover....		
Transition / Turning Point	Network that supports Mary	Features	Functions
Preparing for the care... that really started me thinking today. *never ever did ... they invite Mary to something* *two group home experiences... she lost weight* *Circle thinking* *When each of the five (siblings) moved out, it was their choice, their wish, their plans.*	*Far better we start making the changes now than when you and Dad have gone or about to go or it's all too hard* *... Sisters and the circle... get the monthly calendar out.* *.... living in her unit ... work, gym, the local parish, and the choir.* *... support workers* *... growth in her independence ... knows it was the right choice*	Sisters and the *circle* ... living in her unit ... support workers	*A couple of them (Mary's siblings) are very strong.. and I think oh, she'll be alright*

9.2 What influenced Mary's mother's ideas about the network that will support Mary into the future?

Mary's mother's ideas about the networks that will support Mary into the future were influenced by several turning points and the anticipation of a transition in Mary's living arrangements. The turning points included experiences of group homes, the inspiration of a speaker at a future planning seminar and *circle thinking*. Her anticipation of a transition in Mary's living arrangements was associated with her parents' age and health. Mary's mother recognised that while Mary and her parents had enjoyed living together, Mary's living arrangement would not be sustainable when Mary's parents had passed away. Mary's mother's concern for Mary's friendship network and the potential impact on siblings of caring for Mary influenced her ideas. She was also influenced by *circle thinking*.

9.2.1   *Watching that gentleman ... who had started this circle thinking*

Mary's mother agreed to form a circle on the advice of another elderly parent of a son with disabilities whom she heard speaking at a future planning seminar. Mary's sister had invited her parents to the seminar. While Mary's mother captured his ideas, and she was able to imagine how his ideas might be enacted in her family's situation, there was also something *very moving* about what he said. It captured her imagination and she agreed to engage with a circle to *prepare for ... moving on*. She and Mary's father chose to engage with a circle in planning for the future.

9.2.2   *She didn't want a bar of it*

Mary needed to find a living arrangement that would be sustainable beyond the life of her parents. Mary's experiences of living in group homes on two brief occasions in the past, ruled out group homes for the future. Mary had become ill. *The food was appalling*. While hopefully not as traumatic, these experiences had clearly been a turning point, like that in Greg's life, away from group homes.

9.2.3 *never ever did it happen that they'd invite Mary to something*

Mary's mother was concerned about Mary's companionship as Mary had mostly socialised with her parents and people had rarely issued a social invitation Mary. Mary's mother considered a retirement village for Mary because *Mary's heading for fifty and we've noticed over the years in her work situation that they are always older women that befriend Mary. They're not the young whipper snappers ...* Mary would be *part of the community and older people are more generous.* While Mary's mother has been pleased with the circle's course of action, she remains concerned that Mary does not have a companion with whom to share her life. Mary's brothers and sisters have companions in the nuclear families they have formed.

9.2.4 *hate to see any of their marriages or families disintegrate because one of her sisters or one of her brothers says, well I'll look after Mary*

While she understood Mary's brothers and sisters would support her, Mary's mother was concerned about the impact on their nuclear families of doing so. Concern for the impact on sibling's lives was clearly a theme that emerged across these scenarios. In this case, the circle provided a mechanism through which a plan could be made that would ensure Mary's care did not fall to any particular sibling. In this scenario, the life that Mary had previously enjoyed needed to change to accommodate the support the circle was able to harness.

9.2.5 *Circle thinking*

Circle thinking significantly influenced Mary's mother's ideas about a plan for Mary's future. Differences of opinions about the plan for the future were negotiated through the *circle*. Mary's mother compromised and agreed to Mary moving into a unit rather than a retirement village through circle discussions. Clearly these were not easy discussions. One brother *slipped out* of her circle because of *something in the philosophy... something (sister's name) said he objected to. They're great mates usually but they got quite annoyed with each other and their different versions of the theory and he pulled out ...* of the circle. Circle thinking was clearly important to discussing these difficult issues however the discussions were also difficult.

9.3 Future planning processes for *preparing for the care of sons and daughters with disabilities for when parents move on*.

Future planning initiatives were designed to support families in situations similar to Mary's family (Etmanski, 2000). Mary's mother was clearly motivated and inspired by the experiences of another parent who had faced a similar situation to her own. This family engaged with a circle in a person centred planning process that is similar to planning processes described by future planning initiatives.

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Mary's mother found *circle thinking* useful. However, her experience reveals aspects of the planning processes promoted by future planning initiatives that have not been fully explored.

Mary's mothers' experiences revealed *circle thinking* was helpful in negotiating the vision and implementing the plan. However, differences in opinions about social inclusion could cause rifts, this was difficult emotional terrain and the demand on parent's agency placed them in paradoxical situations. *Circle thinking* was helpful in negotiating the vision of Mary's new living arrangement because it resulted in an arrangement that Mary's sisters would be able to support in the future. While Etmanski (2000) recommended parents seek the views of others, parents remain the final arbiters in his descriptions of plans for the future. Final decisions were made by *the circle* in this family. This was important because its sustainability was contingent on the support the circle, particularly her sisters, could offer Mary into the future. This process was difficult in part because of differing, competing and perhaps unspoken agendas about social inclusion. By referring to a 'tribe' who understand one another, Etmanski (2000) perpetuated this myth of conformity which this family's experience clearly challenges. Mary's mother was not fearful of dying or letting go. However, it was understandably confronting to see the basis of decisions she had made for over 50 years be challenged and overturned. Finally, this example again highlights parents' agency of parents that future planning processes fail to acknowledge. In this example, Mary's parents picked up a multitude of tasks, but they also supported one another through what was a difficult time. The invitation to parents to engage in this process is indeed paradoxical. On the one hand, parents are being encouraged to help out with transport, agendas for meetings and ideas. On the other hand they are trying to disengage.

9.4   Conclusion

This chapter explored a scenario that related to the final transition in parent's lives. It describes circle thinking for purposes of fostering a network that will support a daughter with lifelong disabilities through this transition and *after the changeover*. Their experiences revealed the planning processes

recommended by future planning initiatives were helpful. However, these processes failed to acknowledge negotiations about social inclusion may lead to rifts and the paradoxical situation parents' face in participating in strategies that are designed to accommodate their withdrawal. The next chapter presents a collective story of mothers' experiences in the networks that supported their sons and daughters with disabilities that have been described in these chapters. Mothers were the *bottom line* in the networks that supported their sons and daughters with disabilities. When they anticipated *moving on*, the networks they fostered protected the course their sons and daughters with lifelong disabilities had set.

The End ….

You're the bottom line I guess: **Fostering networks that will support sons and daughters with lifelong disabilities *after the changeover*.**

This study investigated the features and functions of the networks that mothers envisaged supporting their sons and daughters with lifelong disabilities when they, and the father of their son or daughter, are no longer able to. Who will look after sons and daughters with lifelong disabilities in the way that their parents have done? This study revealed that *after the changeover*, the *family*, particularly sisters, *circles,* the *service* and/ or *a good village* will feature in the networks that will support a son or daughter with lifelong disabilities*.* These networks will ensure that the lives of sons and daughters stay on course. They will do so by promoting appropriate *ways of thinking* and supporting siblings by sharing responsibilities for the care and support of sons and daughters with lifelong disabilities. Parents invested the assets that they bequeathed to their children in these networks. They invested these assets to *meet the shortfall* in resources that are readily available to people with disabilities.

This study also examined the influences on the networks that they envisaged for the future of mothers' experiences in the networks that supported their son or daughter with lifelong disabilities. Examining the *work that is ... hidden* revealed that the features and functions of the networks that were envisaged for the future were influenced by experiences of transitions and turning points and, mothers' agency. Mothers were *the bottom line* in the networks that supported their son or daughter with lifelong disabilities. Paradoxically, b*eing the bottom line,* that is, exercising responsibility in these networks, involved engaging others, including *society,* in accepting responsibilities. This differentiation of the features and functions of the networks and the influences on them, informs future planning initiatives and future research. This is examined in the next chapter.

This chapter consolidates the findings presented in the previous five chapters. Consistent with a narrative analysis, it includes a collective story of the ideas and experiences of the mothers of sons and daughters with lifelong disabilities in this study (Polkinghorne, 1998). It identifies features and functions of the networks that are described in this collective story and refers to the theoretical framework described in Chapter Two to examine the influences on these networks. This framework incorporated theories about support networks (d'Abbs, 1982; Gottlieb, 1981; Wellman, 2003), social inclusion (Clapton, 2009), social care (Fine, 2007), and social capital (Bourdieu, 1986) into the life course perspective (Elder, 1994; Hutchison, 2005). The chapter highlights the features of the networks that will support sons and daughters with lifelong disabilities into the future and the influence of the incremental process of change associated with transitions and turning points on these features (Hutchison, 2008). It then discusses the functions that these networks will fulfil. These functions were influenced by ideas about social inclusion (Clapton, 2009), social care (Fine, 2007) and social capital (Bourdieu, 1986). Finally, the influence of mothers' experiences and agency in their son's and daughter's networks is discussed. The collective story that opens the chapter does not reflect the experiences of any particular mother. Rather it captures the complex, incremental, life long process of fostering these networks.

10.1 *Being the bottom line* in the networks that support their sons and daughters with lifelong disabilities.

The research questions that this study addressed were:

- What were the features and functions of the networks that the mothers envisaged supporting their son or daughter with lifelong disabilities when they, and the father of their son or daughter, are no longer able to?

- How did mothers' experiences in the networks that supported their son or daughter influence their ideas about the networks that they envisaged supporting their son or daughter with lifelong disabilities into the future?

In brief, the study revealed that the networks that mothers' anticipated supporting their son or daughter with lifelong disabilities into the future will feature the *family*, particularly sisters, *circles,* the *service* and/ or *a good village.* These networks will embody appropriate *ways of thinking* about the inclusion of people with disabilities; support siblings by sharing responsibilities for the care and support of a son or daughter with lifelong disabilities and, through inheritances, *meet the shortfall* in resources. The collective story that emerged with the narrative analysis revealed the complexity of the influences on the networks that mothers' envisaged supporting their son or daughter with lifelong disabilities into the future. Mothers' collective story provided a narrative explanation for the features and functions of the networks that they envisaged supporting their sons and daughters with lifelong disabilities into the future (Clandinen, 2007; Polkinghorne, 1998).

Edward's mother referred to herself as *the bottom line.* She said: "*The reality is you're the bottom line … if the housemate just said tomorrow "well see you later" … the reality is there's no-one there*", She was referring to the *responsibility* she accepted, and would continue to accept, for Edward's care and support. This *responsibility* came to her because unlike her other children, Edward had not seized responsibility for his life and s*ociety* would not accept responsibility on his behalf. Despite recalling times when they had been inspired and reassured by events in the networks that supported their son or daughter with lifelong disabilities, mothers' experiences in these networks informed them that their sons and daughters with lifelong disabilities were *not society's responsibility.* In fact*, society* was seen to be generally disinterested in the well-being of people with lifelong disabilities. T*he general belief is that … if you're at home with your parents and everything is fine then that's fine.* When there was interest, it was to hold mothers' responsible for decisions about their sons' and daughters' lives and the networks that supported them. Like "key people", *being the bottom line* meant accepting responsibility (Bigby, 2000). This is the hallmark of the collective story in Textbox Ten. Paradoxically, the networks that his parents had fostered on Edward's behalf, like other sons and daughters with

lifelong disabilities in this study, enabled him and *society* to take greater *responsibility* and ultimately to assume aspects of parents' responsibilities into the future. Planning for the allocation of responsibilities was therefore part of a lifelong incremental process of engaging others in a son's or daughter's life. Mary's mother described the process of relinquishing responsibilities to others as *the changeover.* She was planning for *after the changeover*.

The narrative explanation of the networks that mother's envisaged for the future that is presented in Textbox Ten revealed the complexity of the influences on mothers' ideas about the networks. Their collective story of mothers' agency revealed the negotiation of the responsibilities of the *bottom line.* The *bottom line* guarded against *ways of thinking* about people with disabilities that perpetuated profound exclusion and met the *shortfall* in inadequate resourcing for the support of people with disabilities (Clapton, 2009). While some mothers were ambivalent about *dumping the care* of their son or daughter with disabilities onto their other children, they recognised that their daughters will assume responsibilities in the future. They also acknowledged that in the absence of significant changes in the networks, the care and support that their daughter's might be called on to provide will substantially impact on and limit their daughter's life choices. Therefore mothers fostered networks that embodied appropriate *ways of thinking,* supported siblings and continued to *meet the shortfall*. However, paradoxically, mothers' (and fathers') agency was central to these networks.

Textbox 10 - Being the bottom line

Mothers in this study "stood alongside" (Read, 2000) their sons and daughters with disabilities in the networks that supported them. When their children were young, mothers sought out resources and opportunities for their children's development and support. For some, whose children were born in an era in which *there was not much on the ground, plac*ing their son or daughter with lifelong disabilities was the only way to secure support for them.

In anticipation of the transition to adulthood, mothers *pushed* or *groomed* their sons and daughters with disabilities towards *independence*. They gradually stepped back, increased the parameters within which their sons and daughters made their own decisions, supported them in their relationships and imagined possibilities for their lives. They consistently and persistently grappled with *over protection on the one hand and giving independence on the other.* They led their sons and daughters with disabilities towards *other people* with whom they might *have a life* and *a role.* Thus, often despite the *criticism* of others, they fostered their sons' and daughters' *adult... lives* and the uniquely tailored networks that supported them.

Mothers trust in the networks that supported their sons and daughters with lifelong disabilities was deeply challenged when their worst fears were realised and they witnessed their sons' and daughters' abuse or neglect. Mothers *acted* and revised the networks. They became even more vigilant to changes in *services* and were wary of trusting again. Some became the *sheriff* of the network. When they were *battling* against *two sets of households and two sets of rules* their ideas about networks were constrained. Conversely, mothers were reassured and reenergised when they discovered ideas that *captured* the *ways of thinking*, the respect they thought their son or daughter with disabilities should be afforded. They promoted these ideas in the network and embodied them in network relationships.

When mothers anticipated *the changeover* was imminent they engaged with the process of *preparing ... for moving on.* They did not withdraw and hope that *the universe would take care of it*; they set about *getting the vision,* the *enthusiasm and engagement* of others and weathered the *changeover*. They watched carefully as others assumed responsibilities they once had and recognised there were *things* that they *had to let go of because people we*r*e trying to build up relationships to replace* them. At this stage, they were *inclined to give in a bit because ... this is the thinking … that will* predominate in their absence*.*

Despite the limitations of *what was on the ground*, witnessing abuse and the emotional challenge of *the changeover,* mothers persistently pursued the *independenc*e of their sons and daughters with disabilities by imagining and fostering the networks that supported them. It is difficult to convey their sense of *responsibility* and *dogged determination* that was captured in the sense of being *the bottom line.* Paradoxically, as the *bottom line,* mothers' assumed responsibility for nurturing networks that would accept responsibilities into the future. They anticipated t*he family*, particularly sisters, *circles,* the *service* and/ or *a good village* will feature in the networks that support their sons and daughters with lifelong disabilities when they, and the father of their son or daughter, are no longer able to. The networks will hold the trajectory of sons and daughters lives on course by embodying appropriate *ways of thinking*, supporting siblings and *meeting the shortfall* in resources.

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10.2   Features of the networks that will support a son or daughter with disabilities after *the*

***changeover*.**

This study differentiated features of the networks that mothers anticipated supporting their son or

daughter with lifelong disabilities. It revealed the diversity of the network structures that might

support a son or daughter with lifelong disabilities when their parents are no longer able to. Siblings,

and particularly sisters, will be central to these networks. However, each network was uniquely

configured. Circles maybe akin to a social convoy in some. Clusters around *the family*, *circles, services*

and/ or the *good village* were described in others. Neighbourhood networks were named in several.

They had all developed incrementally in response to transitions and turning points in the lives of sons

and daughters with lifelong disabilities (Hutchison, 2008). Therefore the network that supported the

adult... life of a son or daughter with lifelong disabilities provided the foundation into which the

features of the networks for the future dovetailed.

In brief, mothers envisaged that in the future:

- geographically based networks will continue to support the *adult… life* of a son or daughter with

  disabilities and maximise their *independence*.

- a fiancée and/ or siblings, particularly sisters, will be *central* to the networks. In networks that had

  stalled due to parents' inability to agree on a course of action, the connections between this core

  of a fiancée and/ or siblings and the other aspects of the network remained unclear.

- t*he family*, actually sisters, and/ or a *circle* will *bring enquiry*. When sons and daughters with

  lifelong disabilities had been supported by a *service* over many years, this *enquiry* would guard

  against being *sucked into the service system*. The *enquiry* will perpetuate the influence of mothers'

  preferred *ways of thinking* including the respect and regard they felt towards their son or

  daughter.

- sisters and the circle will support a daughter who had lived with her now elderly parents for most

  of her life. C*ircle thinking* enabled the family to *prepare* for elderly parents *moving on* by revising

the network that supported their daughter's *adult... life.* The living arrangement was revised such that it would be compatible with the support that will be available *after the changeover*. Living in her unit and exploring new social groups boosted Mary's independence.

- multilayered networks will provide *checks and balances* for the safety of sons and daughters with lifelong disabilities who have high support needs associated with complex health issues. Greg will be supported by his siblings, *the service*, the *circle* and friends. Edward will be supported by his siblings, the circle, the *house* and a *good village*.

Therefore this study revealed the layering of networks over time. Mothers' plans for the future, and the networks that emerged from them, dovetailed into the networks that had supported the *adult... life* of a son or daughter with lifelong disabilities. Therefore, as the *adult... life* of the son and daughter with disabilities in the first scenario described in Chapter Five, was supported by a service, the potential domination by this service, called for a *circle's* and *the family's monitoring and advocacy*. In the second example, a *circle* will support the daughter in the fifth scenario discussed in Chapter Nine having reconfigured the geographically based network that supported her *adult... life*. Finally, the connections mothers (and fathers) held across the various layers of the networks that supported and protected the safety of their sons in the third scenario discussed in Chapter Seven will be assumed by the network *after the changeover*. Despite their high support needs, their networks enabled these sons to pursue their *adult... lives* independently in suburban homes owned by their parents. While their mothers were continuing to prepare for the future it was anticipated that their daughters, a support coordinator, *circle* and a *good village/ service* would continue to share the responsibility of supporting and protecting these sons into the future. In summary the features of the networks that will support a son or daughter with lifelong disabilities into the future, such as *the circle*, *the family* and/ or *sisters*, as depicted in the far right column of Table 8, were additional layers that dovetailed into an existing network.

Siblings were integral to the future networks identified in this study. Consistent with previous research the siblings in these families enjoyed close relationships (Bigby, 2000; Prosser, 2000). Further, daughters rather than sons will be *central* in the networks (Bigby, 1997, Burke et al, 2012; Davys, Mitchell & Haigh, 2010; Grant, 1989; Greenberg et al., 1999; Heller & Arnold, 2010; Heller & Factor, 1991; Heller & Tamar, 2009; Krauss & Seltzer's, 1993). Where network development had been stalled by parents' inability to agree, non-disabled daughters will be relied on to support their brother or sister with lifelong disabilities into the future.

Several of the networks included circles of support. Members of Greg's circle were his *trusted friends*. Mary's circle moved her into her new home and helped her to pursue new interests. These were akin to a social convoy (Kahn & Antonucci, 1980). However, Edward's circle supported his *house* and Hamish's circle supported his sisters. Therefore, these circles will not necessarily assume the place of a social convoy.

There were also distinct subgroups in these networks. These clusters related to the layers that were introduced. Examples of these included *the family* and / or a *circle* and *the service*. Often one cluster, such as the *circle* emerged to counteract the influence of another, such as a *service*. However, membership of these clusters was not necessarily exclusive. Network members moved between these clusters. Edward's h*ousemates,* for example, became *circle* members. Conversely Frank's *team leader* was a valued member of his circle as well as a paid support person.

Table 10:

Incremental process of developing networks that will support sons and daughters with disabilities
after the changeover

	... a truly adult phase of life	*Preparing for ... moving on*	*After the changeover*
Scenario 1 *Bringing enquiry* **You can place her** **I captured that** **.... ways of thinking**	the flat, her flatmate, support coordinator, work, church, art, soccer & *the service*	*She told me to back off ... I was really struggling at that point.*	*the family* *... monitoring and advocating*
	the cottage & the service	*not getting any younger* *Initiative has to be taken*	*the circle* *... bringing enquiry* based in preferred *ways of thinking*
Scenario 2 *A truly adult phase of life*	*In her own place, close to public transport, close to a shopping centre... social activities*		
	His/ her own place ... other people... to have a life with ... Having a role rather than being amused ... Someone is there to do something in a crisis		his siblings, the circle, the house & a *good village* *... stays alive*
Scenario 3 *Checks and balances* *... thought he was safe*	*the service, the circle & ... his social network.*		his siblings, *the service, the circle* and ... *his social network.*
Scenario 4 *I'll do it one day* **Parent's split**	2 sets of households,2 sets of rules		Siblings, sister ... *the nucleus* *..having a life stuff*
			Fiancée and/ or sister
Scenario 5 *... the changeover* **Preparing for the care... that really started me thinking today.**	*... own home with a bird bath*	*Circle thinking*	Siblings and the *circle* *... she'll be alright*

In summary, this study revealed that the networks that will support a son or daughter with lifelong disabilities when their parents are no longer able to were uniquely crafted and therefore their features varied. Consistent with the life course perspective, the networks that supported sons and daughters with lifelong disabilities evolved incrementally to maintain sons' and daughters' lives on course. Layers and /or clusters were associated with transitions and turning points. There were identifiable clusters; however cluster membership was not necessarily exclusive. Some circles may become social convoys; others will not. The networks that will support sons and daughters with disabilities when their parents are no longer able to are not the same as the networks that supported their *adult... lives*. Siblings, and particularly sisters, will be *central* to the future networks described by this study. Finally, the networks that will support sons and daughters with disabilities into the future were configured to support all of the sons and daughters within the family, not just the person with disabilities.

10.3 Functions that will be served by the networks the will support sons and daughters with lifelong disabilities *after the changeover*.

After the changeover, that is, when parents have handed over their responsibilities, networks will hold the life trajectory of a son or daughter with disabilities on course. The life trajectory may differ from the course that mother's had established. Rather than following a preconceived plan, mothers anticipated that the networks will assume responsibilities for holding *ways of thinking* and avoiding *dumping the care of a son or daughter with disabilities* on their siblings. They also anticipated that future returns on their investment in these networks will continue to meet *the shortfall* in resources. Therefore these networks will serve functions associated with social inclusion (Clapton, 2009), social care (Fine, 2007) and social capital (Bourdieu, 1986).

10.3.1 ... *ways of thinking* about people with disabilities

Mothers embedded their preferred *ways of* thinking into these networks. For example, in the first scenario, described in Chapter Five, *sisters* and/ or *a circle* were specifically tasked with *bringing enquiry* based in their mother's preferred *ways of thinking*. The privately owned homes referred to in the second scenario in Chapter Six reflected family values about *independence*. Home ownership bolstered *independence* from state funding in one example and offered *independence* to pursue an *adult... life* in the other. The l*ifestyle support facilitators* described in the third scenario in Chapter Seven were employed by a service that upheld the *right philosophies* that in turn ensured that the staff they employed embodied these *philosophies* in their work. Therefore this study revealed parents' values and attitudes were perpetuated by these networks. Having said that, mothers' *ways of thinking* about the inclusion of their son or daughter with lifelong disabilities were often articulated in terms of what was to be avoided, rather than what was to be perpetuated.

When mothers referred to the *ways of thinking* that they wanted the networks to embrace, they wanted to curtail the influence of the *medical model*, segregation, dependence and being *punitive and controlling.* Many had witnessed and experienced "profound exclusion" (Clapton, 2009) and they did not want to perpetuate it. However the social inclusion that they fostered in the networks spanned Clapton's (2009) metaphorical quilt. Where sons and daughters with disabilities had been supported in residential settings, mothers highlighted not being *sucked into the service system* and connections with the world beyond *segregated services*. They wanted their son or daughter with lifelong disabilities to be treated *the same as everybody else* and their *right* to be treated as such acknowledged. They wanted what Clapton referred to as "legislative inclusion" (2009). Some mothers wanted their son or daughter with disabilities to experience the *normal patterns of life* or "technical inclusion" (Clapton, 2009). Some mothers emphasised the unique *personhood* of their son or daughter with disabilities. They wanted their son or daughter to experience valued social roles and emphasised the relevance and desirability of relationships. For these mothers relationships associated with the disability sector

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were as important as those that signified connection with the mainstream and/ or age appropriateness. One mother simply said she wanted her daughter to be loved. These aspirations were akin to "ethical inclusion" (Clapton, 2009). Thus the *ways of thinking* these mothers described spanned technical, legislative and ethical inclusion. As such, while they wanted to avoid profound exclusion, the values and attitudes about inclusion that mothers wanted networks to embody varied.

Subtle differences in *ways of thinking* had resulted in confusing rifts in some of the networks that mothers had fostered. While Betty's mother promoted social inclusion, she felt ostracised and misunderstood by a family support organisation that promoted a different interpretation to hers. In another network a brother *slipped out* of a circle because of *something in the philosophy... something (*sister's name*) said he objected to. They're great mates usually but they got quite annoyed with each other and their different versions of the theory and he pulled out ...* of the circle. Differences in the interpretation of the *right philosophies*, and the passion with which particular philosophical perspectives were held, could split networks of support.

Paradoxically, when mothers in this study negotiated *the changeover*, that is, when they allowed others to have greater influence in the networks that supported their son or daughter with disabilities, they struggled as they witnessed the often subtle differences of interpretations about *ways of thinking*. Mary's mother's experiences of the *changeover,* discussed in the fifth scenario In Chapter Nine, were telling in this regard. While she knew her daughters wanted the best for Mary, and she trusted their judgement, *it* (was*) difficult.* Her experiences revealed just how difficult it might be to renegotiate the terms of a relationship that spanned fifty years and allow values and attitudes that dismissed exclusion yet interpreted inclusion differently, to influence life choices. *T*here were "*things that (I) have had to let go of because ... this is the thinking of her sisters and that's what's going to be when I'm not here."* Thus the *changeover* involved recognising values and attitudes would need to be held by the networks into the future and witnessing the introduction of new *ways of thinking* that may

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indeed deeply challenge parents' ideas about support. Mothers might be able to reassure themselves that it will *be alright* but that it might also be *difficult* is undeniable.

10.3.2 *... do not want to dump the care of our son with a disability ... on his brother and sister*.

This study also revealed that mothers revised the networks that supported their son or daughter with lifelong disabilities in order to ensure that the lives all of their children will stay on course. Mothers anticipated that in the absence of parents, siblings, particularly sisters, will be called on to accept responsibility for the care and support of their brother or sister with lifelong disabilities. Consistent with research that described parents' reluctance to plan; several of the mothers were *preparing* networks out of concerns for the siblings of their sons and daughters with disabilities (Prosser, 1997). Mary's mother *know(s)* her siblings will *step in but*... she would... *hate to see any of their marriages or families disintegrate because one of her sisters or one of her brothers says, well I'll look after Mary.* Emily's mother was concerned about restricting (Emily's brother) and (Emily's sister) to *being in the same city as Emily and being in a situation of being able to care.* Hamish' mother was concerned his sisters do not have sufficient experience to draw on. When mothers anticipated the situations in which their daughters would support their brother or sister with disabilities in the future, they recognised it may limit their opportunities to live where they chose, impact on their nuclear families and that their experience may not sufficiently prepare them for it. Finally some were concerned in principle and did not want *to dump the care of* … (their)… *son with a disability on …* (their*) ... other children*.

Mothers anticipated that siblings might be called on to make alternative arrangements for support; *bring enquiry,* anticipate change and prevent situations arising that might jeopardise the *adult... life* of their brother or sister; and signal a course of action *in a crisis*. Despite the multiple sources of care and support, 'warm modern care' (Hochschild, 2003) assumes families will accept ultimate responsible for ensuring that citizens are supported. Mothers had accepted this responsibility on behalf of their sons

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and daughters with disabilities. They anticipated that current models of care will encourage siblings, particularly sisters, to do so in the future. However they did not want to *dump* this responsibility onto any one of their children. In resistance, they engaged networks.

Mothers introduced several features into the networks to reduce the demand on siblings for choices about care and support *after the changeover*. Firstly, the networks that supported their *adult... lives* boosted *the independence* of sons and daughters with disabilities. Some reinforced the robustness of the network with multiple layers. Secondly, circles were established *to do something in a crisis* and to assist siblings in *bringing enquiry.* Thirdly, services based in the *right philosophies, a good village* and the interconnections between the layers of networks will prevent risk. They also invested their assets in the networks.

10.3.3 *... meeting the shortfall...*

Parents invested in the networks that will support a son or daughter with a disability into the future. They anticipated that their son or daughter will reap the rewards of the return on parents' investment. Consistent with "warm modern care" (Hochschild, 2003 in Fine 2007) parents met *the shortfall* of the networks that supported their son or daughter with lifelong disabilities. Parents supplemented the support that was available with their own direct support, money, coordination and/ or management of support workers, and social capital. The support *society* offered people with disabilities, be that in funding packages, services or naturally occurring personal networks, was limited and mothers (and fathers) met the *shortfall*. Their endeavours drew *society*'s resources such as funding for support hours and relationships with friends and neighbours, to the networks of their son or daughter with a disability. Inheritances from parent's estates will continue to subsidise these networks into the future.

Parents invested heavily to address *the shortfall* in direct support, support coordination, and affordable housing that supported the *adult... lives* of their sons and daughters with disabilities. They did so in part in anticipation that the future returns on their investments would improve the lives of

their families. Mothers (and fathers) boosted the inclusion of their sons and daughters with disabilities by washing clothes that had not been laundered properly and supporting them in using public transport. They built social capital by hosting social events on behalf of their sons and daughters with disabilities and driving them to social events. Mary's mother and father were *covering pretty much everything …* arranging for Mary to attend *… Mass on a Sunday… the gym and singing.* Mothers built the pool of competent support workers through their contributions to selection, recruitment, mentorship and management of the people who supported their sons and daughters with disabilities. They provided a home when other arrangements failed. They purchased or subsidised rent for the *places* in which their sons and daughters with disabilities lived.

Mothers anticipated that the assets that they and the father of their son or daughter with lifelong disabilities invested will reinforce the network's sustainability. Hamish's mother captured her *learned experience*, the social capital of connections and skills she had accumulated by lobbying for change in the disability sector, with the *circle*. Mary's circle mobilised the family social capital to resource Mary's new living arrangement. Edward's parents' mobilised colleagues, friends and neighbours, such as a women his mother met at the gym, in the development of *a good village* for Edward.

Mothers (and fathers) invested a wealth of resources into the networks that would support their sons and daughters with disabilities after *the changeover*. They invested financial capital, time, skills and social capital. Many of these families were well financed, were well established in a geographical area and/ or had substantial experience in the disability sector. Mothers who had retired, and/ or worked part-time in paid employment were able to invest their time. They had substantial capital to invest. Conversely as one mother said, it's *hopeless for people who have not got any language skills or … don't know the area or … Are poor or they haven't got any time or they are working full-time and are completely flat out or whatever the reasons might be.* The sustainability of these networks relied on family investment. However future planning initiatives fail to acknowledge differences in family's assets (Etmanski, 2000).

10.4   Influence of mothers' experiences in the networks that supported their son or daughter with lifelong disabilities on the networks that they envisaged supporting them into the future.

This section returns to the collective story of the influence of mothers' experiences in the networks that supported their son or daughter with lifelong disabilities on the networks that they envisaged for the future, presented in Textbox Ten. It explores the agency of mothers and its influence on the networks that they anticipated for the future. *Being the bottom line* meant having the *dogged determination* of engaging *society* against a tide that, consistent with 'warm modern care' assumed they, that is mothers (perhaps alongside fathers), should be the *bottom line (*Hochschild, 2003 in Fine 2007*).* This study provided a longitudinal perspective of this process.

10.4.1   *Grooming* or *pushing for independence* and *taking control*

The nature of the relationship that mothers fostered with their son or daughter with lifelong disabilities was central to the *adult... life* that their son or daughter pursued*.* Sons and daughters with lifelong disabilities did not claim their *independence*, mothers *made it happen*. Mothers stepped back, increased parameters within which sons and daughters with disabilities made their own decisions, supported them in their relationships and, helped them to imagine possibilities for an *adult life*. *Pushing for independence* was not a simple one off event of "letting go" (Etmanski, 2000). For Betty's mother, for example, it meant discussions with Betty over many years about where she might. For Edward's mother it meant purchasing a house, securing *housemates*, finding a suitable model through which to manage the housemates, moving Edward into his home, weekends in the family home and with it, repeated reminders at the end of the weekend that it was time go back to his own home. This is more than allowing someone to leave home. Their persistence fundamentally influenced the relationships and opportunities their son or daughter with disabilities might be persuaded to embark upon.

The networks that supported adulthood fostered i*ndependence*. However, parents remained central to these networks and at times *took control*. While their son's or daughter's *own place* was located in familiar geographical settings with ready access to public transport and facilities, it was often close to parents. Having other *people …* (to)*… have a life with*; *a role*, or perhaps roles, *rather than being amused*; and having *someone … there to do something in a crisis* also featured in these networks. Again however, mothers were often integral to these arrangements. Edward's *housemates* and *circle*, for example, responded in crises, but they looked to his mother to guide their actions. Where an *adult ... life* involved living in supported accommodation, mothers and sisters *advocated and monitored* to avoid sons and daughters with disabilities being *sucked into the service*. Where health conditions raised safety concerns, *housemate*s or *lifestyle facilitators* kept watch, *circle* members were alert to signals of distress and mothers *acted*. Therefore, sons and daughters with lifelong disabilities were able to pursue *independence* in their networks because their mothers participated in the networks and protected their son's and daughter's interests.

Networks that were fostered to support the *adult... life* of a son or daughter with lifelong disabilities were contingent on the ability of their parents to reach, at least, tacit agreement. More realistically, the more complex networks in this study resulted from parents' investment of their financial, cultural and social capital. If, as occurred in the fourth scenario described in Chapter Eight, parents were unable to come to agreement, the momentum for fostering a network that supported an *adult … life* stalled. Further in addition to agreement, several mothers in this study were able to invest their time in the network because they chose to work part-time in paid employment or had retired. Some were able to do so because the father of their son or daughter with lifelong disabilities was able to financially support the family. Therefore, parents' ability to reach agreement about the lifestyle and support of their son or daughter with lifelong disabilities influenced the networks that emerged.

Networks were also influenced by the opportunities that mothers pursued. Paid positions were established to oversight direct support. The team leader of Greg's *lifestyle facilitators*, for example, increasingly became involved in all of the layers of Greg's network. Opportunities for support funding were successfully pursued. A position for a *community coordinator* who has *the linking role in making the community happen* was included in the proposal for the *good village*. Support workers, *housemates, flatmates* and *lifestyles facilitators* assisted with maintaining the momentum for sons' and daughters' pursuit of an *adult ... life.* Friendships were nurtured with people with common interests. On the other hand services changed, *housemates* moved on and circle members were called away to other responsibilities. Thus, while networks were in place to support to support and protect the adult life of a son or daughter with lifelong disabilities, mothers continued to be the *bottom line.*

10.4.2 *Preparing for ... moving on*

The shift from pre-planning to *preparing for... moving on,* was arbitrary for many of the mothers in this study. These mothers had been fostering networks that accounted for the future support of their sons and daughters with disabilities throughout their son's and daughter's lives. For others, consistent with previous research, the shift into planning was triggered by their age or health (Chou, 2009; Heller et al, 2007; Prosser, 1997). At the point in time that they decided to plan, mothers assessed the network that supported their son's or daughter's *adult... life*.

In particular, as discussed in the previous section, mothers in this study anticipated the impact of their declining capacity on all of their children. The plans these mothers made curtailed the restrictions that supporting a brother or sister with lifelong disabilities might place on siblings. While siblings in this study were aware of their parent's arrangements for establishing the *adult... life* of their brother or sister with disabilities, and shared in their brother's and sister's *adult... life*, they were not necessarily integral to the process through which their brother's or sister's life was established. Many siblings were actively pursuing their own adult lives. Previous research indicated that siblings wanted more

involvement in the planning process (Heller et al, 2007). This study indicated mothers and daughters negotiated the timing of planning and their daughters' involvement. Mothers acknowledged that their daughters were juggling competing responsibilities. Paradoxically, this phase did not result in mothers' input to the networks reducing; it increased with responsibilities for preparing and conducting circle meetings, developing plans collaboratively and completing follow up tasks.

10.4.3   *Backing off ... and the changeover*

Mothers stepped back when their daughters' invited them to. Claire's sisters suggested to Claire's mother to *"back off. Give her space and let her tell you when she wants to come home".* Claire's mother agreed. Mary's sisters invited their parent to seminars about future planning. It was with this stage in the incremental process that mothers could be seen to be actually 'letting go' and reducing their responsibility in the network (Grant, 1993). As discussed in chapter nine, this was a difficult stage. Mothers witnessed others making decisions perhaps differently from the decisions they would have preferred. While they welcomed their daughters signalling it was time to *back off* it was indeed *difficult*. However, others availability and offers of support influenced mothers' decision to *back off*. This was much later in the process than future planning research suggests (Grant, 1993).

10.4.4   *Being the bottom line*

This study identified mothers were the *bottom line* in the networks that supported their son or daughter with a disability and that the ways in which mothers exercised their responsibilities as the *bottom line* influenced the networks that emerged to support their son or daughter. Mothers realised that *no-one* was *there* for their son or daughter and in the absence of their efforts the *adult... life* of their son or daughter with lifelong disabilities might have gone off course. Paradoxically mothers' engagement of networks represented their resistance to *message*s ... of indifference *... from society.*

The *work that is ... hidden at the moment,* the agency required to envisage and nurture these networks, placed mothers in paradoxical situations.

Mothers confronted paradoxes as they exercised their agency. In the first scenario in Chapter Five, accessing the *services* that offered to support their son or daughter with lifelong disabilities resulted in experiences of profound exclusion. As they imagined the networks that would support their sons' and daughters' *adult ... lives*, as described in Chapter Six in the second scenario, mothers straddled the paradox of *pushing* sons and daughters towards i*ndependence* by taking control. As they planned for the future, as Llewellyn (2003) identified, mothers confronted the paradox of involving those who were members of a *society* that had profoundly excluded, or included provisionally, people with disabilities. As they struggled in conflict with the father of their son or daughters with lifelong disabilities they were blocked from pursuing the networks that might address the *split* caused by divorce. Finally, they increased their involvement in the networks that supported a son or daughter with lifelong disabilities in order to prepare for *moving on*.

Mothers' agency and the networks they fostered helped them to grapple with these paradoxes. Recognising the paradox of *pushing* sons and daughters with disabilities towards *independence*, one mother encouraged her son's relationships with other people to *balance* her influence over his decisions. Another regularly questioned the extent to which she had allowed her daughter to disagree and form her own opinions. Appropriately configured networks as well as mothers' vigilance, reassured them signs in the networks of untrustworthiness, impending abuse and neglect would be identified quickly and dealt with. Mothers bided their time when their actions were blocked. Finally, as they weathered *letting go,* their experiences of the network in action reassured them that in fact, the people who were now involved in the network were *good people*. As one mother summed it up, "*They're great people our (*children*) ... a couple of them are very strong ... and I think oh she (*that is Mary*) will be alright*." This study identified therefore that mothers' agency challenged and engaged *society* in its *responsibility* to people with disabilities.

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10.5   Conclusion

Previous literature proposed a network of support based on theoretical perspectives (Dillenburger & McKerr, 2010) or idealised models of networks and network development (Etmanski, 2000; Klees, 1996; Hole, 2007). This study differentiated the actual networks that will support sons and daughters with lifelong disabilities *after the changeover* and influences on these networks. It identified that the networks that will support sons and daughters with lifelong disabilities when their parents are no longer able to, will feature the *family*, particularly sisters, *circles,* the *service* and/ or *a good village.* These networks were uniquely crafted and varied markedly. However siblings, particularly sisters, were *central* to the networks in this study. Most included distinct clusters such as the *family*, *circle* and/ or the *service*. The features that will support sons and daughters with lifelong disabilities into the future were influenced by the networks that supported the *adult... lives* of these sons and daughters. They dovetailed into them and their configurations were influenced by transitions and turning points.

This study also identified that the networks that will support sons and daughters with lifelong disabilities when their parents are no longer able to will ensure that sons' and daughters' lives continue on their established trajectories. Networks will embody *the right philosophies* and ensure the responsibility for the care which, in the absence of parents, will fall to siblings and particularly sisters, will not be onerous. This study also acknowledged that these networks offered opportunities for returns on the investment of family assets and that these returns were needed to *meet the shortfall* in resourcing.

Finally, networks for the future were influenced by mothers' *dogged determination* in engaging their son or daughter with lifelong disabilities in claiming their *independence* and *society* in taking responsibility. The negotiation of *the changeover* was a culmination of a lifetime of experiences in the

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networks that supported sons and daughters with lifelong disabilities. It involved the repeated

reinforcement of *independence* of sons and daughters with disabilities and incremental revisions to

the networks that supported them. It culminated in the addition of features that dovetailed into the

network that supported the *adult ... lives* of sons and daughters with disabilities to support them *after*

the changeover.

No wonder older parents postponed planning and struggled to conceptualise viable alternatives! The

fostering of networks that will support sons and daughters with lifelong disabilities *after the*

changeover was dependent on significant family investment. Yet, networks stalled in well-resourced

families when parents were unable to agree. The *society* in which mothers were encouraged to foster

networks was at best indifferent to the plight of their sons and daughters with disabilities. It was more

likely *society* had assumed the support of sons and daughters with disabilities was the responsibility of

parents. Engaging networks of support for sons and daughters with disabilities involved a*ll this work*

that *is in fact hidden.* Paradoxically, mothers were being encouraged to engage *society* in networks to

assume responsibilities that *society* had offloaded responsibilities for in the past. Therefore "*it takes*

the motivating, facilitating, pursuing, persevering that comes with someone with the dogged

determination of being a mum. It doesn't have to be a mum, but it takes that determination, the same

tenacious manner". The final chapter reflects on this study. It identifies how these findings inform

future planning initiatives and anticipates further research in this area.

Chapter Eleven

Implications of the Study

11.1   Overview of this Study

This phenomenological study uncovered, identified and examined the features and functions of the networks that will support sons and daughters with lifelong disabilities when their parents are no longer able to. It penetrated mothers' rich narratives of their experiences in, and ideas about, the networks that supported their sons and daughters with lifelong disabilities. The findings inform conceptualisations of the networks that support people with lifelong disabilities, future planning initiatives and further future planning research. By uncovering mothers' complex agency, their *dogged determination*, in engaging their son or daughter with lifelong disabilities and *society* in accepting responsibility, the study took a political turn. Thus this chapter returns to the concerns about *society's* collective responsibilities raised in the quote that opened this thesis (Corrigan, 2009). It considers how future planning initiatives might be informed by the findings of this study. As described in Chapter Four, I chose this research design for its suitability, and the rigour and trustworthiness that it offered, to this study. This research design also serves valuable political purposes of giving due recognition to the *hidden* care work of women.

11.2   Summary of Key Findings

The networks that the mothers in this study envisaged supporting their son or daughter into the future were uniquely crafted and diverse. They will feature the *family,* particularly sisters, *circles,* the *service* and/ or a *good village*. They will embody appropriate *ways of thinking* about the inclusion of people with disabilities, support siblings by sharing the care and support of son or daughter with disabilities and, through inheritances, *meet the shortfall* in resources.   While the networks were uniquely crafted

to the son or daughter with disabilities, they were all influenced by experience of transitions and turning points. The study also confirmed the complex, often subtle, influence of mothers in the networks that support their son or daughters with disabilities. The collective story that emerged revealed the complex influence of mother's *dogged determination* and social and temporal contexts on these networks. Thus, in addition to differentiating features and functions of "networks of support" and thereby expanding current conceptualisation of future plans, this study identified the lifelong, incremental nature of the development of networks that will support sons and daughters with lifelong disabilities when their parents are no longer able to (Dillenburger & McKerr, 2010).

11.3   Reflections on the research design

The strength of this study was in its refusal to perpetuate the invisibility of the *hidden* care work performed by women. By repeatedly examining the mothers' narratives and returning to them for further clarifications, the mothers of the sons and daughters with lifelong disabilities in this study influenced every aspect of the research design. Therefore, the research process engaged with them in engaging others in their advocacy for networks that will effectively support their sons and daughters.

The choice of a phenomenological methodology focused the study on the meaning that mothers made of these networks. Mothers' experiences of care provision might have been rendered invisible through the nature of their performance of care and the lack of social recognition of women's care work (Fine, 2007). This methodology acknowledged mothers' experiences provided a well-informed, richly subjective view of these networks. It delved into the sense that mothers made of these networks (Crotty, 2008). Rather than blaming or reprimanding mothers for setbacks in planning, this research design sought to understand the sense mothers made of the influences on these networks. Rather

than assuming what a future plan and a support network that enabled its implementation might be, this research design allowed for exploration of what might be envisaged.

The social constructionist view acknowledged the influence of the context on the construction of mothers' ideas. The theoretical framework was inspired by mothers' narratives about the networks they envisaged supporting their sons and daughters with lifelong disabilities in the future. Their collective story revealed the influence of significant events on the networks and the Life Course Perspective provided a theoretical framework that captured what they had described (Hutchison, 2008). Their collective story also revealed the influence of social inclusion (Clapton, 2009), social care (Fine, 2007) and family assets, including social capital (Bourdieu, 1994). Rather than overriding mothers' perspectives, the theoretical framework raised points for clarification which were then investigated in the data.

Narrative analysis enabled mothers' ideas to influence the research process. In the initial stages, the structures of mothers' stories guided the analysis. Rather than breaking up the text according to themes that were of interest to me, narrative analysis enabled the emphases mothers brought to the stories to lead the analysis. The themes that emerged in the mothers' stories inspired the research questions. Thus the research questions addressed areas of enquiry that mothers wanted to this research team to know about. Mothers influenced the direction of the research through repeated contact throughout the study (Doyle, 2007). Feedback in the initial stages confirmed that the concept of *the bottom line,* the words of one mother, fitted for others. In the latter stages, their feedback clarified the key themes as well as more specific analyses of their data. Again this enabled their expertise and informed position to influence the analysis and narrative explanation.

The transcripts selected for this study provided a particularly rich source of data because of the range of mothers' experiences. The experiences of these mothers represented a wealth of experience in negotiating with the disability sector and the broader community. Their experiences of mothering a son or daughter with lifelong disabilities ranged from birth to middle age, in differing social policy eras and; as sole parents and in shared parenting. Their diverse circumstances as well as their wealth of experience contributed to the explanatory power of the collective story that provided the narrative explanation of the networks that they envisaged for the future. For example, the mothers who were constrained by their relationships that followed divorces had markedly different social backgrounds and experience. Yet they described very similar circumstances in negotiating with their former partners. Further, as these mothers' situations spanned a lifetime of parenting experiences, the longitudinal view became a particular strength of the study. Thus the influence of both social and temporal contexts on network development was revealed.

This research tapped into a source of data that has been *hidden*. Mothers' stories of their experiences in these networks revealed the complex situations that they negotiated. Future planning research repeatedly revealed parents' ambivalence towards future planning (Prosser, 1997). Mothers' detailed descriptions of their experiences in the networks that supported their sons and daughters with lifelong disabilities revealed the paradoxical decisions mothers negotiated repeatedly, throughout the lives of their sons and daughters with lifelong disabilities. Unravelling these paradoxical situations offered further and plausible explanations about their ambivalence towards planning. Their stories also revealed mothers' subject position in the negotiation of power. Rather than accepting a position in which extensive responsibilities were imposed upon them, these women skilfully negotiated to engage others in effectively sharing these responsibilities. These mothers will hand responsibilities for care to their daughters. However, this study revealed that they resisted and refused to curtail the lives of their daughters to unacknowledged and unsupported caring roles.

11.4   Limitations of this research

This research offers a rich description of the experiences of fostering networks that support people with lifelong disabilities and ideas about the networks that might serve these purposes into the future. Narrative analysis, longitudinal engagement, member checking and team discussions reinforced this study's rigour. However, its value is in experiences and ideas that it uncovered that were previously unacknowledged and explaining the influences on the networks that will support sons and daughters with lifelong disabilities when their parents are no longer able to, rather than its generalisability.

This research drew on the perspective of only one member of each network. Mothers' perspectives were integral to understanding these networks and their creation, but clearly, it is only one perspective. The perspectives of the sons and daughters at the centre of these networks have been described elsewhere (Hillman et al, 2013). Fathers might have held quite different views about the process of fostering networks and the futures they envisaged. Some mothers indicated that this was certainly the case. Further, the daughters that mothers typically anticipated as being central to the networks of the future might also hold quite different views about these networks and the process of their development. Clearly this study does not claim to have captured a diversity of views. Describing a network from the perspective of only one member is clearly a limitation of a study about networks.

While other families might, as I was, be interested in, and inspired by, the ideas and experiences of the mothers in this research, the networks that have been described are not offered as models which might be prescribed for other families or which families might emulate. If anything, the explanatory value of the life course perspective, confirmed by this research, indicates the opposite. Multiple factors impacted on these networks and prescribing any particular feature or function of a network for

the purposes of future planning, misinterprets the generalisability of this research. However, several findings emerged that could inform future planning initiatives and further research.

Participants were recruited based on their interest in fostering networks. The profile of these families bore similarities to others that have been positively associated with future planning; such as, having a sibling who would accept caring responsibilities, previous engagement with services, higher family income, higher levels of family social support and greater abilities of sons and daughters with lifelong disabilities. These families invested a wealth of assets in these networks. This is not to suggest that other families are without assets. Rather, it confirms that substantial investment is needed for these networks to flourish. The financial, practical and emotional support of the father of their son or daughter with lifelong disabilities is not readily available to all mothers and these assets are not readily available to all families.

This analysis risks blaming mothers rather than recognising the unreasonable demand that is placed on mothers in fostering these networks. The motivational tone that underlies several future planning initiatives implies the sole deterrent to planning is parents' motivation (Etmanski, 2000). This tone is exactly what this analysis risks. The way in which mothers perceive and negotiate independence with their sons and daughters with disabilities is clearly crucial however their fears for the profound exclusion of their sons and daughters are grounded in experience. Rather than suggesting that other women should aspire to emulate their efforts, I would hope that this research begs the question of how *society* might acknowledge their efforts and respond more effectively to its responsibilities to people with lifelong disabilities.

Finally, this study adopted a phenomenological approach that was developed by Husserl (1970b in Crotty, 1996). For me, Husserl's approach, rather than another phenomenological approach,

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encouraged the clarity of focus. Mothers emerged as ideal informants and I chose to be informed by

their expertise and wisdom such that this study did not further the invisibility of women's care work.

Heidegger abandoned the exploration of culturally derived meanings, focusing instead on 'being' and

the influence of the researcher's process of sense making (1962, in Crotty, 2008). The fact that the

implicit influence of my views remained unexamined might be seen as a limitation of this study.

However, the implicit influence that I exercised was in choosing to unveil mothers' *hidden* work and

examine their nuanced subject experience. The mothers' acknowledgement of the findings of this

study, their feedback and repeated engagement with the study, and the similarities between the

pivotal positions of the mothers in this study with those described in the literature indicate the

trustworthiness of the findings of this study and reiterate for me that this was a wise choice.

11.5   Implications of this research.

The answers to "Who will look after my child ... and in the way that I have done?" identified by this

research have implications for future planning research and the design of future planning initiatives.

11.5.1   Contribution to conceptualisations of networks that support people with lifelong disabilities

Findings from this study confirmed parents, particularly mothers, were pivotal in the networks that

support their son or daughter with lifelong disabilities (Grant, 1993; Read, 2000). The mothers were

selected as key informants because of the pivotal positions they occupied in the networks in this study.

Their experiences in the networks and descriptions of the features and functions of the networks that

were being fostered also confirmed that without purposeful intervention, the networks that supported

their son and daughters with disabilities might remain "distinct social spaces" (Todd et al, 1990). The

networks embodied "sites of struggle" (Stehlik, 2000) and had called mothers into "extended caring

roles" (Traustadottir, 1991), "political activism" (Wickham- Searl, 1995) and "crusadership" (Seligman

and Darling, 1997). Contrary to concerns about the invisibility of women's care work, network

members acknowledged the quality, expertise and nature of the support provided by the mothers.

11.5.2. Contribution to future planning research

Findings from this study revealed the incremental lifelong nature of planning for the future. On the

one hand, findings from this study differentiated several stages to future planning. Mothers described

them as: fostering networks that supported the *adult... lives* of their sons and daughters with

disabilities and bolstered *independence*; *preparing for... moving on* and; *backing off ... and the*

changeover. Distinguishing these phases revealed the incremental and therefore longitudinal nature of

planning. Progression through these stages was timed in accordance with family life. On the other

hand, findings from this study indicated that the demarcation between pre-planning and planning, that

was implied in future planning literature, is actually arbitrary (Bowey & Mc Glaughlin, 2006; Grant,

1993; Haley & Perkins, 2004; Mansell & Wilson, 2010; Prosser, 1997; Weeks et al, 2009; Walker &

Walker, 1998). Past experiences in the networks that support sons and daughters with lifelong

disabilities influenced the networks that are envisaged for the future. Rather than deterring them from

planning as previous research had identified, their past experiences motivated these mothers

(Llewellyn, 2003; Stehlik, 2000). Their ideas about the future were perpetually being influenced by

their experiences in the networks that supported their sons and daughters with lifelong disabilities.

These findings confirm the revision of future planning to lifelong planning (Disability Policy & Research

Working Group, 2010).

This study confirmed that the emotional terrain traversed by future planning is indeed difficult. It described further aspects of planning and network development that were emotionally challenging and that have not been fully explored in the past. Mothers were repeatedly confronted by paradoxical situations in which they were required to make, and accept responsibility for, decisions about the care and support of their son or daughter with lifelong disabilities. Grant (1993) recognised the dilemmas faced by mothers when 'letting go' and Llewellyn (2003) described the paradoxical situation parents confronted when they anticipated planning for their sons and daughters with lifelong disabilities being supported by the services from which they had protected their son or daughter. However, repeated negotiations of paradoxical situations and the repeated process of 'letting go' have not to my knowledge previously been described.

This study extends the current understandings of the nature of future plans. Parental plans have been described as "key successor plans", "residential plans" and/ or "financial plans"' (Bigby, 1997). These plans are compatible with the networks that this study identified. The siblings who were central to these networks may be "key successors" and, "residential plans" and "financial plans" were incorporated into the networks that these mothers described (Bigby, 1997). However, the mothers in this study were concerned about *dumping the care* of their son or daughter with lifelong disabilities onto their siblings in what might be perceived to be a 'key successor' role. Findings from this study may be unveiling the networks into which current models of parental plans fit. This study revealed that networks of support vary. However, they incorporated features that included *the family*, *the circle*, the *services* and/ or the *good village*.

Future plans have been promoted for the purposes of ensuring sons and daughter with lifelong disabilities have a good life (Etmanski, 2000). The networks that were identified in this study will hold

the trajectory of the lives of sons and daughters with lifelong disabilities on course. However, the trajectory that they will hold will not necessarily follow a life plan that has been described and documented by parents. These networks will support siblings by reinforcing the independence of the person with lifelong disabilities and sharing responsibilities for their care and support. The networks will also ensure that decisions about son's and daughter's future lives are influenced by preferred *ways of thinking*. Parents invested in these networks. They did so to meet *the shortfall* in current and future resources. Fulfilling these functions will in turn hold the trajectory of the life of a son or daughter with lifelong disabilities on course.

11.5.3 Contribution to the design of future planning initiatives

This study also informed future planning processes. The planning approach that these mothers described was similar to the person centred, strengths based planning approaches used in the future planning initiatives described in Chapter Two (Etmanski, 2000; Klees, 1996; Hole, 2007). However, this study differentiated features of networks that supported an *adult ... life* from those that will support sons and daughters with disabilities when their parents are no longer able to. Future planning processes rolled these transitions together. Planning for the future of the sons and daughters with lifelong disabilities in this study involved assessing the capacity of son's and daughter's networks to hold their life trajectories on course. It then involved making plans to bolster its capacity through the addition of features specifically tailored to the existing network. These planning cycles were repeated, with the earlier cycles having an eye to the future through the fostering of *independence* in an *adult... life* and the later cycles focusing more keenly on nurturing the context that will secure the life course of a son or daughter with disabilities. Therefore considering future planning as a lifelong process is clearly pertinent (Disability Policy & Research Working Group, 2011). This lifelong process involves repeated, incremental planning cycles.

Future planning initiatives described in Chapter Two, support parents by providing them with information about the planning process; skilled facilitators to support the planning process; opportunities to meet with other families who are planning; supportive case managers; and funding for individualised programs (Bigby, Ozanne & Gordon, 2002; Carers NSW, 2007; Department of Communities, 2011; Department of Family and Community Services, Ageing, Disability and Home Care, 2012; Family Advocacy NSW, 2007; Mamre Association, 2007). The findings from this study uncovered specific issues that might be pertinent for future planning initiatives to address.

Future planning information could acknowledge the enactment of the inclusion of sons and daughters with lifelong disabilities in the network and that approaches to social inclusion vary (Clapton, 2009). Facilitators need to consider how the potential for conflict over *ways of thinking* might be acknowledged and addressed in these networks. Rather than reinforcing ideas about the cohesiveness of the 'tribe', workshops that bring families together might avoid excluding people with diverse views about social inclusion by acknowledging the diversity of approaches to social inclusion (Etmanski, 2000). Further, the broader Social Inclusion policy initiatives need to progress such that society is engaged effectively in supporting people with disabilities (Commonwealth of Australia, 2009).

This study revealed multiple features that were introduced to boost the independence of sons and daughters with lifelong disabilities and share responsibilities for their care and support. These networks were fostered in part for the purposes of supporting siblings into the future. Siblings have indicated that they would like to be involved in planning (Burke et al, 2012; Davys, Mitchell & Haigh, 2010; Grant, 1989; Greenberg et al., 1999; Heller & Arnold, 2010; Heller & Factor, 1991; Heller & Tamar, 2009; Krauss & Seltzer's, 1993). Findings from this study indicated that timing was contingent on balancing competing commitments of several family members. Future planning initiatives need to consider how to support this negotiation between mothers and other network members, particularly daughters.

This study also revealed that networks that support sons and daughters with lifelong disabilities were contingent on the resources that parents invested in them. Assets of time, money, expertise and social capital are not readily available to all families. Sons and daughters with disabilities who do not have families who are able to invest in these networks are clearly disadvantaged. Individualised funding packages address these differentials in part. Yet these funds rarely account for the substantial and ongoing work involved in planning and fostering these networks that the findings of this study uncovered. In fact, despite the availability of assistance in the planning process, assessing eligibility for individualised funding on the basis of a well drafted and sustainable plan discriminates in favour of families who are sufficiently resourced to produce these plans. Funding under the proposed National Disability Insurance Scheme (NDIS) will also be based on individual's plans. The NDIS acknowledges "the role of family, carers and other significant persons in the lives of people with disability" (Commonwealth of Australia, 2013, p.4). Further "the funding or provision of the support takes account of what it is reasonable to expect families, carers, informal networks and the community to provide" (Commonwealth of Australia, 2013, p.5).

This study advises and informs notions of reasonableness. By fostering these networks mothers indicated that it was not reasonable to typically expect one of their daughters to assume a key successor role into the future if that role was not supported by an effective network. Rather they were deliberately fostering networks that will ensure that what was expected was reasonable. Examining the experiences of mothers in their son's or daughter's networks revealed the on-going and significant work involved in *monitoring and advocating* with services, anticipating change and revising networks as circumstances change. As this *invisible* work has not been recognised in previous individualised funding rounds, it is not clear if it will be recognised in the proposed rules for the NDIS. Findings from this study also indicated that networks were contingent on the agreement of parents and their combined resources. Family law negotiations might attempt to establish the at least tacit agreement

of separating parents in relation to future plans for their sons and daughters with lifelong disabilities such that the networks that support these sons and daughters might progress.

Finally the findings from this study clearly revealed the complex situations that mothers repeatedly faced. Bigby et al (2002) described a model of case management that offered ongoing support which might be pertinent to these mothers. Fostering these networks required their *dogged determination* in persistently negotiating paradoxical situations. Having someone to assist in the process and acknowledge the paradoxical nature of these situations might prove helpful to them.

11.6   Future research directions

The study drew on the experiences of a very specific population. Further research is needed to ascertain the relevance of the findings to the broader population of people with lifelong disabilities and their families. For example, the influence of parental divorce and acrimony on the networks that support sons and daughters with disabilities warrant further investigation. Further research into the process of transition through this life phase is also needed. Investigations into the negotiation of the *changeover* between mothers and daughters would be one example of this. How do others grapple with the paradoxical situations that these women face when fostering the networks of their sons and daughters with disabilities? More needs to be understood about the post-parental phase and, the extent to which the trajectories that parents envisaged, and the networks that supported those trajectories were utilised. Approaches to case management that support families through transitions and turning points warrants further investigation. . In recognition of potential shifts in care provision under 'warm modern care' (Hoschhild, 2003), the views of fathers about networks that will support their sons and daughters with disabilities into the future and their experiences of fostering networks warrant further exploration. In relation to social inclusion, how future planning initiatives might address the negotiation of differences of opinion about social inclusion in the networks needs further attention. Finally, more needs to be understood about the influences of family's varying social

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circumstances on their ideas conceptualisations of networks that will support sons and daughters with disabilities into the future and their capacity to foster them. In particular, the implications of differences in family's capacity to invest in these networks needs to be considered to avoid perpetuating social injustices. In essence further research should ascertain how *society* might support people with disabilities throughout their lives to avoid situations arising in which it is perceived that "the arm of any brother, sister or relative" needs to be twisted to take over their care.

11.7 Concluding remarks

Delving into and uncovering the rich vein of mothers' *hidden* experience proved informative. It revealed that public concern about the support for people with lifelong disabilities who are facing the death or incapacity of the family members who care for them was justified. Identifying who will look after a son or daughter with lifelong disabilities is clearly complex. It is complex because it requires difficult conversations about the inclusion of people with lifelong disabilities, the sharing of care and support and the realisation of returns on investment. It is also complex because it relies on the *dogged determination* of mothers throughout the lives of their sons and daughters with disabilities and particularly when facing the paradoxical situations in which they are repeatedly placed. Nevertheless, this study revealed that by fostering these networks mothers engaged their sons and daughters with lifelong disabilities and *society* to take greater *responsibility* and ultimately to assume aspects of parents' responsibilities into the future. The findings from this study indicated future directions in social policy, future planning initiatives and further research.

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Appendix 1

University of Sydney Human Research Ethics Committee Approval

The University of Sydney

NSW 2006 Australia

Human Research Ethics Committee
www.usyd.edu.au/ethics/human
Senior Ethics Officer:
Gail Briody
Telephone: (02) 9351 4811
Facsimile: (02) 9351 6706
Email: gbriody@usyd.edu.au
Rooms L4.14 & L4.13 Main Quadrangle A14

Human Secretariat
Telephone: (02) 9036 9309
                (02) 9036 9308
Facsimile: (02) 9036 9310

16 February 2007

Professor T Parmenter
Centre for Developmental Disability Studies
PO Box 6
RYDE NSW 1680

COPY

Dear Professor Parmenter

Thank you for Michelle Donelly's correspondence received on **6 February 2007** addressing comments made to you by the Human Research Ethics Committee (HREC). After considering the additional information, the Executive Committee at its meeting on **15 February 2007** approved your protocol entitled *"Moving beyond crisis management: Creating a future for people with disabilities living with ageing parents"*

Details of the approval are as follows:

Ref No.:   *02-2007/9680*
Approval Period: *February 2007 to February 2008*
Authorised Personnel: *Professor T R Parmenter*
                             Associate Professor R J Stancliffe
                             Dr M Knox
                             Dr M Donelly

The HREC is a fully constituted Ethics Committee in accordance with the *National Statement on Ethical Conduct in Research Involving Humans-June 1999* under *Section 2.6.*

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.

Special Condition of Approval
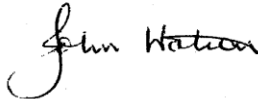
A copy of the certified translations or Statutory Declarations should be provided when the document/s are translated into different languages.

Chief Investigator / Supervisor's responsibilities to ensure that:

(1)   All serious and unexpected adverse events are to be reported to the HREC as soon as possible.

(2)   All unforeseen events that might affect continued ethical acceptability of the project are to be reported to the HREC as soon as possible.

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(3)   The HREC must be notified of any changes to the protocol. All changes must be approved by the HREC before continuation of the research project. These include:-

- If there are any changes to investigators (e.g. Leaving the University)
- Any changes to the Participant Information Statement and/or Consent Form.

(4)   All research participants are to be provided with a Participant Information Statement and Consent Form, unless otherwise agreed by the Committee. The Participant Information Statement 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 and the following statement must appear on the bottom of the Participant Information Statement. *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@usyd.edu.au (Email).*

(5)   The HREC approval is valid for four (4) years from the Approval Period stated in this letter. Investigators are requested to submit a progress report annually.

(6)   A report and a copy of any published material should be provided at the completion of the Project.

Yours sincerely

John Watson

Associate Professor J D Watson
Chairman
Human Research Ethics Committee

cc   Dr Michelle Donelly, School of Occupation and Leisure Sciences, Faculty of Health Sciences, Cumberland Campus – C42, The University of Sydney

Encl.
        Participant Information Statement
        Family/Community Member Information Statement
        Guardian/Person Responsible Information Statement

Appendix 2

Family/ Community Member Information Sheet
Participant Consent Form

The University of Sydney

Centre for Developmental Disability Studies

59 Charles Street, Ryde
NSW 2112 AUSTRALIA

PO Box 6
Ryde NSW 1680
AUSTRALIA

Telephone: +61 2 9808 0500

PARTICIPANT CONSENT FORM

Networks of Support

1. I, ... of ....

    ....…......................,

    agree to take part in a research study called- Networks of Support which has been described in the Information Statement attached to this form.

2. I have read the Information Statement or someone has read it to me. The information statement explains that the research is about the people who I know, how I got to know them and what they mean to me. I understand that I will be telling the researchers about these things and that they will meet with me at my home, at my work and other places where I regularly spend time. This was also explained to me and all of my questions answered.

3. They have also explained to me if there is any way I could get hurt by agreeing to meet and talk with them.

4. I understand that I can stop meeting or talking with the researchers, at any time and nothing will happen to me or anyone I know because I decided not to continue.

5.   I agree that information I and others provide, may be published, provided that I cannot be identified and that my name and address are kept secret.

6.   I understand that if I have any questions about the interviews or visits or anything about this research, I may contact Trevor Parmenter on telephone 02-8878 0500 who will be happy to answer them.

7.   I have been given a copy of this Consent Form and the Information Statement.

....

Signature   Signature of Witness

....

Please PRINT name   Please PRINT name

....

Date   Nature of Witness

The University of Sydney

Centre for Developmental Disability Studies

59 Charles Street, Ryde
NSW 2112 AUSTRALIA

PO Box 6
Ryde NSW 1680
AUSTRALIA

Telephone: +61 2 9808 0500

PARTICIPANT INFORMATION STATEMENT

Networks of Support

You are asked to take part in a research study called **Networks of Support.** This research will look at the personal networks of a group of people with disabilities and their families. We are interested to find out about the people you know who are important to you. We are interested to know about the people in your life, how you got to know them and what they mean to you.

The research is being done by **Trevor Parmenter, Roger Stancliffe, Marie Knox, Louise Whitaker, Anne Hillman and Michelle Donelly**. Trevor is from the *Centre for Developmental Disability Studies*, a non-profit research centre that is associated with the College of Health Sciences, the University of Sydney. He may be contacted on 02-8878 0500. Michelle, Anne, Louise and Roger are also from the University of Sydney, they can be contacted on 02-9351 9208. Marie is from the Queensland University of Technology. She can be contacted on (07) 3138 4614. This research is supported by a grant from the Australian Research Council.

To find out about the people that you know, who are important to you, we would like to meet with you from time to time and speak with you. We would like to meet you a few times, in each of the places where you spend most of your time and spend some time there with you. We would also like to have a conversation with you for about one hour each time. Altogether, we would like to meet up with you about six times spread out once every two or three months.

If you agree we would also like to make an audiotape of our conversation. This will help us to remember everything that you have said. You don't have to agree to taping if you don't want that and you can ask that the tape be turned off at any time. We will keep all the information you tell us and the information on the audiotape secret.

There is no payment to you for taking part in the research.

All information collected as part of the research will be kept private and confidential. Information will be stored at the *Faculty of Health Sciences, in the University of Sydney* in lockable filing cabinets and/or in files on password protected computers housed in locked offices. Only people working with us on this research will see the information, except as required by law. They will write reports about the research but will not mention anyone's name or where they live. All the information that has anyone's name on it will be destroyed when the research is over.

A report about the research and the findings will be written and sent to you and your family. Other reports might be published in journals or books or presented at conferences. None of these reports will mention anyone's name or where they live.

Being part of this research is entirely *voluntary*. That means you can decide if you want to join in or not. If you do join in you can stop at any time. Choosing to join in or not to join in, or deciding to stop will not affect anything that happens to you. If you stop being part of the research you can ask to have any information about you destroyed (e.g., audiotapes destroyed) if you wish.

If you want to be part of the research about your support networks, you need to sign the consent form or have a form signed by a guardian or person responsible (such as a close family member) if you cannot consent for yourself.

If you have any questions about the research now or at any time you can contact Trevor Parmenter on **02-8878 0500**. This information sheet is for you to keep.

Any person with concerns or complaints about the conduct of a research study can contact the Senior Ethics Officer, Ethics Administration, University of Sydney on (02) 9351 4811 (Telephone); (02) 9351 6706 (Facsimile) or gbriody@usyd.edu.au (Email).

Appendix 3

Excerpt from a transcript of an interview demonstrating the analytic process.

Interview at the home of the mother and father of F. The interview was conducted over afternoon tea. FF, FM and I are sitting around the dining room table.

Prior to the interview there had been several telephone discussions with FM. She had suggested that she would be happy to be involved in the study and she would find it helpful if the interviewer asked her questions. As such, I made some attempts to guide the interview. Prior to turning on the recorder I had provider an overview of the research project.

I   Now that's recording so we can just leave that. (Interviewer sits the reorder to one side of the table MF and FF are signing the permission form as the interviewer turns on the recorder) Printed my name if you want to print your

FF   Here

FM   Here I think darling.

FM   Yes well I think that's it's absolutely vital to have support. Even on yesterday F typed out what's going to happen to me when Mum and dad die.

I   Really

FM   And um we I think that is probably the fear that it is utmost in every parent's mind and obviously also in the people with the disability

I   And how often does he refer to that?

FM   Well this isn't the first time. He will mainly refer to it if he has a facilitator with whom he is absolutely relaxed and he's. IT's this one particular facilitator who has known him now for number of years, is on his circle of support, initial circle of support and with whom he ah an absolute

FF   Now is that alright? – (handing the form back to me).

I   Thanks I can make a copy.

FF   Is this your pen was it?

I   Yeh

FM   He has absolute complete trust in her. So I don't think he would say it to a lot of people but he's expressed it on a least three occasions.

FF   Yeh. Where did he get that from? Did he work that out himself or has overheard someone saying that we're on our last legs?

FM   Oh I think it's. Look he is aware. I mean historically he would be aware without us. I mean we're hopeful what we've set up will give him some, fragile element of support. I'm not totally confident of the level of support that will sustain but without us he was extremely vulnerable. I mean very very much at risk. So I think life has shown him that without us, or without some very very strong areas of support we've put in place, he hasn't much hope of survival really. Or the form of survival is not something that would be desirable. I meant that's historically what he's seen really isn't it?

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Comment [I1]: Phase 1 – This an example of an opening story

Comment [I2]: Phase 1 - His mother insists on restating her position about her son's concerns for his future support.

I   What have you put in place?

FM   Right. Well what we've put in place with the will we've tried to set up a financial situation. Which this was ...

…Discussion continued …

I   That sounds incredibly complex.

FM   It's all very complex.

FF   Mm

Fm   Sadly, sadly I don't have any faith in it.

I   Don't you?

FM   I mean I'm amused when people say things to me like the universe will take care of it. I mean I wish that were true and maybe it will and maybe those people have sufficient trust and something more but what we saw was any time we didn't aggressively set up some sort of support for F it let us down. I mean we did yes naively as young people we did believe that people did the right thing. We thought he was safe and we thought that he was. When he was with the department that the fact we were bringing him home fortnightly ringing daily in some instances, popping in on him and we were on a committee which provided a house for him, we couldn't, where it fell down, and this is what we've since taken charge of. The physical environment is one thing but we had no say at that stage over the personnel involved and we realise that's what made it extremely vulnerable. The people in the environment, which .. so we naively believed when we were young, that the, the what we'd put in place at that time would protect home and help him. That he would be safe. And then of course when we found him abused we realised these things just don't happen and you can't put your trust totally. I mean you have to hope that people, and there are many wonderful people, but you need layers of checks and balances put in place.

I   It's a sad lesson really isn't it

FM   Well it, it shocked us. We naively honestly believed in the good of, intrinsic good, of mankind at the stage.

I   As we all do

FM   Yes. We all hope to. Unless you be had some shocking experiences younger and we probably didn't really. And see the people who actually did abuse him were the people who were coming in here and accepting hospitality. So ..

I   Oh dear

FM   So it made. It shocked us to the level where it affected both of our health but of course it also shocked F. And I can remember at one stage after we did bring him home, we had a man in the house here while we were here. You know we'd be going about our things and he'd be you know involved with F and then one day we went to take him into this person's place and we were staying at A and we

said now F we're going to be away for an hour or so and F said but he'll hit you with a big stick. Because although he was safe here, he realised mum and dad aren't going to be watching therefore this man will now take the opportunity to bash me if they're not watching. So ..

I   And he did?

FM   Well he didn't. That one didn't. But Fs lesson that he had learnt from before with people being in the house. You know the visitors, the carers used to visit with them, well they didn't bash him while they were here with us, but of course, when they got him away they did. So he assumed that this is what people did once parents took their eye off them. So it's been a huge battle to get him to feel any level of trust and of course he's only got a level of trust after we've established through along tedious procedures. So yes, we, we now know that you need to have many layers of safety. So one XXX hopefully with the will we will have some funds going into the special needs trust and some into the disability. The disability one at the moment is so narrow that it will only allow for actual direct care. So I mean that means if he needs medical or any other emergency, it's not provided. So there, you know, some will go to a special needs. And as I said we have our daughter's son and one other person as trustee at the moment and they must consult with the circle of friends which we've set up.

I   Where did the expertise come from to help you set that up? Was that easy to find? Or did you work it out yourselves?

 … Discussion continued …

FM   It was actually called. It was XXX.. and what we did was we realised the environment was certainly.. People were all just plonked in. I mean F there was some situations where the environment drove them frantic you know and those people. No one ever paid attention to compatibility. It was simply a bed is there. These men F was in with the only one things they had in common was that they were all regarded as , what wording do they use?, I can't remember all those negative words, what were they called? "challenging"

I   Yes

FM   Extremely challenging. They put them all in together. So they put X extremely challenging people in one house.

I   In one house

FM   In one house, yes. and so what we did do, like any. We had a bedroom for each of them, because prior to that they weren't and a couple of sitting rooms.   They could be separated and big yard. So there was some areas to get away from each other. But ah

I   Was he in XXX prior to that? Was that "XXX".

FM   Yes he was, he went into XX originally.

I   Right

Fm   and then moved into the XX system from there. Yes so that's how that happened, but um. Well I've lost track of where we were then. Yes well when we realised that. We had a XXX enquiry and the enquiry found that ah, well it didn't find anything really did it. One of their suggestions was that this poor elderly gentleman who was the most fragile in the entire group of the five (5) men probably was the perpetrator.

I   Wow. Did that make sense?

FM   No of course not.

FF   No

FM   This man had trouble standing on his sticks. This would have been the story given to them by the people who were the perpetrators.

I   Goodness me

… Discussion continued …

FM   yes that's right even since institutional reform there's a closed channel. Yes so where have we got to now? We've looked at the organisation.

I   There's the organisation .. and part of that came from saying what do you do with your week .. but it's fulltime. So are you both on the management committee?

FM   FF's not now. He was initially. But I mean, one person on is tons. One per family is really probably all we think we need.

F   But we're both on the circle of friends.

FM   We're both circle of friends. Both involved.

I   So tell me …

FM   OK, well the circle of friends was through XXX which was wonderful.   A talk by XXfrom XXX and it had always been something that seriously concerned us because just having a service is certainly not enough protection, not enough in a person's life. So XXX is our facilitator and we have, how many people have we got on that now love? XXX the facilitator, there's you and I and, um, there's

FF   XX,

FM   XX XXs parents

FF   XX

FM   XX, XX I think that's' all, um the number

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I		and are they friends of Fs?

FF		That's not bad but

FM		Actually how they all came about. It has fluctuated. There have been different people over the years. XX actually was an ex-student of mine which was amazing. She actually, ah, I don't know what she did exactly, but she did work for XX at one stage and, someone, XXX actually, I'd lost contact with her. XX called her in to do a little bit of coordinating at one stage when we were out of a coordinator and we found that we knew each other of course. She's no longer in XX. She's actually back at uni at the moment, but she came on the circle and has been on from its inception which is how many years? About 5 years I think? And she asked her parents to come on and XX worked for F for over 8 years and she is still employed but in a very minor capacity because she's got there (3) children now. But all throughout the whole 8 or so years she's demonstrated more than just a paid capacity. I mean she's been involved in probably every aspect of F's life. She's supported him the whole time. So that's .. now who else .. XX is, was colleague of mine. Now her four (4) children have, the last ones at uni now so, she's now got that little bit more time.

I		Is that the group?

FM		That's probably it at the moment yes. .. but ah ...

I		and do you meet, have a barbecue once a month?

FM		Once a month, no no that's a different thing

I		That's a different one .. ah ah

FF		That's a different one again

FM		Yes once a month the circles meet. Now initially we had to meet here all the time because we did attempt to take some of the people to F's and he initially nearly collapsed, you know, the trauma of having people there. But then eventually we managed to get introduce him to them, tell him what their purpose was, he kept seeing or hearing of the same people and realising that they weren't going to vanish over night or whatever terrible thing he thought. So now we've got him to the point of where every second meeting we have at Fs house. And the ones we have at Fs house people bring. They all bring a dish or something like that and the ones at Fs are all just joyous sharing of food and he's typed out things like. The circle is great, thank you for coming, I really appreciate it. You know, what else did he say? Although he's really started to get a very positive image of it.

I		Ah ha

FM		And there's , what was that? People from the circle are now, I mean previously they couldn't do it, but they are now able to pop in. And his confident to have them calling. And one of the reasons I wanted that to happen of course is it's also a safe guard and I wanted him to, him to feel confident. They don't announce their coming, so the staff. If there were. I mean we're checking staff all the time. But I mean if we're not around you can't. So the staff can't be setting up an environment that's artificial. So XX when she's not at uni, I mean she came Wednesday, she's coming tomorrow. She can facilitate with F too. She did come every week but she hasn't come quite as much with uni. XXXpops in

or rings. XXX she was there today. She picks up his library books. See Fs still agoraphobic as a result of the posttraumatic stress. And she brings back the library books. She brings ..

FF   DVDs

FM   The , what's that darling?

FF   Music, DVDs

FM   Yes she brings music, DVDs. And she brings seedlings over for the garden and encourages him to have his vege garden and so forth. And XXX he's, what is he a cabinetmaker perhaps?

FF   Mm

Fm   He's made frames for Fs paintings and so. And XX, she's only just come on the circle but she popped over one day with her two (2) little dogs to see F. SO they're starting the popping in on a regular basis.

I   How long has that taken? If you've had a circle of support?

FM   How long did it take to even get to Fs? Well when we first tried it, it was (deep sigh) .. exhausting. He just wasn't, oh dear, it took, I'd say we wouldn't have been going to Fs for any more than two (2) years. It probably took three (3) years before he

I   Mentioning names ..

FM   Yes consistently, talking about these people, photographs of them and then starting to introduce them. It probably took three (3) years before we got any headway at all. So hopefully we can keep the circle going/ The circle are totally aware of well, what we've set up in the will, what the memorandum of wishes. They know Fs history, so they know the vulnerability. They know his abilities. They know his dreams. So they're well versed in .. They know it probably nearly as well as we do. I mean not quite

I   And what is it about them that gives you confidence in the fact that you can hand over the resin if you like in the future?

FM   Well part of it is the consistency with which they, particularly say XX and Xx who've been there the whole time. They've probably demonstrated that they're not going to walk away. I mean, they've all had some pretty big glitches with him. I mean F isn't coping with children which is something we have to address very much. And actually happened at the last barbecue. We'll have to be trying to address Monday or start to address. But we don't know if it's the unpredictability of children, the noise, the unpredictable movements or the fact that these children are children of the people that have devoted time to him, but XX brought her little girl on Saturday and as she walked past F gave her smack. She didn't cry so it couldn't have been hard, but, it's still a concern and he was traumatised. He spent all the next day, sick and he's typed out. I've got what he's typed there, if you're interested.

I   Mm

FM   But he doesn't want to do it. He feels himself getting stressed but it's one action we need to look at. But XX just, as I was saying now why we trust XX, what XX did was she removed the little girl. Took her out, gave her to someone else to mind and when the little girl was happy. Thought she didn't cry. She just said "f hit me", sort of what's this about. XX came back and she said oh F I shouldn't' have put you in that spot in. I want you know I love you, I'll be back Monday, you know., she's' demonstrated that she understands and she's not judgemental and going to punish him for that sort of thing and XX They've both consistently. As I said they've been coming to the circle for 5 years visiting F. No matter what. I mean they've had babies, illnesses, all sorts of things and they've still kept coming and they do understand. F calls them my trusted friends. He'll sing a song when he sees them coming "my trusted friends, my trusted friends" He uses often a song to demonstrate something deep. I mean he can type really eloquently and express his feelings then. But verbally he can't. So often he has to use a phrase or a song of something. But those two (2) he totally trusts. I mean they're all lovely or our generation thought it's more the younger ones. We hope we can get more. Yes continuity is the big thing. Sustainability, continuity. Life for everyone has its ups and downs

I   Yes and how many staff are there?

Fm   How many have we got? XXX, XXX, who comes on after that, XXX, XXX, XXX but XXX leaves for holidays, very long holiday very soon. I must tell him not tell F today, XXX, XXX. At the moment we've got six (6). XXX, will be going, we've got to replace.

FF   There's a new one coming in too isn't there.

FM   We hope to. I've got to ring him back today to see if he did. He met F Tuesday. We like to ring back to see that there's a mutual. Yes so

I   And who. How does the recruitment happen? ... IS it through the organisation?

Fm   It is partly. Probably some of the most effective is through contacts is through contacts isn't it love?

FF   Mm

FM   Probably the most effective. XXXcame via her brother and XXX through another friend and this gentleman we saw Tuesday is our daughters' friend. XXX do advertise. It's somehow harder, often when you're getting someone unknown. I mean we do like people we've known. We don't specifically, we probably don't like so much people trained by other people.

I   Ah ah

….

… Discussion continued ….

FF   It's like the guy on Bondi beach.   It's like he had this machete. What could we do? We had to shoot.

FM   Why do you have to kill? It's so cowardly .. (further discussion about police response, women in the police force, physical nature of police work)

FM brings it back into track ...

FM   Now where have we gotten too. We've looked at organisations. We've looked at circles.

I   We have. We have.

FM   But that doesn't provide the whole lot.

I   No

FM   So as well as that we're trying to get his monthly barbecues. The purpose of that is well maybe from that eventually well maybe we might get people who will be able to join the circle.

I   OK. So it's' the build a bigger circle potentially?

Fm   Yes it's another layer. Really introduce people to F. People we think may be supportive, maybe interested. And we're rotating the groups every month trying to get people. I mean last Saturday didn't work at all. (laughs)

I   Ah ah

Fm   You know we've had so have been very successful and some that haven't, but the main thing is not to give up. You need to look at the mix of people and. Well the purpose of that is so that he has people who visit. Because he won't go out, we 're then needing more people to come in and hopefully some of those people will pop in on him and form a relationship and then become part of the circle. So that's the barbecue group.

I   SO it that another role if you like that the two (2) of you play is

FF   Hosts at the barbecue

I   Host at the barbecue and always thinking ah maybe I could invite them to the barbecue?

FM   yes. I'm afraid we look at every as potential

I   everyone s with potential barbecue eyes?

Fm   yes

I   Is that yes. So constantly think oh I wonder what F would think f them?

Fm   Yes. Constantly and what they think of F and whether they're open to a relationship yes yes that's very true. So there's the services, the circle, then there shits social network (FM is drawing widening circles with her hands.

I   and is that how you see it? In circles? Going out, like concentric circles

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Fm   Possibly yes. Possible I suppose so. I suppose we do really but we're hoping that they don't all stay in those rigid circles. I mean for one thing we're hoping that for one thing we feel that when we physically no longer be on the management committee, someone from the next circle who has a good knowledge of F form the circle of friends. They they will be. Someone will take the position there. Hopefully rotate around. SO yes we're hoping that the circles will move in and inward manner and the people from the barbecue circle we're hoping that some will become potential either if not circle of friends, visitors. Someone F can call upon as a friend or someone who'll pop kin. Actually we've got one delightful new young lady. She called yesterday to see F. She actually was supporting F, wonderful personality. She's a social worker. At uni as a social worker. She's very young thought. She just turned 21. When I put her on. OH wonderful potential but very young and I was thinking oh I don't; know. Anyway, they got along famously but F, and this apparently is part of a movement disorder, that they' not always aware of their extremities and so on