UNFULFILLED EXPECTATIONS:

A FAMILY PERSPECTIVE ON

TRANSITION TO ADULT LIFE FOR YOUNG PEOPLE WITH

COMPLEX DISABILITIES

Pauline Ruth Penney

A dissertation submitted to

Auckland University of Technology

in partial fulfilment of the requirements for the

Masters in Health Science (MHSc)

2007

School of Health Care Practice

Primary Supervisor: Dr Antoinette McCallin

Acknowledgements

This dissertation was conducted under the academic supervision of

Dr Antoinette McCallin
Head of Research
School of Health Care Practice
Faculty of Health and Environmental Sciences
Auckland University of Technology

Her unfailing support, knowledge and sense of humour have seen me grow through the highs and lows that accompany any research project. I gratefully acknowledge her patience and wisdom.

I am also grateful to the following people for their support and assistance over the past year:
- The focus group participants who freely gave their time and shared their experiences.
- The Rotary Club of Takapuna, the Wilson Trust and Wilson School for their financial sponsorship of the research.
- The intermediaries who undertook to contact participants in their own time, and provided encouragement for the research.
- Jan Moss from the Complex Carers group for her wisdom and support.
- My wonderful family – Michael, Corey, David and Dylan for support, encouragement and patience.

Ethics approval for this research was granted by the Auckland University of Technology Ethics Committee (approval number 07/08) on 2nd April, 2007.

Abstract

The concept of a transition phase from childhood to adult life is a well-recognised stage in human development. However, young people with complex disabilities experience this transition differently from other young people. Little is known about what impact these experiences have on the life of the family supporting the young person or the young person themselves.

This small qualitative research study explores the recurring issues that affect families of young people with complex disabilities and the young people themselves as they transition to adult life. The study focuses on the family perspective of the transition period. The research draws on descriptive data generated from two focus group interviews. Seven parents of young people with complex disabilities participated in the focus groups. Data was analysed using constant comparative analysis. The overall perspective was social constructivism.

Three themes emerged from the data analysis. These include service mismanagement, caretaking tensions and perpetual childhood management. The over-arching concept within which these themes rest is *parental loss.* Research findings suggest that the transition period for these parents is a highly stressful time, when services and funding are lost, yet the needs of the young people are not decreasing. Parents' influence is diminished, as society perceives the young person as an autonomous adult, however this is not parental reality as families must continue to care for a young person with the cognitive ability of a child.

This research highlights the need for young people with complex disabilities to be recognised as having differing needs from others with less severe disabilities. To address this, policy and funding discrepancies would need to be considered at a governmental level. At a local level, service agency recognition of the ongoing role of parents, and a continuation of the family-centred model of care would assist parents with the daily challenges and losses they experience as their young people transition.

Table of Contents

Appendices

    Appendix One   Participant Information Sheet

    Appendix Two   Ethics Committee Approval letter

    Appendix Three   Consent Form

    Appendix Four   Confidentiality Agreement

    Appendix Five   Question Guide

    Appendix Six   Data Analysis- examples of initial coding

    Appendix Seven   Research Journal Excerpts

Chapter 1: Introduction

This dissertation reports on a qualitative study that explores the family perspective of transition to adult life for young people with complex disabilities. The perception of transition as a change or passage from one life stage to another is well recognised by society (Hanline, 2006; Sheehy, 1996). Yet in many ways, transition remains a vague concept. Understandings are both cultural and social. The concept of a transition phase from childhood to adult life has been present in a variety of forms since ancient times. Indigenous races often marked the period with initiation rites and demonstrations of skill and competence. In recent times, coming of age rituals in the New Zealand setting such as the 'key to the door' celebrations at age 21 have informally marked the transition to adulthood. Currently, a combination of young people tending to remain at school longer, along with the ability to vote and drink at age 18, appear to have lowered the age commonly perceived as transitioning to adulthood to 18 years. The research literature supports this view of adulthood, commonly relating transition to adult life in terms of leaving school or stopping being a student (Alwell & Cobb, 2006a; Halpern, 1994).

In this first chapter the background literature about transition is presented. The national context of disability issues, the position of the family in the research, the research problem, aim and significance are clarified. A short discussion on the researcher's own interest and assumptions is outlined. The chapter concludes by defining specific terms used during the research and outlining the structure of the dissertation.

Background to the Research

Transition issues for young people with complex disabilities have been well documented in the literature over the last two decades with recent meta analyses and literature reviews focusing on identifying transition models that improve outcomes for young people with moderate disabilities (Alwell & Cobb, 2006a; Blum, Hirsch, Kastner & Quint, 2002; King, Baldwin, Currie & Evans, 2005; Social Care Institute for Excellence, 2005). While this evidence is valuable, the literature remains sparse on detailing what happens to those young people with more complex disabilities, and identifying the ways their families cope with the young people's transition from school to adult life.

While the milestone of leaving school is significant, in reality moving on from education forms only one part of the transition to adulthood. Transition is multifaceted (Hudson, 2006) and one can view it from two different perspectives – the transition *from* childhood compared with the transition *to* adulthood. Leaving, or transitioning from childhood is particularly significant for young people with complex disabilities and their families, as most of the specialised services that have been available to them during childhood are left behind when they leave school.

Services that the young people with complex disabilities transition away from may include: Specialised educational services, free developmental therapies, (physiotherapy, occupational therapy, speech therapy), teacher aides and family support services such as psychologists, counselling and respite services. Health care systems are also specialised for children with complex disabilities, with expert

medical and surgical care available if required through paediatricians, paediatric neurologists, orthopaedic surgeons and psychologists. These professionals are often involved with the child and their family on a regular basis from birth through to when the child leaves school. They develop relationships with the families and provide a valuable framework of support, which is left behind when the young person leaves school.

Conversely, the other way of viewing the transition period involves focusing on what the young people with complex disabilities are moving towards – adult lives. Transitioning *to* adulthood means moving away from those established paediatric health, educational and social systems and entering the adult health and social systems. In the health care environment, this means moving to doctors who may have little knowledge of the young person's specific disabilities. It also means moving away from family-centred care (Casey, 1988; Dickinson, Smythe & Spence, 2006; Shelton & Stepanek, 1995), which is the basis of paediatric health care, into individualised treatment, with little regard for the needs of the families supporting the disabled young people. This shift in philosophy of care has huge implications for the family of these young people, who often feel sidelined by the health and social systems after years of previous full involvement (Blum et al., 2002; Social Care Institute for Excellence, 2005).

In the social environment, transitioning *to* adult life for young people with complex disabilities represents a moving away from the established routines, structure and behavioural expectations of school into an unexplored world where the expectations and rules are unclear. The expectations are equally vague for the

families of these young people during this time. While the young person has been at school, families fitted into the societal norm of parents supporting children at school. Once their young person leaves school however, these parents can feel different from other parents. This is usually a time of life when, in the normal course of events, parents reduce the amount of support they give their offspring, as their able-bodied young people move onto work, vocational training or university. In contrast, parents of disabled young people with complex disabilities continue their parenting role. Their young people are not able to move onto these 'normal' adult activities, due to the complex nature of their disabilities. The young people are left in a void (Morris, 1999) with few services available to fill their lives. Their parents often report a lack of understanding from society that their parenting job does not ease with their child leaving school (Wong & Wong, 2003). This societal pressure, combined with the removal of the families' established support links of educational and health professionals, makes for a very challenging time of life for young disabled people with complex disabilities and their families in the New Zealand setting.

National Context of Disability Issues

Disability is a relatively common concept in New Zealand society. Disabled New Zealanders are a diverse group, representing all sectors of society and people with all forms of impairments - physical, intellectual, neurological, psychiatric and sensory. In the 2001 census, 20% of New Zealanders (743,800 people), reported some level of disability. This included an estimated 626,500 adults, 90,000 children living in households, and 27,300 people living in residential facilities (Office for

Disability Issues, 2005). It is difficult to compare these figures to international statistics as countries vary depending on the indicators of disability. However, a recent World Health Organization report (2004), which calculated prevalence of severe levels of disability and dependency, placed New Zealand midway amongst established market economies for disability prevalence.

The significance of the large numbers of New Zealanders living with a disability is recognised politically via a strong legislative framework; a government department devoted to disability issues (The Office for Disability Issues); and a Minister for Disability Issues representing the rights of disabled New Zealanders. New Zealand is also involved in disability issues internationally, chairing a United Nations Disability Committee. This committee is currently developing a binding international convention to protect the rights of disabled people, with New Zealand representatives taking a lead role in the negotiation process.

Internationally, New Zealand has won strong praise for its promotion of disability legislation that reaches into every government department and which ensures disability issues are considered within any new government initiative (Quinn & Degener, 2000). The legislation that is creating the most international interest is The New Zealand Disability Strategy (2001). This powerful document presents a long-term plan for changing New Zealand from a disabling to an inclusive society. Underpinning the New Zealand Disability Strategy is a vision of a fully inclusive society where people with impairments can say they live in: 'A society that highly values our lives and continually enhances our full participation' (New Zealand

Disability Strategy, 2001, p. 1). To achieve this vision, fifteen objectives form the

basis of the Disability Strategy:

    Objective 1: Encourage and educate for a non-disabling society

    Objective 2: Ensure rights for disabled people

    Objective 3: Provide the best education for disabled people

    Objective 4: Provide opportunities in employment and economic development
        for disabled people

    Objective 5: Foster leadership by disabled people

    Objective 6: Foster an aware and responsive public service

    Objective 7: Create long-term support systems centred on the individual

    Objective 8: Support quality living in the community for disabled people

    Objective 9: Support lifestyle choices, recreation and culture for disabled
        people

    Objective 10: Collect and use relevant information about disabled people and
        disability issues

    Objective 11: Promote participation of disabled Maori

    Objective 12: Promote participation of disabled Pacific peoples

    Objective 13: Enable disabled children and youth to lead full and active lives

    Objective 14: Promote participation of disabled women in order to improve
        their quality of life

    Objective 15: Value families, whanau and people providing ongoing support

All New Zealand government Ministries and Departments must actively work

towards achieving the objectives of the Disability Strategy, with each Government

Department having to produce an annual report on progress made towards full

implementation of the Disability Strategies' objectives in their area. The Minister for Disability Issues summarises these reports in an annual report to the House of Representatives (Office for Disability Issues, 2006) as required by section 8 of the New Zealand Public Health and Disability Act (2000).

The progress reports of the Ministries of Social Development, Education and Health have particular relevance for this research project as these are the agencies that directly impact on disability funding and policies. In the latest report (Office for Disability Issues, 2006) the Ministry of Education highlighted that it was working alongside other government departments on facilitating youth transitions from school. Their identified focus is on ensuring that young people, including disabled youth, are engaged in education, training, work or other options leading to economic independence. While a laudable aim, this goal does not reflect the realities of young people with complex disabilities, many of whom cannot talk or perform activities of daily living without assistance and for whom the idea of employment and economic independence is far fetched.

The Ministry of Health's latest progress report (Office for Disability Issues, 2006) stated that it was providing more support to enable disabled people to live as others do in their homes and communities. This may flow through to individuals with complex disabilities via increased access to health care and support services. Meanwhile the Ministry of Social Development is leading an inter-agency review of long-term disability support services, aimed at ensuring these services improve outcomes for disabled people and their families, are easier to access, and more

co-ordinated. The Ministry for Social Development also states they are reviewing options for improving support for family caregivers of disabled people (Office for Disability Issues, 2006). The outcomes of these reviews could have a marked impact on young people with disabilities and their families.

While at a national level these reports indicate that disability policies are being implemented and internationally, New Zealand is increasingly respected for its legislative framework, the actual 'grass roots' delivery of service to the local disability area remains problematic. There is a history of disjointed approaches to delivering disability support, with complicated access to services, gaps and overlaps in provision, and significant inequities. Many of the services lack flexibility to respond to differing needs and can create disincentives to participate and be independent (Office for Disability Issues, 2006).

This disjointed service approach is particularly evident in the area of transition from school to adult life. Three government departments – the Ministry of Education, Ministry of Health and the Ministry of Social Development, support transition issues, with the overarching New Zealand Disability Strategy (2001) providing general policy guidelines. This multi-agency crossover is problematic in that transition issues are 'everyone's distant relative', leading to discontinuity of services (Hudson, 2006).

The Office for Disability Issues, developed and run by the Ministry of Social Development, is attempting to address the difficulties inherent in multi-agency service provision. The Office for Disability Issues provides a channel for the

disability sector to raise issues with government and has a leadership role in co-coordinating government agencies, and liaising between agencies and the disability sector (Office for Disability Issues, 2005).

One of the agencies that the Office for Disability Issues liaises with closely is the Disability Services Directorate in the Ministry of Health. The Disability Services Directorate is responsible for the planning and funding of disability support services and provides policy advice to the Minister of Health. Recent discussions between the Disability Services Directorate and families caring for those with disabilities led to the formation of the Complex Carers Group, a national support and advocacy group representing the family members and carers of people with complex disabilities.

The Complex Carers Group undertook a pilot study (Bray, Moss, Forrester & McConnochie, 2005) examining the realities of families caring for children and young people with complex disabilities, using a social model of health perspective. The study identified inadequate levels of service provision and co-ordination, a lack of services for young disabled people leaving school and the need for further development of services for out-of home care for those with complex needs. Another important finding was the identification of high levels of stress amongst families caring for disabled young people and a lack of support (both practical and informative) available to families.

Bray et al. (2005) also highlighted a lack of local knowledge of what happens to young disabled people when they transition from school. As this pilot study

represents relevant and recent local disability research, I have drawn on its findings to refine the direction for this research. I approached the Complex Carers Group to discuss their findings and they indicated that research on how families of young people with complex disabilities, and the young people themselves, experience the transition to adult life would be of value to their group and to the local disabled population.

The Position of the Family in the Research

This is a study about families – families who have a young person with a complex disability. The challenges, thoughts and feelings experienced by family members as their young person transitions to adulthood are explored through focus group discussions. The young people themselves remain an important part of the study, however the complex and severe nature of their disabilities means that they are mostly unable to express themselves verbally and hence could not actively participate in the research. Local data (Bray et al, 2005) documents the range of complex disabilities experienced by this population. Most have multiple disabilities with the most common being communication (83%), intellectual (74%), and physical (64%) impairments. This means that the majority of these young people cannot talk, with some having no means of even giving an accurate yes or no response. Most cannot understand more than a simple phrase without the assistance of pictures or gestures.

Because of the young disabled people's difficulties in communicating and understanding, families have always represented the voice of this population and

hence will provide the data and the focus for this study. This is consistent with Wong and Wong (2003), who comments that parents are the key figures in the life-long rehabilitation of adults with complex disabilities, and continue to advocate on their behalf well beyond childhood. It is this advocacy and ongoing detailed knowledge of their young adult's wants and needs that allows family members to speak effectively for them in this research.

The Research Problem

As already stated, this is a study about a significant life transition affecting both young people and their parents. Transition issues began to appear in the literature in the late 1970's, when transition legislation came into effect in the United States (Halpern, 1994). Alwell and Cobb (2006a), in their review of the transition literature, identified that the focus of the studies to date has been on comparisons of differing models of transition; transitions in health care settings; or evaluations of transition programmes designed for less disabled young people. There is little information available on transition for those with complex disabilities and few studies that address family concerns and experiences during this period. In New Zealand, two works in the recent literature have addressed family issues in the area of complex disabilities (Bray et al., 2005; McCallin, Dickinson & Weston, 2007). These studies focused on the realities of caring for a child with complex disabilities and the issues of support and access. Both studies touched briefly on transition issues but did not address the concerns of young adults with complex disabilities. Hence, there is a gap in local knowledge of how the families of these young people experience and cope with this huge change in their lives and what happens during the transition

from school to adult life. This small-scale study will address this gap in the

literature and provide insight into this topical issue.

The Research Aim

The aim of this research is to explore the recurring issues that affect families of

young people with complex disabilities and the young people themselves as they

transition into adult life. The study focus is on the family perspective of the

transition period.

Significance of the Research

It is argued that this research has social and political significance. The area of

transition from school to adult life has a wide reaching affect on many individuals

and organisations. The families and young people, education and health

professionals, funding providers, local communities and social services are all

affected to some degree by the transition process. The numbers of people

impacted by the process, combined with the ongoing and cyclic need for transition

services, serves to give the topic intrinsic importance. While this life transition

occurs to all young people leaving school, it is argued that those with complex

disabilities have differing experiences and needs during this period of change that

are worthy of exploration.

This importance is not reflected in the provision of transition services. While

internationally, legislation in countries such as America seeks to improve the

process, locally New Zealand struggles to provide services and resources to assist the transition process (McCallin et al, 2007). The New Zealand Disability Strategy (2001) seemingly provides the framework to support transition initiatives, yet the government has released limited funding to assist service providers and families at the grass roots level. There appears to be a lack of resource for follow through, suggesting that government policy is somewhat idealistic. This anomaly affects families.

When service resource is unavailable families, often fatigued from years of care giving and fighting for services, are required to take up the slack, sourcing transition and adult services for their young adult themselves, with minimal assistance from professional agencies (Murray, 2007). There is little information on how this affects these families, how they experience this challenging period or on the outcomes for their young person. The education and paediatric health services simply discharge the young adult into the great unknown (Morris, 1999).

This research aims to explore this gap in the disability literature. Due to the size restrictions of a dissertation, the research is of an exploratory nature. Generalisations cannot be made from the results (Pope & Mays, 2000). However, the knowledge gained may be used to inform discussion on transition issues and the provision of future disability services; allow the experiences of families to be heard at a provider level; and provide the basis for more research. The study will also contribute to the disability and/or special education literature, both nationally and internationally.

The Researcher's Interest

My interest in how transition issues affect young people with complex disabilities and their families arises out of my work as a paediatric physiotherapist. I have worked in the disability sector for the last twelve years, predominately in special schools with children and young people with high and complex needs. I have observed a high level of support for children with disabilities in the years at school, with generally appropriate educational, health, therapeutic and social services in place.

However, I have also seen young people leaving school at age 21 [1] with little to move towards, as much of the service funding is reduced on leaving school. From having a stimulating educational environment to come to each day, with regular input from therapists and support for family members, the young people and their families find themselves in a position of having to fend for themselves. Therapies are no longer available, health care services are reduced as they move from the paediatric into the adult health care model, and there are few services available that provide quality day programmes to provide stimulation. Employment is not a reality for these young people with even sheltered workshops being at too high a level of functioning for most.

---

[1] In the New Zealand Special Education setting, people with disabilities may stay at school until the year they turn 21. This contrasts with the mainstream setting where students may leave from age 15, although many stay till age 18.Other countries have differing leaving ages for those with disabilities. For example in the UK, the leaving age for disabled students is 19.

Families I have assisted through this time have reported immense levels of stress and concern at the lack of knowledge and limited options open to them. Despite this, no one in New Zealand has investigated how families and young people with complex disabilities experience the transition from school to adult life. This gap in knowledge, combined with my pre-existing values and assumptions around transition initiated my interest in the research.

The Researcher's Assumptions

As has been shown above, professional interests often link implicitly with personal values and assumptions that reflect a certain philosophical position in the world. It is acknowledged as a qualitative researcher that research is ideologically driven, with no bias-free design truly possible (Denzin & Lincoln, 2006). In order to minimise the effects of bias or value judgements influencing the results, researchers need to openly identify and acknowledge personal biases and assumptions before commencing fieldwork (Creswell, 1994). Crotty (1998) comments that qualitative researchers should have an awareness that throughout every part of their research they are injecting a host of assumptions. These assumptions may be about human knowledge, or about realities encountered in the everyday world. They impact and shape the way researchers form their research questions, undertake the research and interpret the results. Crotty also goes on to suggest that without clarifying these assumptions, no one can really divine what the research has been or what it is saying.

My own assumptions come from my experiences working as a physiotherapist with young people with disabilities, as well as hearing and absorbing the families'

experiences of the transition period. I work with educationalists, families and health

professionals in a family-centred model, (Casey, 1988; Dickinson et al., 2006)

where physiotherapy integrates into the class setting and the needs of the family.

The first assumption I carried into this study was that many families found life after

the school years difficult, with less support and resources available than when they

were at school. The second assumption I had was that many families were

emotionally drained and physically tired from caring for their disabled person over

the preceding years and hence would want more support and possibly respite or

residential placements as their child grew into adulthood. The third assumption I

held was that the young adult's health and physical abilities might have

deteriorated somewhat in the post school years, as the person stopped having

access to regular rehabilitative therapies and moved from having specialist

paediatric health services into the general adult health system. These assumptions

were upheld in this research. Assumption three was more implicit than the other

assumptions, possibly because discussion in the focus groups centred more on

lifestyle changes rather than change in physical function.

As well as identifying my own personal biases and assumptions, it was important to

understand how the assumptions underpinning qualitative research and the

specific qualitative model used (a social constructivist approach) would affect the

research. The social constructivist approach focuses on the 'collective generation

of meaning as shaped by conventions of language and other social processes.'

(Denzin & Lincoln, 1994, p. 127). Social constructivists assume that the terms by

which the world is understood are social artefacts, produced by interactions

between people. Individuals build the social world in communication with each

17

other, and there is doubt about the existence of objective knowledge (Holloway,

1997, p.145). Within this model, reality itself is seen as the result of normal social

processes in any given context. This means that knowledge and information should

be viewed within the particular context or community group from which it arose. In

this case, the research findings are framed from the perspective of families of

young people with complex disabilities who have recently left school and live in the

wider Auckland region. The context of disability in the New Zealand setting is

currently underpinned by the policies of the New Zealand Disability Strategy

(2001); the Health and Disability Commission's Code of Health and Disability

Services Consumers' Rights (2004); the Human Rights Amendment Act (2001) and

the principles of partnership, protection and participation inherent in the Treaty of

Waitangi [2]. Articulating these theoretical assumptions prior to undertaking the focus

groups raised my awareness of how taken-for-granted understandings and

assumptions influence what is happening in the world around us.

Definition of 'Complex Disability' and 'Transition'

In this final section of the chapter, terminology is clarified. 'Complex disability' is a

term frequently used in health and education circles. There are few clear definitions

of the phrase. There is mention of the term in New Zealand government

documentation, but nowhere is it adequately defined. For this reason, I have

chosen to use a definition based on current local disability research (Bray et al.,

2005). In the current study, the term *complex disability'* is defined as:

---

[2] The Treaty of Waitangi is New Zealand's founding document, brokering partnership between Maori and the Crown of England in 1840. The Treaty's three guiding principles of partnership, participation, and protection underlie all government legislation and policy.

A severe level of disability in at least one area of functioning and effects on

at least three areas of functioning or a moderate level of disability in at least

one area of functioning and effects on at least four areas of functioning. The

areas of functioning are:

Physical; Intellectual; Visual; Hearing; Communication; Continence;

Behaviour; Neurological (including Epilepsy) and Ongoing health needs

(Bray et al., 2005, p.15).

The areas of functioning listed above are based on the current international model

of disability – the World Health Organisation's International Classification of

Functioning (ICF, 2000), which views human functioning as covering body function

and activity as well as participation. The ICF model views the term 'disability' as

meaning impairment of body function and structure, activity limitation and

participation restriction.

The person with complex disabilities will also usually have been recognised as

having 'High' or 'Very High' needs for specialised educational and therapy services

under the Ministry of Education's ORRS (Ongoing Reviewable Resourcing

Scheme) funding for educational resources whilst at school. This formal

assessment of funding requirements undertaken by the Special Education section

of the Ministry of Education, means the young person has been assessed as being

in the most disabled 0.5 – 1% of the national school population.

In contrast to the lack of definition for the term 'complex disability', *transition* has

multiple meanings in the literature. Several meanings are outlined briefly now, and

the concept will be analysed in more detail in the next chapter. Dean (2003) for

instance, defines transitioning to adulthood as a process, drawn out over a period of several years. Halpern (1994) conversely, refers to transition as a change in roles:

> Transition refers to a change in status from behaving primarily as a student to assuming emergent adult roles in the community. These roles include employment, participating in postsecondary education, maintaining a home, becoming appropriately involved in the community and experiencing satisfactory personal and social relationships… (Halpern, 1994, p.116).

For the purposes of this research, Halpern's (1994) view of transition is used. This definition is very general and covers transition for both abled and disabled young people. While useful when considering those with mild disabilities, the definition is less helpful for those with complex disabilities. Despite these issues, Halpern's definition is cited frequently by other authors, has been adopted by the Council for Exceptional Children, and appears in American legalisation such as The Individuals with Disabilities Education Act (2004). As New Zealand government papers do not have their own definition of transition, this meaning was chosen for its international recognition. Halpern's (1994) definition allows both institutional and psychological aspects of transition to be explored, while also reflecting the study's emphasis on the transition from school, rather than the transition within health care systems.

Structure of the Dissertation

This study has been structured to allow the reader to gain background insight into the topics of transition and disability issues before flowing onto the specifics of how families and young people with complex disabilities experience the transition period. In **Chapter One,** the topic has been introduced, the rationale for the study outlined and terminology clarified. **Chapter Two** gives the reader insight into the topic with a review of current literature around transition, disabilities and related family issues. The qualitative methodology used for the study is described in detail in **Chapter Three**, with the research findings presented in **Chapter Four.** In **Chapter Five,** the findings are discussed, the strengths and limitations of the study are noted and the implications for further research are identified.

Chapter Two: Literature Review

Introduction

In this chapter, the literature on transition is reviewed. Initially, the literature search strategies are outlined. General background is presented, and the concept of transition is analysed and situated within the general health literature. This leads onto a section on the socio-historical context of transition in New Zealand, followed by discussion about the experiences of transition. Transitional experiences include the young person's experiences; the parental and family perspective; and the health care system literature. Finally, transition outcomes and the evaluation of transition services are discussed.

Literature Search Strategies

Literature pertaining to the topic of transition appears in several different subject areas e.g. health, allied health, disability, social science, education. The literature search was complex, as a variety of databases and search strategies were required to cover the relevant areas. Key words for searching included 'transition', 'disability,' 'young people', 'handicap' and 'school'. These key words were chosen after initial broader searches indicated common usage. They also reflect the key words chosen by the two most recent large-scale literature reviews [3] (Alwell & Cobb, 2006a; King et al., 2005). I used truncation of these key words to access

---

[3] It should be noted that several authors appear frequently throughout the literature review. The substantive literature reviews produced by Alwell & Cobb, (2006a) and King et al, (2005) are considered seminal works, cited frequently by other authors and hence deserving of more attention. The study by Bray et al, (2005) is also referred to on several occasions, as it represents current New Zealand work in the area.

more articles. The searches were limited to the last ten years, although older, relevant material was also viewed when cited by more recent studies. Initially no limit was placed on the quality of the works, as less scholarly works provided interesting background, commentary, and parental viewpoints. Once these were explored the search was refined to peer reviewed and research papers only.

Three main databases were explored to capture literature from the health, disability and education sectors. These were ProQuest, Google Scholar and Education-Line. Snowballing techniques (Denzin & Lincoln, 2006) were used on the most relevant and recent articles to access references and cited articles.

In the disability sector, useful, quality information is not always published in a journal or book. Because of this, extra sources, such as web sites of well-known disability organisations (e.g. The Pacer Center, USA; Sunfield School, UK; The National Post-School Outcomes Center, USA) were accessed to follow commentary and parental information. Personal communication was also undertaken with several noted workers in the field including Barry Carpenter and Jo Egerton from Sunfield School, United Kingdom, and Jan Moss from New Zealand, to source the most up to date information and current research perspectives on transition.

Background

Taking a very broad perspective, it is evident that the topic of transition from

adolescence to adult life for the disabled population emerged in the literature in the

late 1970's, with the advent of mandated educational access for those with

disabilities in the United States (Alwell & Cobb, 2006a; Individuals with Disabilities

Education Act, 2004). American legislation at the time required a transition plan to

be formulated for every young person with a disability over the age of fourteen

years, which would take them through the period of school leaving. While America

was legislating transition plans, other Western nations lagged behind. New

Zealand, the United Kingdom and Australia, while providing policy guidelines

around transition, still have no mandated, binding requirement for those

transitioning from education. Transition issues are not ignored in these countries,

but with few binding national requirements, different regions are left to find their

own solutions to transition challenges. This anomaly between Western nations may

be partly due to the socio-political variances between countries. For instance,

America is a country where litigation to resolve issues is common. Legislation

making transition plans mandatory sets a standard, whereby people with

disabilities across the nation are perceived to receive similar treatment

(Katsiyannis, Yell & Bradley, 2001). In reality, there are a host of reasons why

equal treatment may not occur, but the American legislation protects the

government from a class action, in what is well recognised as a litigious society.

Conversely, in New Zealand, transition to adult life is seen as an ordinary process,

a normal life stage that all young people pass through once they leave school. This

understanding derives from the developmental framework of life passages

established by Sheehy (1977). Apparently, the New Zealand government perceives little need to legislate for a normal life process. Currently, able-bodied and less severely disabled young people are informally transitioned to adult life with career guidance and work experience during their final school years. Young people with complex disabilities however, face additional barriers and hence require special support to adjust to adult life (Tisdall, 2001; Wells, 2003). It is this support, in the form of transition programmes and service provision, which is missing in the New Zealand setting. Despite many years of international debate about transition issues and post-school outcomes, services are limited for those young people who cannot fit the 'normal' system because of their complex disabilities (Mirfin-Veitch, 2003). Nonetheless, background work has certainly taken place.

For example, the international literature on transition issues for young people with disabilities initially focussed on service evaluation, best practice guidelines and transition outcomes. This reflected an American service led drive to prove that the new legislation and practices were effective in improving post-school outcomes (Individuals with Disabilities Education Act, 2004). These outcomes were typically measured in terms of preventing early dropout from school, increasing levels of employment, community participation and independence, and improving social lives. As the area of transition developed, researchers expanded the areas under study, with more recent studies examining the experiences of transition from a variety of perspectives. Recent large-scale reviews of the literature (Alwell & Cobb, 2006a; Forbes, 2001; King et al., 2005) highlight the ongoing interest in this subject and identify the need for continued investigation.

The Concept of Transition

In the previous chapter, the concept of transition was introduced and Halpern's (1994) description of transition established as the definition guiding this research. The concept of transition is more complex than one definition however, and is not limited just to the disability or youth settings. Transition has many meanings, depending on ideological viewpoint and the transitional context. In the developmental psychology literature for example, Sheehy (1977) describes transition to adult life as one of several normal life passages or stages. Sheehy argues that transitions are normal periods of change that happen at identifiable times throughout the life span.

Consistent with the notion of transition as a normal life experience, Dean (2003) identifies markers that define able-bodied people transitioning to adult life. These include the age of criminal responsibility, the right to consent to medical treatment, leaving school, voting, entering paid work, sexual activity, parenthood and leaving the family home. Shanahan (2000), likewise uses the term transition markers, but argues that transition is not just a discrete set of marked experiences, but rather 'an integral part of a biography that reflects early experiences and shapes later life' (p. 668). This mirrors the widespread adoption of a developmental stance by sociologists, linking transition to the experiences of youth and adulthood (Shanahan, 2000; Sheehy, 1996).

Situating transition in the wider health context, researchers frequently debate the difficulties of translating health research to practice, known as the efficacy-to-

effectiveness transition (Glasgow, Lichtenstein & Marcus, 2003; Weiss, 2007). Likewise, the World Health Organisation monitors health care systems in transition (Hjortsberg, Ghatnekar & Rico, 2001). Clearly, the focus of transition can vary from the disabled individual, to the organisational, to the abstract.

Within the disability literature, Clegg, Sheard, Cahill and Osbeck, (2001) and Beresford (2004) conceptualise transition to adult life for young people with disabilities as requiring both institutional and psychological transitions. Dean (2003) refers to institutional transitions with examples such as moving from children's to adult services in health, social work and education. Studies on institutional transitions form a significant part of the transition literature for those with disabilities (Clegg et al, 2001; Heslop et al., 2001; Morris, 1999). Research on psychological transitions are evident (Bignall & Butt, 2000; Clegg et al., 2001; Hendey & Pascall, 2002; Jones, 2002). These works relate transition to the development of autonomy and independence with authors reflecting on the realisation by family and community of the changing status of the young person.

Another way of viewing transition is in terms of role change (King et al, 2005; Warda 1992). Roles are socially expected behaviours or clusters of meaningful activities that are assumed by individuals in various contexts of their lives (Warda 1992; Wehmeyer & Schwartz, 1997). Conceptualising transition as a process involving roles is a useful way to enable the complexities of transition - such as alteration of identity, relationships, day-to-day activities and lifestyles changes - to be understood (Barnartt, 2001; Kielhofner, 2002). Transition is clearly contextual and also influenced by socio-historical understandings.

The Socio-Historical Context of Transition

While transition literature began appearing in the late 1970's, change was slow to eventuate in New Zealand. At the time, the traditional medical model of disability was, and still is, prevalent. Children with complex disabilities did not usually live to adulthood, and the medical profession presided over the short lives they had (Beresford, 2004; Morris, 1999). Parents were strongly encouraged to institutionalise their offspring, with the paternalistic view that health professionals knew best. Basic human rights of autonomy and informed consent did not exist (Human Rights Amendment Act, 2001) and young people with complex disabilities were seen as being 'handicapped' and in need of care (O'Connor, Orloff & Shaver, 1999).

The traditional model of disability slowly changed with the World Health Organisation's 1980 release of the International Classification of Impairments, Disabilities and Handicaps (ICIDH), recently reclassified as the International Classification of Functioning (ICF), (World Health Organisation, 2000). These classifications moved the concept of disability away from pure pathology towards a holistic framework, inclusive of the person's environment and social context.

Also around this time, de-institutionalisation of people with disabilities began as the social model of disability arose, recognising the whole needs of the young person and the social impact on their families (Murray, 2007). Tossebro and Lundeby (2006) note that initially families resist de-institutionalisation, but longitudinal data

collected ten years after relocation to community settings shows that most families (76%) change their minds after resettlement.

Following de-institutionalisation, the notion of inclusion arose, as disabled people began appearing in society and going to local schools. At the time, government policies and support services struggled to cope with social changes that had occurred without guidelines or adequate funding in place (Murray, 2007). The launch of the pivotal New Zealand Disability Strategy (2001) provided the much needed framework by presenting a long-term plan for changing New Zealand and legislating the rights of inclusion for all.

De-institutionalisation and policies of inclusion have resulted in most children and young people with complex disabilities being cared for by parents at home. Varying degrees of support are provided. This is a trend across most Western nations that looks set to continue (Australian Institute of Health and Welfare, 2001; Murray, 2007). A plethora of governmental reports have evaluated the impact inclusion policies have had on young people, their families and society. These include: Living with Disability in New Zealand (Ministry of Health, 2001a); Pathways to Inclusion, (Ministry of Social Development, 2001); Disability Service Directorate Strategic Plan, (Ministry of Social Development, 2003); To Have an Ordinary Life, (Ministry of Health, 2001b); Just Surviving, (Carpinter, 2000). Yet, while progress has been noted in some disability areas, the reports still paint a negative picture of life for this small population. Indeed, McCallin et al., (2007) state that too many reports have been written with little change occurring at a grass roots level. They argue the time for action and change is long overdue.

Transitional Experiences: Young People

Young people with complex disabilities usually have both intellectual and physical disabilities, as outlined in the previous chapter. As a result, they may experience more stressful transitions than other young people with less severe disabilities as they move from school to adult life (Cope, 2003; Department of Education and Skills, 2004). Egerton (2007) for example, argues that the increased stress occurs both in terms of the barriers encountered during the transition process and also in relation to the young people's experience of the physical process of moving to a different environment. Smart (2004) supports these findings, suggesting that even when the new adult placement is appropriate, the period of transition is still disruptive and confusing for young people that have complex disabilities.

In contrast to this, many authors do not consider those with multiple disabilities when discussing transition issues, but rather limit their discussions to one form of disability or another – often intellectual/learning or physical disabilities. There appears to be a division in the literature between authors considering transition for those with severe learning disabilities versus transition for those with physical disabilities. Whole journals are devoted to one aspect of disability. For example, the journals of Intellectual Disability Research; Learning Disability Practice; Disability and Rehabilitation; Archives of Physical Medicine and Rehabilitation. Authors even contest which disability group face the most difficult transitions. To illustrate this idea, authors such as Ko and McEnery (2004), and Fiorentino, Philips, Walker and Hall, (1998), state that the process of transition is often less satisfactory for those young people with physical disabilities than for those with

learning or intellectual disabilities. Stevenson, Pharoah and Stevenson, (1997,

cited in Ko & McEnery, 2004), comment that transition is particularly difficult for

those with cerebral palsy, because these young people often have more ongoing,

unmet therapeutic and equipment needs than those with learning disabilities in

adulthood. Regardless of the disability, it seems reasonable to predict that any

young person with complex disabilities will experience some degree of transitional

stress.

Heslop et al (2001) discovered that young people's experiences of transition are

helped (or hindered) by environmental stressors. Transitional process is not

necessarily problematic. If young people perceive transition as a positive and

exciting step forward, and suitable adult placements are available, they are more

likely to be happy with the outcomes. However, this is frequently not the case, with

discontinuity of service provision and lack of information causing frustration and

confusion for everyone concerned (Beresford, 2004; Hudson, 2006).

Overall, the literature suggests that transitional experiences for young people with

complex disabilities are characterised by discontinuity, rather than continuity,

highlighting stress and anxiety at an important time in life (Beresford, 2004; Heslop

et al., 2001; Hudson, 2006; Smart, 2004).

Transitional Experiences: Parents and Families

As already stated, parents and families are the main advocates for young people with complex disabilities during the transition period and continue this advocacy well into adulthood (Wong & Wong, 2003). Even young people with less severe disabilities, who are able to self-advocate may need their parents to 'keep the systems afloat'. "You can't coast as an advocate. Parents must stay involved" (Plan Now for Transition, 2005, p. 42).

Pascall and Hendey (2004) examined advocacy and the 'politics of parenting' (p. 165), investigating the roles parents assumed at this vital time. These authors interviewed young adults with mild to moderate disabilities who had jobs, and a group of more severally disabled adults without jobs, to explore what had facilitated their employment and independent living. Although participant numbers in this study were small (n = 17), inclusion of the two groups provides useful comparative information that is lacking in most of the literature. Research findings indicated that regardless of the severity of disability, having 'exceptional parents' who had learnt to be 'successfully political' (p. 166) and skilfully advocate for their offspring, was a key to young disabled people achieving successful outcomes.

'Exceptional parenting' does not necessarily correlate with socioeconomic status either. Using data from a large study (the National Longitudinal Transition Study of Special Education, 1987-1991), Wells (2003) comments that families' socioeconomic resources have a smaller impact on transition to adult life among young people with disabilities than among their able-bodied peers. Wells argues that the resources typically available for families are absent in the area of disability,

due to a lack of services and choices. This effectively blocks the "intergenerational transfer of socioeconomic privilege" (Wells, 2003, p. 803), leading to increased reliance on the state, even in privileged families. This important finding, based on data from a widely respected, large study with a sample of more than 8000 young people with disabilities, has strong implications for state funding of disability and transition issues.

State legislation in most Western nations (e.g. New Zealand Disability Strategy, 2001; Individuals with Disabilities Act, USA, 2004; Department for Education and Skills, UK, 2004) emphasises the importance of partnership between parents and professionals, emphasising the family centred model of working together (Casey, 1988; Dickinson, Smythe & Spence, 2006). While this legislation does not specifically cover the transition period, the continuing partnership model is implicit. Smart (2004) studied partnership and the involvement of parents in transition planning for their young person with severe learning difficulties. Results indicated that while the majority of parents were very involved in transitional planning, basic information and a consistent approach from service agencies was not available. Parents reported a lack of person-centred planning, and 'side-lining' in official processes. Worry, stress and fighting – for funding, placement confirmation and information were commonly reported. Smart concluded that parents are vital advocates in the transition process, particularly when the young people cannot voice their needs. Smart also argued that parents need consistent access to quality information and reassurance that their young people will receive the services they deserve as young adults.

Egerton (2007) supports the need for parents to be given more information, particularly early in the transition process when parents are seeking suitable adult services. Egerton's interviews with parents highlighted ways in which information sharing could be improved between parents and agencies. Egerton (2007) and Smart's (2004) studies provide important background for this research, although the context is different as the young people in question were transitioning from boarding schools for special needs children in the United Kingdom. The parental focus concentrated on residential adult placements, as the children had already 'left home.' There are no residential Special Schools in the area covered by this research; hence the focus of the families in this study may differ. It is also possible that there are differences in information sharing and support between the two countries.

In the New Zealand setting, as reported earlier, there have been many studies on the service needs of young people with disabilities. Despite this, research investigating parental experiences is absent. The emphasis has been on parental experiences during childhood, although some studies touch on transition issues (Bray et al., 2005; Carpinter, Irwin & Rogers, 2000; McCallin et al., 2007; Mirfin-Veitch, 2003). As a local illustration, Carpinter et al., (2000) highlighted the extreme stress parents of children with complex disabilities are under, especially in the early years of parenting, and demonstrated how a lack of support services and inadequate funding increases the burden on families.

Bray et al., (2005) discuss transition issues in their exploration of the family impact of caring for a young disabled person. Bray et al., drew attention to information and

support access, emphasising the importance of locally run service agencies, the young person's school, and the family's General Practitioner. This suggests that parents prefer using contacts they know and feel comfortable with when accessing transition information. The study also established that almost half (43%) of all parents of children with complex disabilities had seriously considered full-time residential placement for their young person either before, or as part of, the transition from school. Common reasons given for seeking such care were the increasing age, size and care needs of the disabled person and illness or injury of the parent. It is also possible that caregiver isolation, burnout and stress may complicate the transition process and lead to permanent care for the young person (King et al., 2005). Decisions about seeking permanent care are usually the result of a long, stressful process for families. This indicates that flexible support services that consider that needs of both the young person and their family are essential (Wong & Wong, 2003).

McCallin et al., (2007) also support service flexibility, commenting that families are strengthened when they have coordinated services, responsive respite care and regular access to caregiver support. This local study criticised the gap between government policy and practice, stating families become isolated when the services that strengthen them are not available. McCallin et al., recommended development of inter-agency collaborative systems between health, education and social services to address the gap in services and support families and children with complex disabilities.

Transitional Experiences: The Health Care System

It is evident that transitioning between services and systems today is problematic. Yet, only a generation ago, transition to adult health care for young people with complex disabilities was a moot issue. Few children survived to adulthood (Beresford, 2004; Morris, 1999). However, in Western countries today, more than 90% of children born with a chronic or disabling health condition will live into adulthood (Blum, 1995; Newacheck & Taylor, 1992). Regardless of the type of health condition or disability, these young people all share a requirement for ongoing health and support services in order to access a good quality of life as adults (Morris, 1999).

The large body of literature focused on health care transitions confirms interest in the increasing numbers of young people with disabilities living to adulthood (Morris, 1999; Reiss & Gibson, 2005; Scal, Evans, Blozis, Okinow & Blum, 1999; Social Care Institute, 2005). Much of the literature arises from the United States, where half a million young people with special health care needs transition to adulthood each year (Blum et al., 2002). Professional health bodies (e.g. the American Academy of Pediatrics, Society for Adolescent Medicine, American Medical Association and the American Academy of Physicians) add to the discussion with regular position papers and consensus statements on adolescent health care transitions (Reiss et al, 2005; Reiss & Gibson, 2002). Overall, these papers present guiding principles for transition programmes and highlight current best practice for effective transition programmes into adult-focused health care.

For example, Blum et al., (2002) in presenting a policy paper on best practice guidelines for transition, state the goal of effective health care transition programmes is "to maximise life-long functioning and potential through the provision of high-quality, developmentally appropriate health care services that continue uninterrupted as the individual moves from adolescence to adulthood." (p. 2) Blum et al go on to state that health care transition services must be patient-centred in terms of flexibility, responsiveness, continuity, comprehensiveness and co-ordination. These principles have been adopted as health care transition policy by the American Academy of Pediatrics, and the American Academy of Physicians.

Following this theme further, Reiss et al., (2005) used focus groups to explore if the goals of effective health care transition planning in the literature and policy statements were reflected in the experiences of young people, their families and health care practitioners. Results showed that in general, health care transition was complex and dynamic, involving emotional challenges, rather than the linear, clinical handover of service suggested by the policy papers. The study demonstrated that most families have trusting relationships with their paediatric health providers, which they are reluctant to leave behind. Reiss et al., argue that paediatric and adult-orientated medicine represent two different subcultures, with families reporting difficulties establishing relationships with adult health providers. Clearly, effective health care transition is not a simple step between services, but involves the breaking and reforming of important relationships. Ideally, transition planning should allow extra time both for appropriate termination of paediatric relationships and the building of new adult relationships.

When health care transition is unplanned, or lacks co-ordination, negative consequences frequently occur, in that young people 'drop out' and do not access adult health services (Fiorentino et al., 1998; Forbes et al., 2001), or experience a deterioration in health (Fiorentino et al., 1998; Hallum, 1995). Dissatisfaction with the paucity of adult health services is common (Reiss et al., 2005), as is displeasure with the lack of disability-specific treatment expertise (Reiss & Gibson, 2002; Social Care Institute 2005).

Ko and McEnery (2004) suggest that there are gaps between services and expertise available in adult health compared with paediatrics. These authors assessed young adults with cerebral palsy, finding that only two-thirds of their assessed needs for health care services were met. Special services did not exist in the adult service, in contrast to the full range of services that had been available in paediatrics. This study should be viewed with caution due to its small sample size (n = 24) and narrow geographic area (inner London). However, findings add support to those authors concerned at the disparity of health services between the paediatric and adult services.

While disparity between paediatric and adult health services continues to be of concern, emerging evidence proposes changes to improve continuity in health transition. Forbes et al., (2001) found that service structures, skilled staff dedicated to the transition period and multi-disciplinary and multi-agency team working, promote transition continuity. Bent, Tennant, Swift, Posnett and Scuffham's (2002) comparative study of a specialised multidisciplinary team working versus ad hoc

health services for disabled young people transitioning to adult care weighs in favour of the specialised team approach.

In relation to service delivery, Forbes et al., (2001) identified a range of factors that promote continuity in health care transition. Planning and preparation, active case management across agencies, strong relationships between health professionals, the young person and their family, and having independent advocates are all important. Beresford (2004), Heslop et al., (2001), and Bethell and Harrison (2003) further develop these components of good practice. Both Beresford (2004) and Forbes et al., (2001) note that there are still many gaps in the literature, and that certain elements of good practice currently being promoted require rigorous evaluation.

Transition Outcomes and Service Evaluations

Outcomes of transition programmes and evaluations of transition services receive frequent attention in the literature. Clinicians and service agencies seek evidence that programmes are worthwhile while fund-holders want proof that money invested results in positive outcomes. However, variability in the quality and nature of the original studies make definitive claims difficult (Alwell & Cobb, 2006a).

The 'What Works' Transition Research Synthesis Project (2007), underway at Colorado State University, USA, addresses this with meta-analyses of six transition-related intervention areas. Areas include transition planning and implementation; vocational interventions; teaching of social skills; self-

determination interventions; life skills and counselling interventions. The first results have been published (Alwell & Cobb, 2006b). Review of 50 studies in the area of life skills provides cautious support for the use of life skills interventions in transition programmes. However, the authors noted difficulty in making conclusive statements due to the state of the literature. While all the studies had acceptable standards of validity, the topic focus varied widely. In addition, while some studies on young people with mild disabilities had multiple participants, many of the studies involving people with severe disabilities were single participant, making it difficult to systematically aggregate and compare research findings.

While results from that particular project will assist with future transition planning, of equal importance is the question 'what happens after transition?' Transition outcomes reflect the success, or otherwise, of the transition service interventions. King et al.'s (2005) and Alwell and Cobb's (2006a) literature reviews provide a useful means of qualifying transition outcomes, by relating outcomes back to Halpern's (1994) original definition of transition. According to this definition, five areas define transition: social relationships, academic involvement, career development and vocational pursuits, maintaining a home, and participation in the community. A successful transition outcome is viewed as one in which a young adult is engaged in, or able to adopt their desired adult roles in some, or all of these five areas (Carr et al., 1999; Halpern, 1994; King et al., 2005). These roles align with an individual's strengths and needs and fit their life goals (King et al., 2005). Success in negotiating these areas of transition is reported as leading to enhanced self-determination (Wehmeyer & Schwartz, 1997), higher rates of postsecondary education and employment, greater happiness and greater

participation in life situations such as recreation and leisure activities (King et al., 2005).

Conclusion

This chapter has reviewed the current literature on transition issues, both nationally and internationally. Overall, transition literature is vague, complex, and variable according to the context. Most research appears politically idealistic, providing general guidelines that may or may not assist in everyday life. The literature is also fragmented and context-specific, making it difficult to draw consistent research based conclusions. Likewise, problems with reliability and validity of evidence mean understanding is potentially limited, with two key meta-analyses finding consensus on issues difficult.

In addition to reviewing the transition literature, this chapter has identified the socio-historical context of disability in New Zealand and highlighted the experiences of transition for young people and their parents. Specific examples of the literature relating to those young people with complex disabilities and their families have been examined. Finally, the work around transition outcomes and service evaluations has been examined. The next chapter moves on to explain the research process.

Chapter Three: The Research Process

Introduction

In this chapter the research process is addressed. The rationale behind the choice

of a qualitative framework and the use of focus groups as a research method are

explained. Practical considerations together with the strengths and limitations of

focus groups are examined. Discussion includes comment on the philosophical

underpinnings; focus group methodology; ethical issues; access to the field;

participant selection; group preparation and group composition; the role of the

moderator; focus group structure; data collection and analysis; reliability and rigour

of the study. The audit trail presented outlines the research process and

demonstrates transparency of process.

Philosophical Underpinnings

This aim of this research is to investigate the recurring issues that affect families of

young people with complex disabilities and the young people themselves as they

transition into adult life. A qualitative approach was appropriate because this

perspective allows for rich, detailed descriptions and interpretations of people and

the social practices and events that influence them and are shaped by them

(Lewis-Beck, Bryman & Futing- Liao, 2004; Stringer, 2004). Qualitative approaches

also enable researchers to share in the understandings and perceptions of others

and facilitate exploration of how people structure and give meaning to their daily

lives (Denzin & Lincoln, 2006). An important distinguishing feature of qualitative

research is that it studies people in their natural settings, rather than in artificial, or experimental ones (Berg, 2001).

As was noted in chapter one (p. 16), this research is undertaken using a social constructivist perspective. Cresswell (1994), a noted social constructivist, comments that qualitative researchers assume that reality is constructed by individuals and that multiple realities may exist in any given situation. In other words, each person has a different understanding of the world with the result that individual understanding within any group will be diverse. Under the social constructivist lens, all information gathered is assumed to be value-laden and biased. This means that the researcher, the research participants, and the reader interpreting the study are likely to have differing understandings of reality.

Further qualitative assumptions articulated by Creswell (1994) include the informal nature of the study, with the researcher being involved to some degree in the research by having a personal voice that shapes the research process. In this research project for instance, while six main questions were asked, as in any focus group, further questions evolved as participants discussed the topics and I encouraged deeper explanation of ideas. Thus, I was jointly involved in dialogue with participants, as they responded to each others thoughts, feelings and experiences.

Focus Group Methodology

Focus groups are a form of group interview that 'capitalise on communication between research participants in order to generate data' (Kitzinger, 2000, p. 20). They are not easy question and answer sessions, but rather involve a carefully planned discussion designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment where participants share and respond to comments, ideas and perceptions (Krueger, 1994, p. 6).

> It is important to keep in mind that the intent of focus groups is not to infer but to understand, not to generalise but to determine the range, not to make statements about the population but to provide insights about how people perceive a situation (Krueger, 1994, p. 87).

Focus group interviews may be either guided or semi-formal discussions that address a particular topic of mutual interest to the group and the researcher (Krueger & Casey, 2000; Edmunds, 1999). Questions are usually sequenced from general to the specific, moving the discussion towards the central focus of the research. A skilled moderator guides the discussion, exercising limited control over the conversation and moving it from one question to another (Lewis-Beck et al, 2004). The role of the moderator is crucial to the success of a focus group and hence it is considered in greater depth further on in the chapter.

By conducting focus groups, group members are able to engage and interact with others in similar situations and the ensuing discussion allows participants to express their thoughts and feelings in a supportive environment. Group processes assist participants to explore and challenge their own views, as well as learn and

be empowered by the experiences of other group members (Bowling, 2002;
Kitzinger, 2000).

Focus groups provide a useful way to explore people's talk, experiences, opinions
and concerns (Holloway, 2005). Because there is a paucity of information about
the families of young people with complex disabilities, forming relevant questions
that were of value to the participants may have been difficult. Focus group
interviews however, allowed participants to generate and pursue their own
priorities around the topic (Kitzinger, 2000). While six general questions were used
as a framework (Appendix 5), participants were encouraged to expand the
discussions into their own areas of interest. This gave breadth to the data by
reflecting the range of participants' experiences and feelings, rather than
containing responses in a pre-set format.

Like any research method, focus groups have both advantages and limitations.
Litosseliti (2005) summarises the main benefits of focus groups: discovering new
information and consolidating old knowledge; obtaining a variety of different
perspectives on a topic; gaining insight into participants' views, attitudes,
motivations and perceptions; examining participants' shared understandings of
everyday life; exploring sensitive or complex topics, and using group dynamics to
brainstorm and generate new ideas.

Clearly, interaction is of primary importance. Focus groups are all about obtaining
rich data through direct open-response interaction between group members.
However, it is this very interaction that potentially limits the methodology.

Limitations of focus groups include: a danger of bias and moderator manipulation of participants; false consensus when one strong viewpoint dominates; the difficulty in distinguishing an individual's view from the group opinion; non-generalisable findings and the analytical challenge presented by the open-ended nature of focus groups (Kitzinger, 1995; Litosseliti, 2005; Morgan, 1993). The impact these limitations had on this study are articulated throughout this chapter and in the discussion chapter.

Ethical Issues

Throughout this research, the key ethical principals of informed and voluntary consent; respect for privacy and confidentiality; risk minimisation; truthfulness; social and cultural sensitivity; research adequacy; avoidance of conflict of interest; and respect for participant vulnerability (AUT Ethics Committee, 2007) were followed to the best of the researcher's ability. Prior to the research commencing, ethical consent for the study was obtained from the Auckland University of Technology Ethics Committee (Appendix 2). This included approval for the overall plan and purpose of the research, as well as endorsement of participant information sheets, (Appendix 1) consent forms (Appendix 3), confidentiality forms (Appendix 4) and the main questions to be discussed (Appendix 5).

All New Zealand institutional ethics committees expect researchers to honour the principles of the Treaty of Waitangi and explain how they have incorporated the three principles of the Treaty into their research. In keeping with New Zealand research principles of best practice, and the Treaty principles of partnership,

protection and participation, guidance was sought from a Maori advisor on ways to encourage Maori participation and ensure cultural sensitivity during the focus groups. As per social constructivism this recognises how different individuals experience multiple realities. This person was also a parent of a child with a disability, and a foster parent to two other disabled children, meaning as well as bringing cultural sensitivity, she also understood the purpose of the research. Article One of the Treaty (participation) was respected by consulting the Maori advisor in the preparation of the study proposal. She assisted by suggesting appropriate ways in which to recruit Maori participants and helped develop the research questions so they were culturally safe and non-threatening. She also made general suggestions regarding Maori participating in group settings. She continued to provide support and mentoring through the research ensuring the safe expression of cultural values and beliefs. In respect of Article Two of the Treaty (protection), participants were offered the opportunity to have members of their whanau (family) or support people present during the focus groups, although no-one chose to do this. Under Article Three (partnership), Maori are offered the same rights and privileges as British subjects. Every effort was made to recruit Maori families to the study to ensure their voice was heard.

Consideration was given to the full use of Te Reo Maori (the Maori language) by individuals in the focus groups; however, the need for continuous translation was thought to impede the natural flow of group discussion, and possibly limit the valuable interjections and vigorous debate that is a positive feature of focus group methodology. The use of phrases in Maori that were translatable without affecting

the group flow were welcomed as part of the research commitment to encourage Maori participation. Participants were encouraged to introduce themselves to the group in a manner they deemed culturally appropriate.

Ethical considerations underpinned research design and decisions made throughout the project, and did not cease when ethics approval was granted, but continued to be woven throughout the study. For example, the use of intermediaries to approach potential participants protected participant privacy and ensured participants did not feel pressured into attending the research group. Giving participants a chance to discuss the research with the researcher prior to the focus groups enabled them to be fully informed about the research before committing to attend and also gave a chance for any queries or concerns to be answered.

During the focus groups, ethical principles of informed consent, respect for confidentiality, risk minimisation, cultural sensitivity and respect of vulnerability were maintained. For instance, at the start of each group, the purpose of the research was again outlined, before participants signed an informed consent form. The right to withdraw from the study at any time up until data had been analysed was explained. The group discussed and approved a set of ground rules, which ensured participants felt comfortable with the way the group would be run (refer to section on 'focus group structure' p. 54). The confidentiality issue was raised, both at the time of setting ground rules, and also when participants signed the consent forms. It was agreed that confidences expressed at each focus group should stay

within the group, with the exception of allowing the researcher to feed general comments from the first focus group into the second group to aid discussion.

Given the relatively small community of people with complex disabilities, it was explained that absolute anonymity could not be guaranteed. However anonymity was maximised through offering participants to right to use a pseudonym name (no-one chose this option) and by removing all record of names and places from the transcripts. The typist who transcribed the data also signed a confidentiality form (Appendix 3).

At the time of data analysis, the ethical principles of confidentiality, truthfulness, social sensitivity and respect for participant vulnerability were adhered to. The researcher was particularly aware of the need to remain truthful to the intent of the participants, and not go beyond the data. The researcher extended this principle by contacting two participants after the data had been transcribed to clarify meaning and intent (refer to section on 'data collection' p. 58).

The audio tapes were destroyed after transcribing and data analysis so that participants' privacy was protected. The completed transcripts were only viewed by the researcher, her supervisor and the typist. Following ethics committee guidelines, an electronic version of the transcripts will be kept for six years in secure storage at the Auckland University of Technology. After this time they will be destroyed.

Access to the Field

As part of the initial preparation for the research, consultation with significant groups was undertaken. Representatives from the Complex Carers Group, and Special Schools Principals Association were approached for support and input. These two groups were approached due to their knowledge and involvement in the area of complex disability. The Complex Carers are a parent-led group, supported by the Ministry of Social Development. They aim to give support and information to people caring for young people with complex disabilities and to influence disability policy at a government level. As has already been mentioned, the Complex Carers were involved in a recent local disability study (Bray et al, 2005) and the outcome of this current research will be of particular relevance to their members.

Representatives of the Special Schools Principals Association deal with transition issues on an annual basis as young people with complex disabilities leave their schools. They had an interest in discovering how parents and families experience the transition period and hence were supportive of the study. Representatives from both organisations assisted with fine tuning the research questions to ensure they would reflect real concerns of their organisations and members. Because of this, participants may have been more open to being approached by the intermediaries, as the study had meaning and relevance for them personally.

The two focus groups were held at different times of the day, to reflect participants' different life commitments. One group was held in the evening, the other in the morning. For the morning group, the researcher travelled to meet the group at one of the participant's homes to enable more participants to attend. Participants were

given a choice to attend whichever of the two focus groups was most convenient for them.

Participant Selection

The sampling for this study was purposive, (Denzin & Lincoln, 2006) with participants being invited to participate by intermediaries from the Complex Carers Group, and the Special School's Principal's Association. The researcher followed through contact with a phone call. Once the initial group was approached, networking led to another intermediary from the 'Adults in Motion' disability support group offering her services and more potential participants being identified. The criteria for selection included any adult who had as a member of their family a young person with complex disabilities who had left school within the last five years. This meant the young people with complex disabilities were aged between 18- 25 years. Participants needed to live in the greater Auckland region to attend one of the focus groups. They also needed to be able to speak English to enable the group to converse freely.

Group Preparation

All potential participants who had indicated interest in the research were sent an information sheet (Appendix 1) outlining the purpose and background to the research. The intermediaries addressed and sent these out to participants, so I did not have access to the participants address or details prior to the research. This

supports the ethical principle of participant privacy and prevents possible coercion of participants by the researcher.

At the time of initial contact, the intermediaries asked permission to pass on interested participants' telephone numbers to the researcher for follow up. Participants were given the option of contacting me directly, or if no contact was made within a week of receiving the information sheet, they were told I would phone them to discuss the project.

As no participants made direct contact, I phoned potential participants within the stated timeframes. This proved a valuable exercise, as participants asked several questions about the research, which I answered immediately. Participants also tended to give more information about themselves and their families during the phone call, which helped me in planning the sessions. As a result of this information I was able to refine questions, by knowing which young people had siblings, how long they had been out of school for, and what services the young people currently accessed. Several people expressed great interest in the topic and outlined some of their views on transition during the phone call. I had to be conscious of maintaining the integrity of the research, and not let too much discussion occur without the moderating effect of the focus group process. Nevertheless, the enthusiasm expressed by total strangers led me to believe there were strong views on the topic, which could be explored in-depth in the focus group.

Group Composition

The week before the focus group, all participants were emailed a reminder, along with the six main questions for discussion (Appendix 4). Eight people had agreed to attend the evening focus group. On the night four were available. This pattern was repeated at the morning group with five confirmations turning into three attendees. In most cases the cancellations occurred on the day, several days after the original confirmation. This was challenging, although it reflects the uncertainty experienced by these parents on a day to day basis. Cancellations were mostly due either to a change in the health of their young person, or a planned alternative caregiver not being available.

One of the people who cancelled still wanted her voice to be heard, and emailed me her responses to the questions I had sent out with the information sheets. As this information was not moderated by the effect of the focus group, it could not be included in the main data analysis, however it is commented on in the discussion section.

Of the seven participants who attended the groups, 6 were female and 1 was male. Ages ranged from 35-59 years, with 4 participants over 50 years old. Five participants identified themselves as New Zealand Europeans, one as English, and one as Maori. The Maori representation (14%) in the study equals the New Zealand 2006 Census data of 14% of the population identifying as Maori (Statistics New Zealand, 2006). As has been stated, all the young people referred to had left school within the last five years, and were aged between 18-25 years.

Two participants were single following divorce; two were living with a partner; and three were married. Two were full time carers to their young adults; three were in part-time employment, with the remaining two in full-time paid work.

The group composition was homogenous, in that participants were all parents of a young adult with a complex disability and hence had shared experiences. As the emphasis in a focus group is on group interaction, having participants with a common interest allows for maximum interaction (Krueger & Casey, 2000; Liamputtong & Ezzy, 2005). Within focus groups, homogenous sampling also allows for increased depth and detail of information. As Morgan (1997) points out, it is the social and cultural homogeneity of a group that allows for more free-flowing conversations amongst participants.

While most researchers recommend aiming for some homogeneity within focus groups, it is interesting to note that Kitzinger (2005) and Litosseliti (2005) suggest that bringing together a diverse group (heterogeneous group composition) can also work favourably. This is particularly true if researchers want to 'maximise the possibility of exploring subjects from different perspectives' (Kitzinger, 2005, p. 61). In this project, as the aim was to elicit depth of information and participant numbers were small, homogenous sampling was viewed as the most appropriate sampling strategy.

Role of the Moderator

A skilled moderator is often the difference between obtaining general commentary versus generating quality in-depth data from a focus group (Lewis-Beck et al., 2004). The moderator sets the tone for the discussions by 'warming up' the group and using group facilitation techniques to ensure participants feel secure enough to discuss the topic at more than a superficial level. It is asking a lot to expect a group of strangers to meet together and discuss their inner-most thoughts on potentially sensitive subjects. A good moderator can overcome these challenges by developing a sense of shared purpose within the group and enabling participants to feel safe sharing these personal thoughts and feelings (Litosseliti, 2005).

One of the most important roles of the moderator is as an active listener, guiding the discussions and encouraging for greater breadth of expression and depth of information (Kitzinger, 2005). In this study I was the moderator. As I have had many years of experience facilitating group processes in the health and disability sector I was professionally confident of group management. I also had current knowledge of the topic and the background literature without the need to refer to notes. These experiences helped me to concentrate on listening, drawing out quieter participants and clarifying responses as required.

Focus Group Structure

Participants arrived at each group having had opportunity to think about the questions. Kitzinger (2000) recommends participants receive questions prior to the group to assist them to focus on the topic and think about their views. This was

positively demonstrated in this study, with several people stating that they had given the matter serious thought in preparation for the focus group.

Participants had also been invited to write down any thoughts or ideas they had prior to the interview (Kitzinger, 2000; Stewart & Shamdasani, 1990). When groups of people meet to discuss ideas, individuals may try to make themselves socially acceptable by conforming to the group view, rather than strongly presenting their own opinions. Carey and Smith (1994, p. 124) refer to this as "censoring and conforming" and comment on the considerable impact it can have on group process. Because group censoring is one of the identified limitations of focus group methodology, it is possible to pre-plan to minimise its effects on the research. Getting individuals to consider their ideas on a topic before a focus group is one way of reducing group conformity by allowing time for participants to process their own opinions and own their comments. In this research, while each group had one personality more dominant than the others, opinions were still freely expressed and disagreement and debate was demonstrated by all participants. This suggests that group censoring did not play a large role in this research.

On arrival, participants were asked to sign a consent form (Appendix 3), which included a statement on confidentiality, as well as approval from their young person to discuss their lives. The Auckland University of Technology Ethics Committee had given approval to use the following statement on the consent form:

> "I have discussed this study with the young person concerned at their level of understanding and *they have given their assent to my sharing of their experiences in the focus group."*

This clause provoked some discussion, as several parents felt that even though they had talked to their young person about the project, their severely impaired cognitive function i.e. they had the mental age of a pre-schooler, meant that true informed consent was not possible. Several participants exercised their right to freedom of choice and crossed out the second half of the statement before signing the form.

The two focus groups were structured in a similar manner; however some differences were anticipated in the second group. Variances were expected due to the researcher having 'practised' the questions on a previous group, as well as having the use of the previous group's answers to add another voice to the second group. Stringer (2000) recommends this strategy of using cumulative data with subsequent focus groups as a means of advancing knowledge.

Following introductions, the format of the group was outlined, with an emphasis on the value of input from everyone. The use of the audio equipment and the timing (60-75 mins) of the group were confirmed. Ground rules, including listening and respecting all opinions; one person talking at a time; confidentiality over shared confidences and the right to not answer any question were clarified. While ground rules can provide useful boundaries to steer a group, in this research positive group dynamics meant that the ground rules did not need to be referred to again after the initial agreement was reached.

One of my concerns as a group moderator was the possibility of participants focusing on long-winded personal stories, rather than discussing the topics as a

group. This was managed by pointing out at the start of the group, that while personal stories were valued, the group was there to draw out and discuss ideas together. Inevitably, personal stories were raised during the sessions, but I was able to use the stories as prompts for discussion thus curtailing excessive narrative by any one individual.

Questions were posed to each group, working from general, open ended questions and moving towards more in-depth answers with the use of prompts and questioning for meaning (Pope & Mays, 2000). The six main questions were all answered by the groups, although it was decided not to formally work through each topic as listed on the question sheet, but rather let the conversations lead the course to the next question (Creswell, 1994). Where the conversations ebbed and did not lead on to related areas, either directive questions were asked, or cue cards were read out to lead into the next point of discussion. Examples of comments on the cue cards include:

"They promised him all sorts of things – 'we'll be getting him out in supermarkets and to the pools etc'. They obviously didn't understand how complex my son was."

"I don't give him Coke because otherwise he's on the ceiling. But at his respite they give it to him. The system says that he should choose because he's an adult. But it doesn't work for him, because he often doesn't realise the consequences of his choices."

These cue cards used comments and quotes from two related studies (Blum et al., 2002; Egerton, 2007) to refocus the group and move them forward into another area of discussion (Stringer, 2000).

At the end of short sections of discussion, I summarised comments and asked clarifying questions where necessary to ensure that I had understood what participants were meaning (Pope & Mays, 2000). For example:

So what you're saying, or what I'm hearing, is there are big hindrances that you all had in getting from there to where you are now. (FG1, p.22)

When you say it's hard, do you mean it was hard finding the service, or hard to let him go to that service? (FG1, p.5)

The clarification and summarising of sections of discussion promoted participant reflection, which often led to further in-depth comment. The process also allowed me time to think about group management.

Data Collection

Audio taping was used as the main means of data collection for each of the focus groups (Holloway, 2005). I had considered the use of video taping to enable non-verbal group interaction to be captured. However, during the pre-group consultation stage, a member of the Complex Carers Group raised the concern that participants could find the use of video intrusive and intimidating.

At the completion of each group, I listened to the tapes and made notes on immediate impressions and interactions between group members. These notes were used later to inform the analysis when the transcript was unclear, particularly when comments were made out of context. The tapes were transcribed by a professional typist. The participants' privacy was protected by asking the typist to sign a confidentiality agreement, (Appendix 3) as well as removing identifying features, such as names and places from the transcripts.

I read the transcripts and listened to the audio tapes several times, while comparing the group impression notes with the transcripts. This was done within two- three weeks of the focus groups, so the impressions and memory of the focus groups was still relatively fresh. One of the participants from each group was contacted to check my impressions and clarify details. These two people had identified themselves at the end of the focus groups as being willing to be contacted for further comment.

Data Analysis

The main tool used for data analysis in this study was constant comparative analysis (Glaser & Strauss, 1967). This method of analysis involves coding a unit of data and comparing it to all the other data that has been coded within a category. Coding is the process of sorting, labelling and organising data (Charmaz, 1994). As the data is coded, comparison with other codes and with the original data helps to sharpen the overall concepts and define their properties (Schwandt, 1997). In this manner, constant comparative analysis develops and refines the

theoretical properties of a category (Finlay & Ballinger, 2006) and assists the

researcher to move from a simple descriptive level of categorisation through to a

higher theoretical point of conceptualisation (Seale, 1999).

The analysis began with reading the transcripts and assigning 'in vivo' codes

(Finlay & Ballinger, 2006, p. 67) that described what was happening in the data.

Many initial codes were identified (Appendix 6). The coding framework from

Liamputtong and Ezzy (2005) was then utilised to organise the codes into a

hierarchical scheme. This involved assigning coding 'stem' titles to the main

categories. Illustrations of stem titles from very early in the analysis include

descriptors such as: *advocates; transition barriers; lifestyle impact; carers;*

bureaucracy; funding; post-school options. These coding stems were followed by

several different coding 'tails' that provided further detail (refer to Table 1 in

Chapter 4 for final coding). For example, the tails of *transition barriers* were *lack of*

services, agency accountability, parental loss of control and funding. These coding

stems and tails changed several times throughout the process, as constant

comparative analysis developed concepts at a higher level of abstraction

(Liamputtong & Ezzy, 2005, p. 270). For instance, *transition barriers* became

service agency influences which eventually turned into *funding mismanagement*.

This stem was recategorised as understanding developed of the emerging themes

and their place in the overall concept.

The analytical process involved much reflection and struggle as I attempted to

'make sense' of the data and develop a deeper understanding of the concepts and

emerging themes. Writing a research journal (Appendix 7) was a valuable reflective

tool that allowed thinking to develop and concepts to become clarified (Finlay & Ballinger, 2006; Liamputtong & Ezzy, 2005).

Study Rigour and Reliability

Unlike quantitative methods, there are no simple algorithmic criteria by which the rigour of qualitative research can be judged. Instead, researchers present evidence they state is reliable, valid, and based on 'truth'. The researcher aims to generate confidence in the truthfulness of their claims by demonstrating the soundness of the evidence base on which the claims are made, and by showing that the possibility for error has been limited as much as possible (Lincoln & Guba, 1985). Murphy and Dingwall (2003, p.174) state that researchers have a responsibility to defend these claims of authoritative knowledge by providing *rigorous* and self-critical conduct, analysis and interpretation of the research.

Rigour within the framework of focus group research depends on four key factors (Lewis-Beck et al., 2004):

- Planning
- Asking the right questions
- Skilful moderation of the discussion
- The use of systematic and verifiable analysis strategies in the write-up stage.

Planning and rigour are intertwined. *Planning* a focus group study consists of determining the number of groups, developing recruitment strategies and anticipating practical concerns (Lewis-Beck et al., 2004). The means in which practical concerns were anticipated and dealt with have been discussed earlier in the chapter. The number of focus groups was contained by the small scale of the study, and the time constraints of a Masters dissertation. The recruitment strategies for this study involved a personalised approach from an intermediary, followed by a phone call from the researcher, and the use of an incentive to attend (petrol vouchers). Lewis-Beck et al., (2004) list these as the three distinctive qualities of successful recruiting. That the actual attendance at the groups was low was due more to the practical difficulties involved in the participants' lives, rather than a supposed lack of desire to participate.

If rigour is to be preserved in research, the *questions* in a focus group should be well planned, and pertinent to the research aims (Lewis-Beck et al., 2004). The six main questions in this research were formed with input from relevant disability groups who understood the research aims, meaning the questions were relevant and acceptable to the participants. This follows social constructivism principles of collective understanding being derived from interactions between people (Holloway, 1997). Initial questions were general and broad, moving to more specific as the discussion progressed, with an emphasis on open-ended questioning. As mentioned earlier, I used summarising questions at the end of each section of discussion. The group facilitation skills of the moderator enabled the questions to flow and probing questions and clarifications to be used to gain greater depth of data.

A *skilful moderator* is required to maintain rigour by establishing a trusting environment that removes barriers to communication. The important role of the moderator has been spelled out earlier.

The rigour of the research analysis is achieved by the use of a *systematic and verifiable analysis protocol* that follows a predetermined sequence for capturing and handling the data. The process is verifiable in that there is an evidence, or audit trail that can be followed. In this study, the analysis followed the systematic framework outlined by Liamputtong and Ezzy (2005). The audit trail is articulated throughout chapters three, four and in the appendices with the use of examples from the data, and explanations of why decisions were made. I have attempted to provide transparency in the analysis through articulating how concepts evolved and noting the reflection and higher level of thought needed through the use of a research journal (Appendix 7).

Conclusion

This chapter has addressed the rationale behind the use of focus group interviews in this study. The strengths and weaknesses of the focus group process have been outlined. A clear audit trail has been presented with description of practical details of the research including information on the focus group composition, structure and participants, as well as the means of data collection and analysis. Ways in which the rigour and reliability of the study have been maintained were also detailed. In the following chapter, the research findings and data interpretation will be presented.

Chapter Four: Research Findings

Introduction

The aim of this research was to explore the recurring issues that affect families of young adults with complex disabilities and the young adults themselves as they transition into adult life. The study focused on the family perspective of the transition period. Data analysis reveals an overarching concept of parental loss. Social definitions of loss suggest that it is: 'the disadvantage or deprivation resulting from losing,' or 'the act or an instance of losing;' (Collins, 2005). This is consistent with research findings in that most participants, i.e. the parents, referred to issues of loss in some form or other, using words such as: failure, bereavement, damage, difficulty, hindrance, lack, removal, waste, and withdrawal - all synonyms for loss, disadvantage or deprivation (English Thesaurus, 2005). Thus, parental loss is grounded in the data and is evident as the general integrating theme.

In this study the main concerns underlying parental loss during transition are expressed in three themes: *service mismanagement, caretaking tensions* and *perpetual childhood management,* all of which contribute to parental loss. It is evident from the data that, as their young people transition to adult life parents experience a loss of service, a loss of influence in caretaking because of diminished parental input, and a loss of normal childhood development expectations. Parental loss is significant because the services, funding and care giving support families received when their child was young, disappear completely, are indeed lost entirely as the young person transitions into adult life. Similarly, the expectations associated with normal childhood – "a normal life" (New Zealand

Disability Strategy, 2001) are lost completely. This chapter will discuss the

research findings that support each of these themes. A summary of the theme

categorisations is tabled below. It should be noted that while each theme is

considered individually, as is typical of many qualitative research findings, the data

showed many examples of overlapping concepts. Hence the findings arising from

the focus groups were interwoven, and are not presented as discrete themes.

Table 1: Parental Loss
Coding stems and tails

Coding stems:	*Stem sub-categories:*	*Coding tails:*
Service mismanagement	Agencies	Funding entitlements, accountability limitation, information access
	Access	Service shut down, service lack, service expectations
Caretaking tensions	Caregiver unpredictability	Caregiver training, trust, caregiver abuse, care giving demands
	Diminishing parental influence	Advocacy, guardianship
Perpetual childhood management	Loss of a normal life	Perpetual parenting, burnout, abusive situations, guilt, vulnerability
	Societal barriers	Social isolation, limited societal understanding, inclusion policies, disabled peer networks

1. Service Mismanagement

Service mismanagement refers to promised services not being delivered and funding entitlements being lost through agency errors. When factors hindering transition were discussed during the focus groups, it became clear what an important influence the management of services had on families' perception of the transition period. The term 'service(s)' was used by participants in the context of external agencies providing care or support services for their young person. Services included respite care, day programmes, caregivers coming into the home, residential care, or medical care'. Service management was generally referred to in negative terms throughout the focus groups and thus, this theme is termed service 'mismanagement'. Without exception, this theme provoked intense feeling within the groups. Participants' body language and tone of voice changed noticeably, with tension evident, when they were discussing their experiences. Because the management of services and control of funding in the area of adult disability is provided by service agencies (in both the public and private sector) this theme has been divided into two service-related sub-categories: agencies and access.

1a. Service Mismanagement: Agencies

Young people with complex disabilities attract government funding from a variety of agencies. A small proportion is given directly to the young person or their guardian in the form of a benefit. However, the majority of disability funding is tendered for by service agencies [4], which contract with the Ministry of Social Development and/or the Ministry of Health via a local fund-holder, to provide specific services. While

---

[4] Participants used the term service agencies or agencies interchangeably.

families are entitled to access these funds and services, they actually have to apply to the agencies to receive the services and it is in this application that problems and mismanagement occur:

> …the [service] agency has been responsible for totally annihilating the whole thing, mismanaging the whole thing, traumatising [the young person] and the family (FG2, F, p.28).

As the agencies have control over the funding and take a fee from the young person's funding entitlement to manage the funds, families feel they have lost out when agencies commit errors and are seen to not be performing their job effectively:

> They're [agencies] still controlling your life and they're not doing their job either. Totally shocking management … what really brasses me off is they're getting a huge amount of her funding to be the management (FG2, E, p. 29).

From the parents' perspective, agencies appear to demonstrate a lack of accountability with little recourse for complaints when service mismanagement occurs:

> I went to the Ministry [of Social Development] and they said "We don't care; we fund [agency] to provide the service. We can't have any control over what they do with the funding after that. There's no accountability at all (FG2, F, p. 33).

This is at odds with objective 6 of the New Zealand Disability Strategy (2001), which aims to 'foster an aware and responsive public service'. Furthermore; it appears that even when parents take the time to meet with agencies and reach an agreement for the agencies to perform a transition service, there is still no-one held accountable for accomplishing the task and managing the service effectively:

> But no one's accountable. Everyone sits around from the [service] agencies and agrees to the stuff on the board and says, "Yep, we'll do all this." Then at the end of the day nobody does anything (FG2, G, p. 34).

The lack of accountability increases loss, as parents feel powerless. Because no one person is seen to be accountable for agency provision and fund management, there is discrepancy in the level of service provided. Discrepancy undermines the transition process. Some individuals working in agency roles provide excellent service, while others fall short of expectations. Families expect a consistent high level of service from agencies and to be treated equitably as per objectives 6 and 15 of the New Zealand Disability Strategy (2001), yet this is not always achieved:

> Our expectations are that people actually do the job they are paid for and I get very angry when I know full well that if you go into this agency, and you know this person in this job then it gets done, and [if you get another] person – it doesn't get done…I think that is a fully justified expectation when other people can go in there and get the service and get the support from that same place that I should be able to go in and get the same treatment (FG1, C, p. 35).

Participants' expectation of a high level of transition services from service agencies was also not achieved when agencies provided poor access to information:

> The information is precious but it's so hard to find…..I don't see why [the agencies], can't give you that information or the information they give you is so out of date ….they just send you on wild goose chases all over the place (FG1, D, p. 42).

The poor access to information led to parents feeling frustrated, with the potential for power imbalances between parents and agency professionals. There was a feeling that the professionals held power over parents by controlling the information they gave to parents and guarding their professional knowledge.

> [They say] 'You should be doing a day programme with the child'. Where, when, how. Tell me. Give me that information. Yes I should be! Yes he should be! But where? Give me the practical information to do these things that the professionals are saying (FG1, C, p.31).

1b. Service Mismanagement: Access

Alongside problems experienced with agencies, participants also spoke about their difficulties with service mismanagement and accessing services during the transition period. The shutting down and loss of services, due to an ideological push towards mainstream inclusion has reduced service access options and runs counter to the vision of an inclusive society, expounded in the New Zealand Disability Strategy (2001):

> Inclusion has been lost again for us. We have just been shut out. [My son's] club at [disability specific service], they shut it down (FG1, C, p. 22).

Service access has been denied because the services that supported disabled people do not exist. Recent government inclusion policy encourages agencies to provide disability services in the community (New Zealand Disability Strategy, 2001):

> So they've shut down all the services. Because they are not inclusive. What they've done even before the transition is just lose, lose, lose with nothing to replace it… for our guys there is nothing (FG1, D, p.22).

The emphasis on community inclusion, with resulting shut down of non-inclusive disability services, is in part a reactionary response to historical problems dating from the time when disabled people were forced into institutions. The consequent deinstitutionalisation of disabled people in the 1980's (refer to Chapter 2) combined with the 1990's health reforms when health and disability services were reduced nationwide (Ashton, 2005; Easton, 2002), has resulted in service mismanagement:

> I think that all came from 50 years ago when somebody would have just been in an institution…so they shut them all down, but then there's nothing to take its place (FG1, B, p. 22).

The ideology behind these inclusion policies is to promote community integration by funding inclusive community projects, yet the reality for many is very different:

> The theories and the strategies and the policies [of inclusion] and all that, it all sounds wonderful. The problem is there is a gaping black hole between that and every day reality. That's the problem (FG1, B, p. 20).

The extremely limited functional level of young people with complex disabilities blocks their access to community services provided for able-bodied young people during transition, such as work experience, university orientation or sports teams. Without access to services, these young people lose the opportunity to participate in society and are frequently left at home to occupy themselves:

> They [Government policy makers] say [our young people] need to be mixing with the community and they're not, they are just sitting at home watching TV or listening to music (FG1, A, p. 19).

Because these young people are unable to participate in most 'normal' community activities and their previous non-inclusive disability services have been shut down, service access is a major issue. As services disappeared they were not replaced. Parents foresaw this problem when their offspring were young, and have lobbied for the government for years. Even so, parents continue to struggle for realistic transition services:

> There is absolutely nothing available [services] and I think what really upset us was that we had been warning the powers that be that these kids were getting older...for at least 10 years prior to them leaving school we had to spend all that time saying "What is going to happen when they leave school?" It just fell on deaf ears really (FG2, F, p. 2).

Despite knowing transition services were not available, parents still hoped the government would become responsive to what are well documented problems in the disabled community (McCallin et al., 2007; Morris, 1999; Neubert, Moon & Grigal, 2002; Office for Disability Issues, 2005):

> The whole leaving school business – we spent a couple of years looking at [service] options for ----, hoping to have something in place for him by the time he left school …but we were just left with nowhere for him to go which was devastating because he is a very social lad (FG2, G, p. 2).

On the rare occasion that services were available, access was limited if they were not perceived as enjoyable, or suitable for the young person:

> I just can't palm him off for the sake of palming him off. If I'm going to have a break and relax and actually feel better I want to think that he is actually getting enjoyment in what he is doing [day programme services] (FG1, D, p. 40).

One participant commented that she did not expect as many services to be provided now her son had left school. Access problems were expected, with parents having few expectations of an effective transition service following years of struggles with service mismanagement and 'the system' (Reiss, 2005; Smart, 2004).

> I don't think many kiwi parents, we don't have very high expectations [of service provision] do we? (FG1, A, p. 30).

After many years of fighting for access to services to which they were entitled but did not receive, it is surprising that the parents could maintain a sense of proportion and not be over demanding:

> I don't expect anybody, or the system to provide [services] like he was when he was at school. Like 5 days a week from 9 to 5. I mean that would just be ridiculous (FG1, D, p. 21).

These years of caretaking and fighting 'the system' take a toll on parents, as can be seen in the following section on caretaking tensions.

2. Caretaking Tensions

In this study, caretaking tensions are defined as the difficulties of sharing the physical caretaking of a young person between parents and external caregivers. Care giving is not unique to those with complex disabilities. All babies and young children require their parents' full involvement as caretakers to keep them safe and ensure their needs are met. With able-bodied children however, the parental role gradually changes from caregiver to mentor, coach and supporter as the child grows and becomes more independent (Biddulph, 1997; Grant & Cowan, 2001). Yet for parents of those with complex disabilities the caretaking role does not lessen, as the young person continues to require care. Parents continue to regard themselves as the primary caregivers, yet the nature of complex disabilities means that care giving is necessarily shared, willingly or not. Too often, it must be shared with untrained people who do not appear to know what they are doing. Loss is incurred as the parent is aware of their continuing parental responsibilities, but after

twenty years of care giving they are no longer physically and emotionally able to do what they did when their child was younger and smaller. They must increasingly share the physical caretaking with external caregivers and battle to retain decision-making authority in their young person's life. The tensions caused by this shared caretaking role are discussed in this section under the headings of *caregiver unpredictability* and *diminishing parental influence.*

2a. Caretaking Tensions: Caregiver Unpredictability

The participants used caregivers [5] in a variety of ways. Some carers provided full time care in a residential setting, some provided out of home respite, both day programmes and overnight, while others worked in the family home assisting the young person while the family went about other activities. Carers were a mix of extended family and paid, untrained (i.e. not registered nurses) workers chosen by the service agencies. Tensions arose between parents and service agencies when parents had little input into choosing their caregivers. Caregiver unpredictability in terms of providing acceptable service was a significant issue for most participants. In particular, the quality of the care provoked much debate amongst participants. Apparently, good caregivers were available although the quality of care giving was unpredictable:

> There are some fantastic ones [caregivers] that we've come across as well, it's just they're a mixed bag (FG1, A, p. 11).

---

[5] The terms caregivers and carers were used interchangeably by participants to refer to other adults who provide care and assistance to their young person.

Caregiver unpredictability is at odds with objectives 7 and 8 of the New Zealand Disability Strategy (2001), which state that the government will 'create long-term support systems centred on the individual' and 'support quality living in the community'. Caregiver inconsistency seems to be partly due to the quality of the training provided to carers. While some service agencies appear to be working towards a non-disabling society, training gaps are evident (Objective 1, New Zealand Disability Strategy, 2001):

> The quality of the carers [training] rather than the caregivers themselves [is important] (FG1, B, p. 11).

Any adult can become a caregiver of a person with a disability. The fact that there are no formal training requirements or qualifications, and no national quality standards causes tension. This was an issue for many participants:

> Because now people with disabilities are out in society, we need caregivers that are trained and to make it a career (FG1, A, p. 43).

Having untrained people looking after young people with highly complex needs such as fragile medical health, seizures, or challenging behaviours causes tension. It undermines objectives one, two and eight of the New Zealand Disability Strategy (2001), as well as potentially endangering the health and well-being of the young person (refer to p. 6). The risk is such that parents often choose to stay close to home when untrained caregivers are on duty:

Even with the 2 carers we had, I don't tend to go far because there are so many different scenarios with the seizures and they [caregivers] all panic and if you had that qualified [nursing] staff I would have been able to have had more of a life for myself (FG2, G, p.25).

Caregiver unpredictability was also emphasised as a trust issue. Parents spoke of having to entrust their young person to the care of a relative stranger, and losing control when they were absent. The unstated tension between those sharing the caretaking responsibility was clear:

You have to be really trusting that they'll [caregivers] look after them don't you? (FG1, B, p. 7).

It's about trusting people who do not have the medical knowledge and have not been trained to look after a young person with complex disabilities. As the young person is not usually able to speak, parents have to trust the word of the caregiver in regards to what has happened through the day. They have to trust that not only has their young person had their physical needs met during the day, but that they have been in an emotionally supportive environment, with caregivers providing stimulation and empathy:

All the time you are hoping that the caregiver will look after him properly (FG1, A, p. 40).

The discussions around trust issues also uncovered an unexpected and significant concern – that of caregiver abuse. In both groups, there were participants whose young people had been affected by caregiver abuse:

The number of kids that have been sexually abused is huge....It was only by chance that our old carer was actually arrested, because if it had just been [our son who was abused] it [the arrest] would never of happened…. because the police won't follow up if the kids are non-verbal and they're not considered to be able to give evidence about people, and these monsters [the abusers] know that and they can't prove anything (FG2, G, p. 27).

When I think about the horrible people that could be looking after them. That's how I get sort of "Oh God they could get a paedophile" (FG1, B, p. 13).

The inherent tension around caregiver abuse may prevent parents from taking up care giving services, resulting in a loss of options and support:

It's terrifying for parents [the risk of abuse]. If [my son] had been a female there is no way I'd ever put him into care. No way (FG1, C, p. 44).

Presenting a balance to the issues of poor caregiver quality, training and trust, comment was made that it was difficult for any caregiver to match up to parents' exacting standards, as no-one else could ever provide the level of care and love of a parent. While most parents acknowledged this point, they still persisted in judging caregivers with the same standard as themselves. This led to caretaking tensions as untrained caregivers failed to meet their grade:

It is a worry for the future. Because nobody can provide for him as well as we can (FG1, C, p. 2).

When parents say no service will measure up, it can be argued that they lose out automatically before the service has even begun. Parents may be contributing to the loss with their unattainable standards. In spite of this, parents did not underestimate the demands of care giving as a job. The role is demanding and stressful, with funding restrictions meaning caregivers frequently have to care for more than one young person at a time:

> It's [care giving] incredibly demanding I think. I find it just exhausting 1 on 1; some of these are like 1 to 10 [care giving ratios]. How you could cope with splitting your energy amongst any more than 2, high dependency people. I just don't know whether that's possible (FG1, B, p. 11).

The demands of care giving lead to a significant level of caregiver burnout and a high turnover of caregivers. This unpredictability of caregivers leads to more pressure on the young disabled people who frequently have to adjust to new caregivers, and also on the families who need to train the new caregivers themselves. The high turnover of caregivers leads to tension and a feeling of loss of control in families:

> It's the quality of the staff. The turnover of caregivers, all of those sorts of things [make it hard] (FG1, A, p. 9).

2b. Caretaking Tensions: Diminishing Parental Influence

As noted previously, when able-bodied children grow to adulthood, parents gradually relinquish control and have a diminishing influence in their lives. For young people with complex disabilities, this natural maturing and parting from parents does not always occur. Caretaking tensions arise because parents resist this loss of control in their young person's life, perceiving them as children who continue to need their support.

> I think it's because they're still kids. You know, like ---'s sister, as she was growing up, as she got more able I just respectively stepped further back out of her life. It was a natural parting. That doesn't happen naturally with our guys because they never can do anything independently so they just don't go off (FG1, C, p. 28).

The inherent tension of caretakers, whether they are parents or agency caregivers, goes back to differing understandings of complex disabilities versus normal needs. For example, service agencies may not share the parental view of the young person still being a child in need of their parent's influence. Indeed, most agencies recognise young disabled people as autonomous adults with individual responsibility for decision making. When agencies treat the young person as autonomous, tension arises with parents feeling diminished as their parental role is reduced:

> You just get so diminished [by service agencies] because they [young people] are now adults and [service agencies] think the [young people] should be making up their own minds (FG2, F, p. 20).

Because service agencies do not grasp the severity of the impairments experienced by young people with complex disabilities, they cannot see the need for continued parental management in these young people's lives. Meanwhile, parents believe service agencies are offering caretaking services at a level that is insufficient for this particular population. The tension between fundamentally differing views leads to service agencies trying to control families in an attempt to align families with their philosophy:

> [Service] agencies still, I think, do control families quite a bit even though the families are meant to be the ones that have the say (FG2, E, p. 32).

Even when parents are included in decision making processes, if those decisions are then cast aside and not implemented, parental control is lost as the service agency again appears to have taken control, with parents feeling their influence is being diminished as their views are ignored:

> Whilst theoretically the care plans and the lifestyle plans and things are all done with families, it's my experience that [service] agencies then just go ahead and do whatever they want to anyway (FG2, F, p. 26).

Extending this idea of wanting to retain influence in their young person's life, some parents insisted on not losing control by assuming the role of a life-long advocate for their young person:

> Nothing gets done for [my son] unless I do it. Total and more. More than an advocate because I make the decisions as well (FG1, D, p. 13).

Parents see the need to advocate for their young person and fight to retain the right to speak on their behalf:

> There's no use asking [my son] if he thinks things are going okay. I've always spoken for him and always will [advocate] for him…he can't ever (FG2, G, p. 7).

When outside agencies would not acknowledge that young disabled people who cannot speak for themselves require parental advocacy, caretaking tensions arose, with some service providers actively attempting to minimise the parent's influence:

> They say "They must be independent; the parents shouldn't be making decisions for the kids and all that sort of thing." … I remember the dental services at --- and the guy was really rude to me when I was trying to explain to [my daughter] what he was saying. I couldn't even get him to listen to the fact that she: a) - didn't understand what the hell he was saying and b) - couldn't talk to him even if he was asking her all these questions (FG2, F, p. 7).

Perhaps as a result of these tensions and diminishing parental influence, most of the participants had followed legal channels to establish the ongoing right to maintain some control over their young person's life – the power of attorney. In New Zealand, once a person reaches 18, they are considered an adult, regardless of disability. From then on, parents have no legal rights to make decisions for their young person, unless they apply for guardianship (power of attorney) through the court system. Guardianship status only applies for three years, so parents must regularly repeat this process. If the parents do not apply for guardianship, either the

young person is presumed to be in control of their own decisions or the service agency may be granted guardianship:

> I went and got it [guardianship] on [my son] because I said, "I'm not even going down this road." Especially with the health issues because they tried to get him to sign his consent form….He's like a 5 year old" (FG1, D, p. 47).

Tension was evident, with agencies appearing not to listen to parents unless they had the legal right (power of attorney) to speak on their young person's behalf:

> Professionals don't seem to trust that parents know their young person best, especially once they are over 18 or 16 or whatever. If I have to get asked one more time if I have power of attorney - I will scream. They would just love that I didn't have it, then they [service agencies] could do whatever they want and it really upsets me that I do have to actually legally have that ability (FG2, F, p. 20).

There seems to be a fundamental paradox here. Parents push to retain influence in their young person's life, stating they must be treated differently due to the complexity of their disabilities. Yet parents still want the same treatment as others in terms of 'being in a fully inclusive society that values their lives and enhances their full participation' (New Zealand Disability Strategy, 2001).

If the service agencies hold guardianship they hold the control, and can legally make decisions regarding the welfare of the young person, including changes to medication, housing and social needs without involving the parents:

We had to rush and do ours [power of attorney] because we were trying to get the care for when he first left school and the [service agency's] lawyer asked for files, he was trying to get rest home care for [our son] and they'd [service agency] written to their lawyers saying "How can we get this guy in a rest home cause it's going to cost them too much money to have him at home with us," ….and it was horrifying (FG2, G, p. 21).

3. Perpetual Childhood Management

In this study, perpetual childhood management is defined as the situation in which parents do not perceive their young person as an adult, but rather view them as being a perpetual child. The management of perpetual childhood occurs with the ongoing task of parenting a perpetual child, who looks like an adult and must live in an adult's world, yet acts like a child. Parents find managing their lives difficult when society insists on treating their young person as an adult:

He doesn't eat unless I feed him. He doesn't go anywhere unless I take him. He does nothing... So he is not an adult and I will sit and argue with people until the cows come home…So this transition to adulthood should not be transition to an independent adult, because he will never be independent, because someone will always have to care for him, manage his life and supervise him as best that they can (FG1, D, p. 8).

Parents understand that their young person needs support and decision-making management to assist them in their everyday life:

> He functions at 5 or 6 year old levels and he just isn't capable of making fine or healthy decisions for himself (FG1, B, p. 13).

The "child" looks like an adult, is the age of an adult and has the behaviour and understanding of a child. But, because the last point is not visible, service agencies view the adult-looking child, possibly not unreasonably, as an adult. This is consistent with the overall vision of the New Zealand Disability Strategy (2001), in that young disabled people are treated as autonomous adults. Nevertheless, it is at odds with objective 13 of the New Zealand Disability Strategy – to enable children and disabled youth to lead full and active lives and also objective 9 – to support lifestyle choices, recreation and culture for disabled people. Young people with complex disabilities are not supported in their lifestyle and cannot lead full lives. They cannot function as autonomous adults and hence their access to normal community is blocked. Tensions between service agencies and parents were evident:

> Well [my daughter] functions at a 2-year-old level. So she actually would like to go to MacDonald's and play in the playground or whatever…. She takes her doll everywhere and we had a huge argument with ------ from [service agency] about that because he's like "This isn't appropriate." I said, "This is very appropriate at her age level" (FG2, F, p. 19).

3a. Perpetual Childhood Management: Loss of a Normal Life

As discussed previously, because parents view their young person as a perpetual child, many choose to remain in control of their young person's life through guardianship. This means perpetual parenting becomes a reality, with the accompanying loss of a normal life. While parents of able-bodied children anticipate a time when their young people will grow up and leave home, these parents never experience that reality. For them, there is no such thing as an ordinary or normal life (New Zealand Disability Strategy, 2001):

> If you ask the Ministry [of Social Development] for their vision, it's all about living an 'ordinary life'. It's just crap. None of us have ordinary lives (FG2, F, p. 12).

Unless they choose some form of residential care, parents will continue to actively manage their young people's lives and care-give into the foreseeable future with the resulting loss of a chance at a normal life:

> Again I'm back to managing his life, that's what transition means to me. It's just losing everything (FG1, D, p. 9).

Everyday activities most people take for granted in a normal life are denied these parents. Even the basic right for parents to earn their own living is lost due to the perpetual childhood status of their children, with the consequent financial burden on society:

> To even attempt to get a job I've just never bothered because it's impossible, there is just no [care giving] back up for me. I have to be there (FG1, D, p. 30).

Ongoing perpetual childhood management results in immense stress and burnout in families. While normal families care for their children until they become independent teenagers that does not happen when a child has a complex disability:

> Don't even go there. It's passed the burnout (FG1, D, p. 12).

> I was so burnt out…. I just couldn't do it all as well as care for her at the same time (FG2, F, p.33).

When parents, burnt out from years of care giving, are faced with the reality of their young person transitioning from school, along with the removal of many other support services, it can precipitate a family crisis. Transition was certainly not a time for celebration:

> She had to leave school and respite and everything else suddenly stopped because of issues. So we kind of lost it all over that period of time. It was just an absolute nightmare …..she wasn't at school and I needed to care for her 24 – 7 and I had a stroke in the process of doing it. So that was a bit of a wake up call to me that it wasn't actually possible (FG2, F, p. 5).

The loss of a normal life had ongoing implications:

> I know of two families in particular, that I've had dealings with, the most abusive situation out, the kids left school and it was fine then, the parents have had to stay home full time, both solo parents, with these kids and there's been nothing in the way of day programmes. So it's now got to the domestic violence situation where the mum's constantly beaten up and

being abused [by the disabled person]….and the kids weren't getting the right treatment either because of the mental state of the parent…now it's gotten to such a dreadful situation, the whole thing, that I think it will take a huge amount of mental health counselling and support to get …I mean I don't know what's going to happen. One of these kids or parents are going to be killed (FG2, F, p. 11).

For other parents, transition from school may be a catalyst to find permanent residential care, or increased respite care for their young person to relieve the burden of perpetual parenting and to try to recover some sort of a normal life. This is never an easy decision, and several participants expressed the guilt and grief they felt in coming to terms with it:

I had to make a decision. I didn't have a choice. I had to do it [choose residential care] and it was just like being wrenched (FG1, C, p. 29).

I do get the guilt feeling from time to time. If he has a seizure and they call me…We feel as though we should be there but there's nothing really you can do anyway (FG1, B, p. 27).

Terrible. I feel grief. The only word I can use is grief (FG1, B, p. 28).

Alongside this, parents also worry that their young people are vulnerable to exploitation by certain sectors of society. Their young people's inability to consistently make good choices may be abused by others. Concerns were

expressed that their young people will be taken advantage of if parents are not around to protect them:

>He'll be vulnerable… he's not good at making decisions (FG2, E, p. 16).

>He'd be taken advantage of… another friend of mine's son has been involved with drugs because he didn't know any better. He's been arrested and all sorts of things (FG2, G, p. 16).

3b. Perpetual Childhood management: Societal Barriers

While the large role parents play in their young person's life as they transition to adulthood has been discussed, there are significant other factors that impact on how the young person with complex disabilities experiences the adult world. The barriers society either consciously or unconsciously places on these young people has a large impact on their lives. For instance, when young people with complex disabilities transition from school they are at risk of social isolation. Caught in a world that perceives them as being adults, yet unable to work or socialise at an adult level, and with few service programmes available to fill their days, many young people become isolated in their homes. This is totally at odds with the vision of supporting quality living in the community (Objective 8, New Zealand Disability Strategy, 2001):

>I hoped to glory that something would come up but it didn't, so he was just on a programme at home but he was quite socially isolated
>(FG2, E, p. 3).

This illustrates how separated this particular group is from a society that probably does not understand and possibly excludes them without thought:

> I'd just like to see ---- (my son) not so socially isolated here. That's sad, very sad for us because he loves meeting people, loves being around a group (FG2, G, p. 14).

Even when caregivers are available to take them out, the young people's behavioural responses often dictate that society won't accept them in many community settings:

> Our problem taking him out in the community now, he can high pitch scream and he tends to do it at little old ladies in the supermarket…And that can cause us dilemmas out in society…He can really scare little children and babies, like really scare them (FG2, G, p. 18).

It is difficult for the public to be inclusive when behaviour is not socially acceptable:

> It's just very difficult because it's so unpredictable [going into society]. We could go out and have a lovely time and then she might hit somebody walking past, or something like that. So you're always on edge (FG2, F, p. 17).

Societal isolation and other societal barriers are frequently magnified by the general attitudes of society. New Zealand is nowhere near the ideal of a 'society that highly values our lives and continually enhances our full participation' (NZ Disability Strategy, 2001). As noted previously, when these young people, who look like adults but function at a child's level, act unexpectedly with inappropriate

behaviour, the general public often react negatively. This is usually due to limited societal understanding:

> These people just don't understand and they are frightened. Because when you get someone who is adult size running up to you and grabbing at you, it's intimidating and it's frightening. I don't blame them one little bit. They don't understand. They've had no experience with people with disability (FG1, D, p. 52).

> People look at him, but as soon as he walks or moves I can tell [he's different] - to me it's obvious, and it stuns me how people take 5 minutes to click. But in that 5 minutes there can be a lot of harm done. The worst one is in shops, I've had people chase him out of shops (FG1, D, p. 48).

When this limited understanding is demonstrated by outbursts from members of the public, parents are made to feel that society won't tolerate their young people out in the community. They have lost their ability to join in normal community activities as a family (Objective 8, New Zealand Disability Strategy, 2001):

> Let's face it society doesn't like our kids out there. I just have to take [my daughter] out there and she says or does something and they're all waving their arms in horror. I often find people saying she shouldn't be out here (FG2, F, p. 17).

This limited societal understanding of people with disabilities is pervasive through all strata of society. Even the professionals that we rely on to look after the vulnerable in society – the police - are not prepared or trained to understand

people with complex disability. Yet again, parents have lost a support and protection network through limited societal understanding:

> Society isn't ready for it. No way. Here's a case with the police. My son got arrested...They had no idea. They [police] didn't know what autism was… The police were furious. Their opinion was that they are not a baby-sitting service...They've got no training in it (FG1, C, p. 46).

The loss of support networks is amplified by the current government's focus on community inclusion. These inclusion policies have led to many disability services being shut down, with the consequent loss of disabled peer networks. It seems that the fundamental right to socialise and meet with their chosen friends has been lost (Objective 9, New Zealand Disability Strategy, 2001):

> It's like - he's not with his peers. So they have withdrawn the things that he loved, that he enjoyed, that worked. They [disabled young people] thought they were having a wonderful time, they were all happy. Everybody was happy until a piece of paper said they can't do it (FG1, D, p. 22).

In effect, inclusion policies have become a societal barrier by limiting the choices:

> Inclusion has been lost again for us. We have just been shut out. ----'s club at ---, they shut it down. But these guys are his mates, they're his friends, they're the ones he goes to school with… Whereas their whole theory was, they should be inclusive; he should be with his [normal] aged peers (FG1, C, p. 22).

Many of these young people find mixing with able-bodied peers difficult, and they may only be able to relax when they are with others of similar abilities:

> I think he will always need the friendship of other disabled people as well as able-bodied people. But I think he feels truly himself and able to relax and he doesn't have to try and be anyone else when he's with his friends who are like him (FG2, E, p. 38).

> So I should join him in with some youth group of a similar age, but they are going to things that he can't understand. They are not his peers. They are people that are a world apart (FG1, C, p. 22).

Conclusion

In this chapter the research findings have been presented. Overall, the data was negative, with parents expressing a sense of promises unmet and unfulfilled expectations towards their young people. Three emergent themes were identified – service mismanagement, caretaking tensions and perpetual childhood management. These themes rest within the over-arching concept of **parental loss.**

The practical realities of everyday life demonstrated through this analysis suggest full inclusion seems to be unrealistic for this population. While ideals within policy provide a vision about possibilities, if this is not supported with adequate resources and training, there is a gap between expectations and everyday life. While this can possibly be accommodated in the short-term, when it becomes long-term reality parents become most upset, not without reason. In the end it is the young person, without a voice who suffers, but that too has flow on effects onto family health and well-being. This raises significant questions in relation to social responsibility and vulnerability that will be discussed I the next chapter.

Chapter Five: Discussion

Introduction

The aim of this research was to explore the recurring issues that affect families of young adults with complex disabilities and the young adults themselves as they transition into adult life. The key issue identified is **parental loss**; loss expressed in terms of service mismanagement, caretaking tensions and perpetual childhood management – the loss of a normal life. Conceptualisation of the findings has brought to light two significant themes. These are the concepts of *social responsibility*, and *vulnerability* of both the young people and their families. In this chapter the over-arching concept of parental loss is examined. The implications of the analysis findings around parental loss are outlined and located within the wider literature. Following this, the two emergent themes of social responsibility and vulnerability are considered. The limitations of the study are explained and the chapter finishes with recommendations and implications for the future.

Parental Loss

When able-bodied young people transition from school to adult life, their parents also transition into the post parental period of life, commonly referred to as the 'empty nest syndrome.' This transition phase is generally understood to include a period of loss experienced by parents as they adjust to a different phase of parenting (Raup & Myers, 1989; Wilson, 2006).For most parents, this normal developmental loss is transitory and passes relatively quickly as psychological adjustment and acceptance of the new stage in life occurs (Boss, 2006). However, for parents of young people with complex disabilities this natural progression

through life stages does not typically occur (Ko & McEnery, 2004). Their young person remains a perpetual child in their eyes, and regardless of whether they live at home or in a residential care facility, the post-parental period is absent. This inability to move through normal life stages brings loss as parents grieve for the lack of normal development and loss of dreams for the future (Niemeier, Kennedy, McKinley & Cifu, 2004).

Kubler-Ross's seminal work around grieving and loss (1969; 1991), describes the grieving process in terms of five stages– denial and isolation; anger; bargaining; depression and acceptance. These stages are worked through as people move towards an acceptance of their loss. There is some debate in the literature over Kubler-Ross's theory, due to difficulties with the research method and concern over people being universally shunted through the stages (Gorle, 2002; Sage, 2003). Despite this, Kubler-Ross's model is still frequently cited when discussing parental grief and loss as their young person with complex disabilities transitions to adulthood (Helff & Glidden, 1998).

Although most literature dwells on the loss and negative effects of disability on family life, Trute, Hiebery-Murphy and Levine (2007) state that, while loss definitely occurs when families have a child with a disability, many parents respond to the challenges with positive coping and resiliency. Likewise, Scorgie and Sobsey (2000) identify positive parental responses in situations of childhood disability, such as personal growth in family members, improved relations with others and positive changes in spiritual values. Parents tend to report more positive family impacts as the disabled child grows, although it is unclear whether these findings last through

to the age of transition (Behr & Murphy, 1993; Glidden & Johnson, 1999). These positive findings differ from that of this research and others, which suggest that by the time the young person reaches transition families are stressed, with parents 'burnt out' from twenty years of caring (Bray et al., 2005; Reiss, Gibson, & Walker, 2005; Smart, 2004). It may be that the 'transformational parenting experiences' described by Scorgie and Sobsey (2000) occur in families with less severely disabled children, or conversely that the parental personal growth is experienced, but then the ongoing stresses and challenges lead to eventual burnout following twenty-plus years of care giving.

Another view of parental loss during transition is adopted by Boss (1999, 2006) with her theory of *ambiguous loss.* Ambiguous loss, which arose out of family stress theory, suggests that stress results whenever there is change within a family. In particular, the most severe stressors are those changes which are not clear cut, but ambiguous (Boss, 2006; O'Brien, 2007; Roper & Jackson, 2007). Consequently, when parents are transitioning a young person with complex disabilities, they may experience situations of ambiguous loss which involve 'an unclear loss resulting from not knowing whether a loved one is absent or present' (Boss, 2004, p. 554). Boss identifies two specific times when ambiguous loss may occur in these families. Firstly, when the young person is perceived as physically present but psychologically absent, due to severe cognitive disabilities, and secondly when they are psychologically present, but physically absent. This occurs when the young person moves to a residential care facility, but the family still perceive them to be in the family and grieves their physical loss.

Loss as defined in this study involves disadvantage or deprivation that results from losing, suggesting an ongoing process, rather than a one-off incident. The aspects of parental loss highlighted in this research (loss through service mismanagement, caretaking tensions and loss of normal development) seem to reflect Boss's (2004) view of parents experiencing ongoing ambiguous loss as their young people transition.

Parental loss experienced through service mismanagement is not a new concept. In fact, government departments throughout the Western world regularly audit their disability services in an attempt to reduce mismanagement and improve outcomes. (Morris, 1999; Office for Disability Issues, 2006; White Paper, 2005). In spite of this recognition, apparently little has changed to improve matters at the consumer level. Parents continue to fight to access services and funding that they are entitled to (Ko & McEnery, 2004; McCallin et al., 2007). They continue to experience loss through service mismanagement and systems that block their young people from accessing their right to as 'normal' a life as possible (New Zealand Disability Strategy, 2001). This continuing experience of loss over the years means that loss never becomes acceptable as in Kubler- Ross' theory (1969).

Similar to the anger within loss (Kubler- Ross, 1969; 1991), the fight to access services is exacerbated for parents by their increasing loss of influence in their young person's life as they transition to adulthood. From being the primary carer when their child was young, parents have had to gradually relinquish some of their influence as external influences such as other caregivers, school, health systems and service agencies came into their family's lives. Through the childhood years,

this involvement of other people in their child's life has been controlled by parents acting as the co-ordinator of their child's needs, with agencies respecting this role, in a family-centred model (Casey, 1988; Shelton & Stepanek, 1995). Though it could be questioned if agency's only respect a parent in a co-ordination role if they are a 'compliant' parent, who fits in with the agency's model of care.

By the time young people with complex disabilities transition from school, the influence and control parents have in their lives has diminished. This is partly due to society recognising the young person as an adult and partly due to the increasing influence caregivers and service providers have in the young person's life. Parents struggling to maintain control, while service providers minimise their input by focusing solely on the young person, is one of the central tenets of this study. Both parties believe they are doing the best for the young person. Parents, who believe their young person remains childlike, are protective and seek guardianship, while service agencies, following government and human rights policies, treat the young person as an autonomous adult. The problem is, the young person with complex disabilities is not an autonomous adult and never will be. With these philosophical differences in mind, it is not surprising that caretaking tensions exist between parents and service agencies.

These tensions and the stress of looking after a young person with complex disabilities can lead to a loss of health within family members, with parental burnout and stress related illnesses common (Bray et al., 2005; Smart, 2004). Parents therefore rely on service agencies to assist in caring for their young people, yet the inadequacy of service agency provision means parents are not able

to access the level of support needed (Beresford, 2004; McCallin et al., 2007).

Tension is complicated further because parents also find it difficult to access

support from the general public. There is a lack of understanding around disability

issues within the wider community, which translates to parents feeling a loss of

support and empathy for their difficulties. These ideas are expanded further under

the following concepts of social responsibility and vulnerability.

Social Responsibility

Rossi (2001) argues that people are innately social creatures, not self-sufficient

individuals and that as such, have an inherent interest in the well-being of those

around them – a view encompassed by the term social responsibility. Social

responsibility is a multifaceted idea expressing the notion of how people see

themselves as contributing to the well-being of others (Erikson, 1963; Rossi, 2001).

Social responsibility sits alongside the concepts of ethical and virtuous behaviour,

and is likely to incorporate aspects of these concepts (Levinson, 1978). In many

ways social responsibility is a subjective concept, in that it requires personal

judgment of whether an action is socially responsible. Yet on a broader political

and ethical level, government policy makers make objective decisions for all, based

on the currently accepted, collective view of socially responsible behaviour

(Erikson, 1963; Levinson, 1978).

Being socially responsible also encompasses the notion of morality, i.e. the norms

about right and wrong that are established through social consensus (Beauchamp

& Childress, 2001). Within morality, there is a distinction between common

morality, the ingrained basic moral norms most people grow up with, versus community-specific morality. These are the moral norms that arise from specific cultural, religious or institutional sources (Beauchamp & Childress, 2001). In this way for example, the differing emphasis each community puts on supporting disability services shows community-specific morality. It is argued that in the current New Zealand setting, with a community not ready to accept young people with complex disabilities and low funding support of their needs, there is a low community morality towards the needs of these young people. Likewise, service agencies may be viewed as morally unprepared (Johnstone, 1999) to support young people, as they cannot provide the services, carers or funding to enable young people with complex disabilities to lead quality lives in the community (New Zealand Disability Strategy, 2001).

Another aspect of social responsibility receiving attention in the psychology literature is that of *generativity*. That is, social responsibility that focuses on caring for the next generation, including generating it, maintaining it and benefiting it (Bradley, 1997; Erikson, 1963; Heimer, 1996). This includes caring for the current generation as a way of maintaining and improving social institutions for the benefit of the next generation. Generativity within social responsibility advocates looking after all children, assisting parents in their role of raising children and providing social supports to assist young people to transition to adulthood (Bradley, 1997; Rossi, 2001). This model does not separate out vulnerable groups, such as disabled youth, for special treatment, but rather advocates equality of treatment and access to services that will assist all of the next generation in their path to adulthood. It is argued that the problems with service mismanagement and access,

caretaking tensions and the lack of support for parents identified in this study and others (Bray et al., 2005; Hendey & Pascall, 2002; Heslop et al., 2001; McCallin et al., 2007) demonstrate a lack of generativity and social responsibility on the part of the government and society. In other words, we may have an internationally lauded New Zealand Disability Strategy, but if the people managing the practical realities do not understand the implications, then the strategy becomes a mere vision.

This lack of social responsibility for young people with complex disabilities and their families is not a new trend. Historically people with disabilities have been treated very poorly by society and they and their advocates have had to fight for many years to gain the rights of autonomous adults. The last two decades have finally seen positive progress towards enabling the rights of all disabled persons, with legalisation enacted to protect those rights (Health & Disability Commissioner's Code of Health and Disability Service Consumer's Rights 2004; Human Rights Amendment Act, 2001; New Zealand Disability Strategy, 2001). This push for equal rights for those with disabilities has been behind current government inclusion policies, which validate mainstream schooling and community experiences with able-bodied persons (NZ Disability Strategy, 2001). Inclusion policies have been a successful and positive strategy for the majority of people affected by disabilities (Office for Disability Issues, 2006). Nevertheless, for those with complex disabilities inclusion policies have worked to remove support structures such as disabled peer networks and disability specific services. This has resulted in a loss of community access and services for young people and their parents (Egerton, 2005; McCallin et al., 2007).

Government social policy encourages young people with disabilities to access their local communities (Objectives: 1, 6, 8, 9, 13 New Zealand Disability Strategy, 2001), yet society does not appear willing to take on the social responsibility of accepting young people with complex disabilities in their midst. It is possible, if not probable, that society per se is quite oblivious of its' social responsibility to others less abled in this respect. This reflects the stigma associated with being different. This study and others highlight the difficulty experienced by families when they take their young disabled person into the community (Mansell, 2006; Morris, 1999; Murray, 2007). It appears the government has implemented social policy which encourages community inclusion, while at the same time removing the disability support systems that may have assisted the process for these young people. When this is combined with a complete lack of education for the public, it is hardly surprising that these young people are not welcomed in their communities.

Through consumer panels and government studies, parents have warned the government of the consequences of closing disability services without replacing them with equivalent supports (Heslop et al., 2001; Office for Disability Issues, 2005). Yet their voice does not appear to have been heard. Currently, the care and support services for young people as they transition are disconnected, with few services even available. Care giving, health, education, family well-being and vocational training are all considered separately by various service agencies. This is causing a fragmentation of knowledge and services, with no one person or agency taking responsibility to ensure the needs of the young people and their families are met during the transition period (Morris, 1999). In effect, it appears that society is trying to manage their social responsibility to young disabled people by

fragmenting the issues. Fragmentation could be seen as a political strategy for dealing with a problem that is too difficult, or has no easy solution. This is costly in terms of overlapping resources in some areas and gaps in services in others (Bent et al., 2002; Beresford, 2004). The result is poor outcomes for the young people and their families.

Because of the fragmentation of services during transition, parents step into the role of case manager by default, trying to co-ordinate and advocate for the best possible services, as they did when their child was younger. However, as identified during this research, parents perceive that this role is diminished when their young person reaches the transition years, as agencies attempt to treat the young person as an autonomous adult, which they are not. The ongoing role of parents in these young people's lives needs re-examining. As an example, the current need for parents to take on guardianship if they want to retain influence in their young person's life is perceived by parents as a loss of support after their years of care giving and a negation of their ongoing parental role.

However, government policy and indeed, most disability rights groups are generally against the concept of guardianship for most disabled people (Mirfin- Veitch, 2003; New Zealand Disability Strategy, 2001). Concern over parents undertaking guardianship of young people with complex disabilities is understandable given the historic poor treatment of people with disabilities. Nonetheless, there is a need for this small segment of the disabled population to be recognised as different from the rest. Young people with complex disabilities are particularly vulnerable and require extra support over and above that given to others with less complex disabilities

(Bray et al., 2005; Smart, 2004). They are not capable of making informed choices at an adult level. Parents do not perceive guardianship as taking away their young person's autonomous rights, but rather view guardianship as a continuation of parenting – protecting the young person who remains a perpetual child in their eyes. They view themselves as being socially responsible by continuing to be advocates for this vulnerable group of people.

Vulnerability

To be vulnerable is to be capable of being physically or emotionally wounded or hurt (Collins, 2005). The word can also refer to being defenceless, exposed or weak (English Thesaurus, 2005). In the socio-ethical model, the term vulnerable is often used in the context of vulnerable population groups. Typically placed under this heading are the young, the elderly, ethnic minorities, the sick and the disabled (Blumenthal, Mort & Edwards, 1995).These groups are deemed the most in need of society's protection and support as they are subject to exploitation (Macklin, 2003). Government social funding often targets these vulnerable groups and legislation such as the New Zealand Disability Strategy (2001), the Health and Disability Commissioner's Code of Health and Disability Services Consumers' Rights Act (2004) and the Human Rights Amendment Act (2001) seek to protect them.

However, in spite of socio-political attempts to protect certain groups in society, people with complex disabilities remain vulnerable. This vulnerability occurs in most facets of their lives. Physically, people with complex disabilities are

vulnerable as they must negotiate a world designed for able-bodied people. For example, they usually require assistance to move, eat and use the bathroom; they may need others to speak on their behalf; they may require high tech medical equipment with them at all times. This need for the physical assistance of others reduces the young person's autonomy and makes them vulnerable to the choices and actions of others (Beresford, 2004). Intellectually, young people with complex disabilities are equally vulnerable. As discovered in this research and others, these young people are at risk of being exploited and taken advantage of by others (Clegg et al., 2001; Hames, 1996).

At its extreme, this vulnerability and exploitation can manifest in sexual abuse of the young person (Hames, 1996; Joyce, 2003). It was significant that in this small research project several of the participant's disabled young people had experienced sexual abuse and one caregiver had been convicted of the crime. Joyce, Ditchfield and Harris (2001) in reviewing the abuse literature found that on average, 14% of less severely disabled people articulated incidents of abuse, and were themselves sometimes the abuser. As the young people in this study are unable to tell people if abuse occurs, the numbers of undisclosed incidents may differ from the percentages expressed in the literature. However, while these young people cannot talk, they may show other signs, such as a sudden change in behaviour or emotions, which lead parents and caregivers to suspect abuse. It is difficult for parents to get recognition and police involvement in this crime. Because the young people are generally unable to speak and have low cognitive function, police find it difficult to prosecute abusers (Joyce, 2003). Physical evidence is required, the gathering of which is in itself traumatic for young disabled people.

Abusers appear aware of this legal loophole and may specifically target this vulnerable group, knowing they are unlikely to be prosecuted.

Interestingly, while society generally acknowledges that young people with complex disabilities are a vulnerable segment of the community, service agencies do not manage them as if they are vulnerable. There is an incongruous tension between disabled people being protected as a vulnerable population on the one hand and on the other, inclusion and equal rights legislation recognising these young people as autonomous adults (Health and Disability Commissioner's Code of Health and Disability Service Consumer's Rights 2004; New Zealand Disability Strategy, 2001). Health professionals are now expected to gain informed consent for procedures from the person with a disability, rather than the caregiver who brings them to appointments. Right Seven in the Health and Disability Commissioner's Code of Health and Disability Service Consumers Rights Act (2004) states that people are presumed competent to make choices and give consent unless there are reasonable grounds to conclude otherwise. It goes on to state that if a person has diminished competence they should be allowed to make choices and give consent to the level of their ability. After years of disabled people being ignored, or treated as incompetent, this is a worthy and much needed change in attitude. However, for the very small segment of the disabled population with complex needs, being treated as autonomous adults is inappropriate and even frightening for some. Right Seven of the Act seems to have been taken to extremes in some cases, with some service providers and health professionals treating people with complex disabilities as competent to give informed consent. As

an example, participants in this research clearly indicated how bewildered their young people became when strangers tried to ask them questions.

The effect of these young people's vulnerability impacts on families. While the young people with complex disabilities are noticeably affected, the parents and families of these young people also experience more hidden aspects of vulnerability. McCallin, Dickinson and Weston (2007) refer to the economic vulnerability of families in this context. Their findings highlight the vulnerability of families relying on agencies for funding approval to access caregivers and services. Families of young people with complex disabilities are also rendered economically vulnerable by the difficulty of managing paid work with a disabled person at home and by the high numbers of single parent families.

In addition to economic vulnerability, families of young people with complex disabilities are also psychologically vulnerable. These families' lives are not 'normal' (Office for Disability Issues, 2006), but are constrained in many ways. This research joins other literature in acknowledging the burnout and stress experienced by parents after years of constant care-giving and 'fighting' the system (Cummins, 2001; Heslop et al., 2001). This burnout leaves them vulnerable to stress related illnesses and mental health challenges. Levine (2005) argues for support for vulnerable families, questioning the social justice of supporting just the young disabled person, without considering the needs and stressors of the whole family. Other literature notes the emotional vulnerability of siblings and the family unit when the young person transitions from school to the community (Egerton, 2005; Smart, 2004). This is often a time when parents are required to put all their

emotional energy into the needs of the young disabled person and have nothing left to support each other, or other members of the family (Murray, 2007).

These families also experience a tremendous sense of vulnerability when they consider the future (Pascall & Hendey, 2004). In this research, virtually all participants had a pessimistic outlook on the future. There was a sense of resignation, with some people unable to look beyond tomorrow, as the future seemed too bleak to contemplate. For many parents, looking beyond the daily struggle is too hard, while others experience extreme stress at the thought of what will happen to their young person when they are no longer able to cope (Roper & Jackson, 2007; Shelton & Stepanek, 1995). Parents' experiences to date leave them unconvinced that relying on current service provision and fluctuating government policies will be enough to support their young people through their adult years (Carpinter et al., 2000).

Perhaps the crux of this long-standing issue lies with the New Zealand Disability Strategy (2001). Currently, the strategy appears to be more a visionary statement, with laudable ideals, rather than a plan for action. What is lacking is the operationalising of the strategy. This is problematic because it raises expectations both politically and in the disabled community, that are simply not fulfilled in a society that appears unaware of their responsibilities. The recommendations for political and service changes need to align with the New Zealand Disability Strategy and flow into real action at the grass-roots level. Change management, strategic leadership and service evaluation are required to allow the unfulfilled expectations of these vulnerable young people and their families to be realised.

Study Limitations

This small qualitative research project was designed to explore the family perspective of transition to adult life for young people with complex disabilities. The research was undertaken within the scope of a dissertation carried out in partial fulfilment of the requirements for a Masters in Health Science. The size of the study and the facilitation of two focus groups with seven participants mean the findings cannot be generalised beyond this group of participants at this point in time and setting.

Because of the emotional nature of the topic, the subjectivity of the study could be considered a potential limitation. While the qualitative approach used in this study assumes the researcher has an influence on the study, and social constructivism would suggest the participants and the researcher construct their reality together, there was also the potential to be drawn into the strong sentiment expressed and lose some objectivity. It is up to the reader to decide whether a balanced argument has been presented.

Nonetheless, the findings will contribute to the limited local body of disability literature. It is possible that parents in similar settings may identify and relate to the experiences and findings of this research. The research also presents an opportunity for groups involved in disability service to pause and explore their practice. The findings suggest that the area of complex disability is intricate and rich in unexplored experiences and would benefit from further qualitative study.

Implications and Recommendations

The participants in this research gave freely of their time, wisdom, and insight, in exploring transition experiences from a family perspective. When people open up their experiences and perceptions for discussion, the observer becomes aware of the many layers and complexities hidden beneath the surface. New information is uncovered, which can lead to recommendations for future practice and policies. In this manner, the concept of parental loss was drawn from the research findings. The loss identified from the findings focuses on issues of service mismanagement, care giving tensions and the ongoing management of a perpetual child. If social responsibility and vulnerability for this small population in NZ is to change, some strategies for future planning are required.

Firstly, the ongoing role of parents in these young people's lives needs re-examining. For the variety of reasons discussed earlier, parents continue to be fully involved in their young person's life. The existing tension between parents and service agencies over the parental role and control issues impacts negatively on all concerned. Parents in this study wanted service agencies and professionals to acknowledge their expertise and knowledge of their own offspring and to be actively involved in decision making.

Secondly, several participants wanted the family-centred model of care, with its emphasis on supporting and involving the whole family unit, to continue through the transition years. Continuation of family-centred care may also provide some of the much needed support for vulnerable families, argued for by Levine (2005).

Because these families lives are not 'normal' (Office for Disability Issues, 2006) and significant burnout and stress occur, the support needs of the whole family should be considered by service agencies. When parents are supported with appropriate, timely, and efficient care giving services, respite and funding, they are enabled to continue their parenting role.

Thirdly, this very small segment of the disabled population needs to be recognised as different from the rest, with government policy allowing for these differences. This minority sector of society is actually a specialist group in their own right, but unlike other specialist sectors, such as the deaf community, their lack of recognition means they slip between the cracks in terms of policy, services and funding. There are very few services available for young people with disabilities as they transition. The few services that are available tend to cater for those with mild to moderate disabilities, and follow the governmental policy of community inclusion. This exposes a significant gap in service provision, with nothing available for those with complex disabilities. Young people with complex disabilities are particularly vulnerable and require extra carer and funding support over and above that given to others with disabilities (Bray et al., 2005; Smart, 2004). They are not capable of making informed choices at an adult level, and find most enjoyment when allowed to mix with disabled peers, as well as the community. Acknowledgement of this extra need with governmental policy and service agency changes would improve the daily lives of young people and their families and go some way to addressing the unmet objectives of the New Zealand Disability Strategy (2001).

To assist the recognition of people with complex disabilities as a specialist minority group, the fourth recommendation is for a public education campaign to improve disability literacy in society. Public education can break down societal barriers, as seen by the recent Mental Health media campaign to reduce the stigma of mental illness, by increasing mental health literacy in the general population (Jorm, Barney, Christensen, Highet, Kelly & Kitchener, 2006). When people with complex disabilities are recognised as a speciality group in society, and the public's understanding of this group increases, the New Zealand Disability Strategy's vision of an inclusive society may move from being a dream to a possibility for these young people.

Finally, support for care giving as a career, or at the very least, provision of caregiver training would assist in improving the quality of caregivers, and hence show adherence to objectives 1, 7, and 8 of the New Zealand Disability Strategy. Care giving unpredictability, with the associated issues of poor training, trust and the potential for caregiver abuse identified in this study, is not supportive of young people with complex disabilities. Recognition of this important, but unheralded role is needed. There is however, some hope for the future for those caring for young people with complex disabilities. During the course of this research, the New Zealand government announced the formation of a new Carers Strategy, to be launched in 2008. This strategy is the result of strong lobbying by the New Zealand Carers Alliance, a coalition of forty- three non-profit groups, whose untrained members care for people ranging from sick babies and disabled children, through to the infirm elderly. The government is working in partnership with the Carers Alliance to develop a vision and principles to improve the lives of untrained carers

(Caring for New Zealand Carers, 2007). While some people remain sceptical, it is hoped this new legislation giving carers formal recognition and support, will have some flow on effect at a grass roots, practical level. While this new strategy is aimed more at supporting unpaid family carers, rather than paid care giving workers, it is at least an acknowledgment that government recognise the need to provide increased support in this area.

These recommendations have implications for those working with families and young people with complex disabilities in the areas of special education, health care provision, disability services, and disability policy. It is suggested that service agencies and individual professionals reflect on the way they relate to parents and in particular consider the benefits of continuing the family-centred model of care through the transition years. Parents also need professionals to be upfront about the lack of adult services and get them involved early in the transition process, while the young person is still at school. In this way, parents have several years to prepare and can advocate for change to provide the services they need when their young person transitions from school.

At a governmental level, work is needed to ensure that disability policy reflects the needs of all disabled people and that the vision of the New Zealand Disability Strategy is advanced. Recognition that this small group of disabled young people is a specialty group with distinct needs, which differ from other disabled people, is essential. When those who have complex disabilities are treated under the general disability umbrella, service provision is not only inadequate, but in many cases, non-existent. Also, the proposed Carers Strategy (Caring for New Zealand Carers,

2007) needs to be robust, with support for care giving as a career, as well as practical and financial support for family carers.

Further qualitative research exploring the differing needs of those with complex disabilities versus those with lesser disabilities would support these recommendations. Additional research into the impact the lack of adult disability services are having on disabled people and their families would also be of benefit.

Concluding Statement

This research has provided an insight into the experiences of parents living with a young person with complex disabilities as they transition from school to adult life. The complexity of their daily lives, as they struggle to adjust to the loss of services, their loss experienced through unfulfilled expectations, the tensions associated with care giving and the management of a perpetual child have been highlighted. The role of societal responsibility in looking out for this vulnerable section of the population has been questioned. Ongoing fragmentation of services, that are under-resourced and difficult to access, means that this group of people has a low priority status in terms of disability services. In particular, governmental policy supporting an inclusive, non-disabling society, where all people are valued and encouraged to participate in society, just does not occur for these young people and their families. Much work remains to be done if these young people are to be supported in this vision and have their unfulfilled expectations met.

References

Alwell, M., & Cobb, B. (2006a). A map of the intervention literature in secondary special education transition. *Career Development for Exceptional Individuals, 29*(1), 3-27.

Alwell, M., & Cobb, B. (2006b). Teaching functional life skills to youth with disabilities. National Secondary Transition Technical Assistance Center. Retrieved April 15th, 2007 from http://www.nsttac.org

Ashton, T. (2005). Recent developments in the funding and organisation of the New Zealand health system. *Australia and New Zealand Health Policy, 61*, 253-262.

Auckland University of Technology Ethics Committee (2007). Ethics knowledge base. Retrieved September 7th, 2007 from http://www.aut.ac.nz/about/ethics

Australian Institute of Health and Welfare. (2001). *Australia's welfare 2001.* AIHW cat. No. AUS 24. Canberra, Australia: AIHW.

Barnartt, S. (2001). Using role theory to describe disability. In S. Barnartt & B. Altman (Eds.). *Exploring the scope of social science research on disability.* (pp. 53-75). Baltimore, Pennsylvania: JAI Press.

Beauchamp, T.L., & Childress, J.F. (2001). *Principles of biomedical ethics* (5th Ed.). New York: Oxford University Press.

Behr, S.K., & Murphy, D.L. (1993). Research progress and promise: The role of perceptions in cognitive adaptation to disability. In A. Turnbull, J. Patterson, S. Behr, & D. Murphy (Eds.). *Cognitive coping, families and disability* (pp. 151-163). Baltimore, Pennsylvania: Brookes.

Bent, N., Tennant, A., Swift, T., Posnett, J., Scuffham, P., & Chamberlain, A. (2002). Team approach versus ad hoc health services for young people with physical disabilities: A retrospective cohort study. *Lancet, 360*, 1280-1286.

Beresford, B. (2004). On the road to nowhere? Young disabled people and transition. *Child: Care, Health and Development, 30*(6), 581-587.

Berg, B.L. (2001). *Qualitative research methods for the social sciences.* (4th ed.). Boston, USA: Allyn and Bacon.

Berglund, C.A. (2001). *Health research*. Victoria, Australia: Oxford University Press.

Bethall, J. & Harrison, M. (2003). *Our life, our say! A good practice guide to young people's peer mentoring/ support.* York, UK: Joseph Rowntree Foundation/ Pavilion Publishing.

Biddulph, S. (1997). *Raising boys.* Sydney, Australia: Finch.

Bignall, T., & Butt, J. (2000). *Between ambition and achievement: Young black disabled people's views and experiences of independence and independent living.* Bristol, UK: Policy Press.

Blum, R.W. (1995). Transition to adult health care: Setting the stage. *Journal of Adolescent Health, 17*, 3-5.

Blum, R.W., Hirsch, D., Kastner, T.A., & Quint, R.D. (2002). Consensus statement on health care transitions for young adults with special health care needs. *Pediatrics, 110*(6), 1304-1307.

Blumenthal, D., Mort, E., & Edwards, J. (1995). The efficacy of primary care for vulnerable population groups. *Health Services Resources, 30,* 253-273.

Boss, P. (1999). *Ambiguous loss.* Cambridge, MA: Harvard University Press.

Boss, P. (2004). Ambiguous loss research, theory, and practice: Reflections after 9/11. *Journal of Marriage and Family, 66,* 551-566.

Boss, P. (2006). *Loss, trauma and resilience.* London: Norton.

Bowling, A. (2002). *Research methods in health. Investigating health and health* services (2nd ed.). Buckingham, UK: Open University Press.

Bradley, C.L. (1997). Generativity- Stagnation: Development of a status model. *Developmental Review, 17*(3), 262-290.

Bray, A., Moss, J., Forrester, K.,& McConnochie, K. (2005). *Evaluation of the complex carers group project.* Dunedin, New Zealand: Donald Beasley Institute.

Carey, M.A. & Smith, M.W. (1994). Capturing the group effect in focus groups: A special concern in analysis. *Qualitative Health Research, 4*(1), 123-127

Caring for New Zealand Carers: Your life, your work, your say. Consultation document. Wellington: Ministry of Social Development. Retrieved 17th November, 2007 from http://www.msd.govt.nz/work-areas/cross-sectoral-work/carers-strategy

Carpinter, A., Irwin, C & Rogers, G. (2000). *Just surviving: Talking with parents of children with very high disability support needs about how they get by.* Ministry of Health, Wellington, New Zealand.

Carr, E.G., Horner, R.H, Turnbull, A.P., Marquis, J.G., Magito-McLaughlin, D.M., & McAtee, M.L. (1999). *Positive Behaviour Support for People with developmental Disabilities: A research synthesis.* Washington, DC: American Association on Mental Retardation.

Casey, A. (1988). A partnership with child and family. *Senior Nurse, 8(*4), 8-9.

Charmaz, K. (2000). Grounded theory: Objectivist and constructionist methods. In Denzin, N. and Lincoln, Y. (Ed), *Handbook of qualitative research* (2nd ed.). Thousand Oaks, California: Sage.

Charmaz, K. (1994). The grounded theory method: An explication and interpretation. In B.G. Glaser (Ed.), *More grounded theory methodology: A reader.* California, USA: Sociology Press.

Clegg, J., Sheard, C., Cahill, J., & Osbeck, L. (2001). Severe intellectual disability and transition to adulthood. *British Journal of Medical Psychology, 74,* 151-166.

Collins English Dictionary (2005). Glasgow, UK: Harper Collins.

Cope, C. (2003). *Fulfilling lives: Inspection of social care services for people with learning disabilities.* London, UK: Department of Health.

Cresswell, J.W. (1994). *Research design – qualitative and quantitative approaches.* Thousand Oaks, CA: Sage.

Crotty, M. (1998). *The foundations of social research.* St. Leonards, Australia: Allen & Unwin.

Cummins, R.A. (2001). The subjective well-being of people caring for a family member with a severe disability at home: A review. *Journal of Intellectual and Developmental Disability, 26*(1), 83-100.

De Laine, M. (1997). *Ethnography. Theory and applications in health research.* Sydney, Australia: MacLennon & Petty.

Dean, J. (2003). *Scotland's young disabled people: Their housing experiences, aspirations and beliefs.* York, UK: Housing Studies Association*.*

Denzin, N.K., & Lincoln, Y.S., (1994). *Handbook of qualitative research.* Thousand Oaks, CA: Sage.

Denzin, N.K., & Lincoln, Y.S., (Eds.), (2006). *The Sage handbook of qualitative research*. Thousand Oaks, California: Sage.

Department for Education and Skills (2004). *Removing barriers to achievement: The special educational needs strategy.* Annesley, UK: DfES Publications.

Department of Labour (2001). *Pathways to inclusion: Improving vocational services for people with disabilities.* Wellington, New Zealand: Department of Labour.

Dickinson, A., Smythe, E., & Spence, D. (2006). Within the web: The family practitioner relationship in the context of chronic childhood illness. *Journal of Child Health Care, 10(*4), 309-325.

Easton, B. (2002). The New Zealand health reforms in context. Retrieved November 7th, 2007 from http://www.eastonbh.ac.nz

Edmunds H. (1999). *The focus group research handbook.* Thousand Oaks, CA: Sage.

Egerton, J. (2005). *From the far side: Parents perceptions of information sharing to support transition for young people with severe and complex learning disabilities.* Unpublished MSc. Dissertation, Birmingham: University of Birmingham.

Egerton, J. (2007). Transition solutions, looking to the future. In B. Carpenter & J. Egerton (Ed.), *New Horizons in Special Education* (pp. 212-221). Birmingham, UK: Sunfield Publications.

English Thesaurus (2005). New Lanark, Scotland: Geddes & Grosset.

Erikson, K. (1963). *Childhood and society.* New York: Norton.

Finlay L., & Ballinger, C. (2006). *Qualitative research for allied health professionals.* CA, USA: John Wiley & Sons.

Fiorentino, L., Philips, D., Walker, A., & Hall, D.(1998). Leaving paediatrics: The experience of service transition for young disabled people and their family carers. *Health and Social Care in the Community, 6(4), 260-270.*

Forbes, A., While, A., Ullman, R., Lewis, S., Mathes, L., & Griffiths, P. (2001). A multi-method review to identify components of practice which may promote continuity in the transition from child to adult care for young people with chronic illness or disability. Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation. Retrieved April 6, 2007 from http://www.scie.org.uk/publications/briefings

Glaser, B.G., & Strauss, A.L. (1967). *The discovery of grounded theory.* New York, USA: Aldine de Gruyter.

Glasgow, R.E., Lichtenstein, E., & Marcus, A.C. (2003). Why don't we see more translation of health promotion research to practice? Rethinking the efficacy to effectiveness transition. *American Journal of Public Health 93, (*8), 1261-1267

Glidden, L.M., & Johnson, V.E. (1999). Twelve years later: Adjustment in families who adopted children with developmental disabilities. *Mental Retardation, 37,* 16-24.

Gorle, H. (2002). Grief theories, Elizabeth Kubler- Ross. Retrieved November 12th, 2007 from http://www.bereavement.org/e_kubler-ross.htm

Grant, I & Cowan, J. (2001). *Growing boys.* Auckland, New Zealand: Parenting with Confidence.

Green J. & Thorogood N. (2004). *Qualitative methods for health research.* London, UK: Sage.

Hallum, A. (1995). Disability and the transition to adulthood: Issues for the disabled child, the family and the pediatrician. *Current Problems in Pediatrics, 25*(1), 12-50.

Halpern, A.S. (1994). The transition of youth with disabilities to adult life: A position statement of the Division on Career Development and Transition, the Council for Exceptional Children. *Career Development for Exceptional Individuals, 17*, 115-124.

Hames, A. (1996). The effects of experience and sexual abuse training on the attitudes of learning disability staff. *Journal of Intellectual Disability Research. 40(*6), 544-549.

Hanline, M. (2006). Transitions and critical events in the family life cycle: Implications for providing support to families of children with disabilities. *Psychology in the Schools 28(*1), 53-59.

Health and Disability Commission's Code of Health and Disability Services Consumers' Rights (2004). Retrieved October 6, 2007 from http://www.hdc.org.nz/theact

Heimer, K. (1996). Gender, interaction and delinquency: Testing a theory of differential social control. *Social Psychology Quarterly, 59*(1), 39-61.

Helff, C.M. & Glidden, L.M. (1998). More positive or less negative? Trends in research on adjustment of families rearing children with developmental disabilities. *Mental Retardation, 36,* 457-464.

Hendey, N., & Pascall, G. (2002). *Disability and transition to adulthood: Young disabled people speak.* Brighton, UK: Pavilion.

Heslop, P., Mallett, R., Simons, K., & Ward, L. (2001). *Bridging the divide at transition: What happens for young people with learning difficulties and their families?* Bristol, UK: Norah Fry Research Centre.

Hjortsberg, C., Ghatnekar, O. & Rico, A. (2001). Health care systems in transition. Retrieved November 10th from http://www.who.int/publications/en/

Holloway, I. (1997). *Basic concepts for qualitative research.* Oxford, UK: Blackwell Science.

Holloway I. (Ed.), (2005). *Qualitative research in health care.* Berkshire, UK: Open University Press.

Hudson, B. (2006). Making and missing connections: Learning disability services and the transition from adolescence to adulthood. *Disability and Society, 21*(1), 47-60.

Human Rights Amendment Act (2001). Retrieved November 1, 2007 from http://www.hrc.co.nz/index

Individuals with Disabilities Act (2004). Retrieved from Education Resources Information Center on April 12, 2007 at http://www.eric.ed.gov

Johnstone, M.J. (1999). *Bioethics: A nursing perspective* (3rd Ed.). Sydney, Australia: Harcourt Saunders.

Jones, G. (2002). *The youth divide: Diverging paths to adulthood.* York, UK: YPS.

Jorm, A.F., Barney, L.J., Christensen, H., Highet, N.J., Kelly, C.M, & Kitchener, B.A. (2006). Research on mental health literacy: What we know and what we still need to know. *Australian and New Zealand Journal of Psychiatry 40*, 3-5.

Joyce, T.A. (2003). An audit of investigations into allegations of abuse involving adults with intellectual disability. *Journal of Intellectual Disability Research, 47(*8), 606-616

Joyce, T.A., Ditchfield, H., & Harris, P.(2001). Challenging behaviour in community services. *Journal of Intellectual Disability Research, 45,* 130-138.

Katsiyannis, A., Yell, M.L., & Bradley, R. (2001). Reflections on the 25th anniversary of the Individuals with Disabilities Education Act. *Remedial and Special Education,* 22, 57-63.

Kielhofner, G. (2002). In G. Kielhofner (Ed.), *A model of human occupation: Theory and application.* (pp. 63-80). Baltimore: Williams & Wilkins.

King, G.A., Baldwin, P.J., Currie, M., & Evans, J. (2005). Planning successful transitions from school to adult roles for youth with disabilities. *Children's Health Care, 34(*3), 195-216.

King, G.A., Cathers, T., Miller Polgar, J., MacKinnon, E., & Havens, L. (2000). Success in life for older adolescents with cerebral palsy. *Qualitative Health Research*, *10*, 734-749.

Kitzinger J. (1995). Introducing Focus Groups. *British Medical Journal 311*: 299-302.

Kitzinger J. (2000). Focus groups with users and providers of health care. In C. Pope & N. Mays (Eds.), *Qualitative research in health care.* (pp. 20- 30). London: BMJ Books.

Kitzinger J. (2005). Focus group research: Using group dynamics to explore perceptions, experiences and understandings. In I. Holloway (Ed.), *Qualitative research in health care.* Berkshire, UK: Open University Press.

Ko, B., & McEnery, G. (2004). The needs of physically disabled young people during transition to adult services. *Child: Care, Health and Development, 30*(4), 317-323.

Krueger R.A. (1994). *Focus groups: A practical guide for applied research* (2nd ed.). London, UK: Sage.

Krueger R.A., & Casey, M.A. (2000). *Focus groups: A practical guide for applied research* (3rd ed.). Thousand Oaks, CA: Sage.

Kubler- Ross, E. (1969). *On death and dying.* New York: Macmillan.

Kubler- Ross, E. (1991). *On life after death.* New York: Macmillan.

Levine, C. (2005). Acceptance, avoidance and ambiguity: Conflicting social values about childhood disability. *Kennedy Institute of Ethics Journal, 15*(4), 371-383.

Levinson, S. (1978). *Social interaction.* Cambridge, UK: Cambridge University Press

Lewis-Beck, M., Bryman, A., & Futing-Liao, T. (Eds.), (2004). *The Sage encyclopaedia of social science research methods.* Thousand Oaks, CA: Sage.

Liamputtong, P., & Ezzy, D. (2005). *Qualitative research methods.* Melbourne, Australia: Oxford University Press

Lincoln, Y.S., & Guba, E.G. (1985). *Naturalistic inquiry.* Newbury Park, CA: Sage.

Litosseliti L. (2005). *Using focus groups in research.* London, UK: Continuum.

Macklin, R. (2003). Bioethics, vulnerability, and protection. *Bioethics, 17*(5), 472-486.

Mansell, J. (2006). Deinstitutionalisation and community living: Progress, problems and priorities. *Journal of Intellectual and Developmental Disability, 31*(2), 65-76.

Mays N., & Pope C. (1996). *Qualitative research in health care.* London, UK: BMJ Publishing.

McCallin, A., Dickinson, A., & Weston, K. (2007). *Family support for children with complex disabilities*. Auckland, New Zealand: AUT University.

Ministry of Health (2001a). *Living with disability in New Zealand*. Wellington, New Zealand. Retrieved 16th October, 2007 from http://www.moh.govt.nz/moh.nsf/indexmh/disability-news-publications

Ministry of Health (2001b). *To have an ordinary life.* Wellington, New Zealand. Retrieved 16th October, 2007 from http://www.moh.govt.nz/moh.nsf/indexmh/disability-news-publications

Ministry of Social Development (2001). *Pathways to inclusion.* Wellington, New Zealand. Retrieved 16th October, 2007 from http://www.odi.govt.nz/publications

Ministry of Social Development (2003). *Disability Service Directorate strategic plan.* Wellington, New Zealand. Retrieved 16th October, 2007 from http://www.odi.govt.nz/publications

Mirfin- Veitch, B. (2003). *Education for adults with an intellectual disability, including transition to adulthood.* Review of the literature prepared for the National Advisory Committee on Health and Disability to inform its' project on services for adults with an intellectual disability. Dunedin, New Zealand: Donald Beasley Institute.

Morgan D.L. (1993). *Successful focus groups: Advancing the state of the art.* Newbury Park, CA: Sage

Morgan D.L. (1997). *Focus groups as qualitative research.* (2nd ed.). Thousand Oaks, CA: Sage.

Morris, J. (1999). *Hurtling into a void: Transition to adulthood for young people with complex health and support needs.* York, UK: Joseph Rowentree Foundation.

Murphy, E., & Dingwall, R. (2003). *Qualitative methods and health policy research.* New York: Walter de Gruyter

Murray, S. (2007). Families care of their children with severe disabilities in Australia. *Community, Work and Family, 10(*2), 215-230.

Neubert, D.A., Moon, M., & Grigal, M. (2002). Post-secondary education and transition services for students age 18-21 with significant disabilities. *Focus on Exceptional Children, 34*(8), 1-11.

New Zealand Disability Strategy (2001). *Making a world of difference – Whakanui oranga.* Ministry of Health, Wellington, New Zealand. Retrieved February 14, 2007 from http://www.odi.govt.nz/publications/nzds

New Zealand Public Health and Disability Act (2000). Ministry of Health, Wellington, New Zealand. Retrieved 16th February, 2007 from http://www.moh.govt.nz/moh.nsf/indexmh/disability-news-publications.

Newacheck, P.W., & Taylor, W.R. (1992). Childhood Chronic Illness: Prevalence, severity and impact. *American Journal of Public Health, 82*, 364-371.

Niemeier, J.P., Kennedy, R.E., McKinley, W.O., & Cifu, D.X., (2004). The loss inventory: Preliminary reliability and validity data for a new measure of emotional and cognitive responses to disability. *Disability and Rehabilitation, 26(*10), 614-623.

O'Brien, M. (2007). Ambiguous loss in families of children with autism spectrum disorders. *Family Relations, 56*(2), 135-146.

O'Connor, J., Orloff, A.S., & Shaver, S. (1999). *States, markets, families: Gender, liberalism and social policy in Australia, Canada, Great Britian and the United States.* Melbourne, Australia: Cambridge University Press.

Office for Disability Issues (2005, September). *Briefing to the incoming minister: Making a world of difference*. Wellington, New Zealand: Ministry of Social Development.

Office for Disability Issues (2006, December). *Work in Progress.* Wellington, New Zealand: Ministry of Social Development.

Pascall, G., & Hendey, N. (2004). Disability and the transition to adulthood: The politics of parenting. *Critical Social Policy, 24*(2), 165-186.

Plan now for transition to adulthood (2005). Anonymous. *The Exceptional Parent, 35*(3), 41-44.

Pope, C., & Mays, M. (2000). *Qualitative research in health care.* London: BMJ Books.

Puchta C., & Potter J. (2004). *Focus group practice.* London: Sage.

Quinn, G., & Degener, T. (2000). *A survey of international comparative and regional law reform on human rights and disability: The current use and future potential of UN human rights instruments in the context of disability.* New York: United Nations.

Raup, J.L., & Myers, J.E. (1989). The empty nest syndrome: Myth or reality. *Journal of Counselling and Development, 68(*2), 180-184.

Reiss, J., & Gibson, R. (2002). Health care transition: Destinations unknown. *Pediatrics, 110*(6), 1307-1314.

Reiss, J.G., Gibson, R.W., Walker, L.R. (2005). Health care transition: Youth, family and provider perspectives. *Pediatrics, 115*(1), 112-121.

Rice P.L., & Ezzy D. (2000). *Qualitative research methods – a health focus.* Victoria, Australia: Oxford University Press.

Roper, S.O., & Jackson, J.B. (2007). The ambiguities of out-of-home care: Children with severe or profound disabilities. *Family Relations, 56*(2), 147-161.

Rossi, A.S. (2001). *Caring and doing for others.* Chicago: Chicago University
　　　　Press.

Sage, N.A. (2003). The Psi Caf, A psychology resource site. Retrieved 14th
　　　　November, 2007 from
　　　　http://www.psy.pdx.edu/PsiCafe/KeyTheorists/KublerRoss.htm

Scal, P., Evans, T., Blozis, S., Okinow, N., & Blum, R. (1999). Trends in
　　　　transitioning from pediatric to adult health care services for young adults
　　　　with chronic conditions. *Journal of Adolescent Health, 24,* 259-264.

Schwandt, T. (1997). *Qualitative inquiry.* Thousand Oaks, CA: Sage.

Scorgie, K., & Sobsey, D. (2000). Transformational outcomes associated with
　　　　parenting children who have disabilities. *Mental Retardation, 38,* 195-206.

Seale, C. (1999). *The quality of qualitative research.* London: Sage.

Shanahan, M.J. (2000). Pathways to adulthood in changing societies: Variability
　　　　and mechanisms in life course perspective. *Annual Review of Sociology, 26,*
　　　　667-692.

Sheehy, G. (1977). *Passages: Predictable crises of adult life.* London: Bantam
　　　　Books.

Sheehy, G. (1996). *New passages: Mapping your life across time.* London: Harper Collins.

Shelton, T.L, & Stepanek, J.S. (1995). Excerpts from family-centred care for children needing specialized health and developmental services. *Paediatric Nursing, 21(4),* 362-364.

Smart, M. (2004). Transition planning and the needs of young people and their carers: The alumni project. *British Journal of Special Education, 31*(3), 128-137.

Social Care Institute for Excellence Research Briefing 4. (2005). Transition of young people with physical disabilities or chronic illnesses from children's to adult's services. Retrieved March 3, 2007 from http://www.scie.org.uk/publications/briefings/briefing04

Statistics New Zealand (2001). 2001 Census Data. Retrieved August 11st, 2007 from http://www.stats.govt.nz

Statistics New Zealand (2006). 2006 Census Data. Retrieved November 1st, 2007 from http://www.stats.govt.nz

Stevenson, C.J., Pharoah, P.O., & Stevenson, R. (1997). Cerebral Palsy: the transition from youth to adulthood. *Developmental Medicine and Child Neurology*, *39*, 336-342.

Stewart D.W., & Shamdasani P.N. (1990). *Focus groups – theory and practice.* Thousand Oaks, CA: Sage.

Stringer, E. (2000). Focus groups. In C. Bassett (Ed.). *Qualitative research in health care.* (pp. 6-29). London: Whurr.

Sunfield School, Birmingham, UK. Retrieved March 15, 2007 from http://www.publications@sunfield.worcs.sch.uk

Tisdall, K. (2001). Failing to make the transition: Theorising the transition to adulthood for young disabled people. In M. Priestley. (Ed.), *Disability and the life course: Global perspectives.* (pp. 167-178). Cambridge, UK: Cambridge University Press.

The National Post-School Outcomes Center, USA. Retrieved February 10, 2007 from http://www.psocenter.org/secondary.html

The PACER Center, Minnesota, USA. Retrieved February 12, 2007 from http://www.pacer.org

Tossebro, J., & Lundeby, H. (2006). Family attitudes to deinstitutionalisation: Changes during and after reform years in a Scandinavian country. *Journal of Intellectual and Developmental Disability, 31(*2), 115-119

Trute, B, Hiebery-Murphy, D., & Levine, K. (2007). Parental appraisal of the family impact of childhood developmental disability: Times of sadness and joy. *Journal of Intellectual & Developmental Disabilities, 32*(1), 1-9.

Warda, M. (1992). The family and chronic sorrow: Role theory approach. *Journal of Pediatric Nursing, 7,* 205-210.

Wehmeyer, M., & Schwartz, M. (1997). Self-determination and positive adult outcomes: A follow-up study of youth with mental retardation or learning disabilities. *Exceptional Children, 63*, 245-255.

Weiss, A.P, (2007). Measuring the impact of medical research: Moving from outputs to outcomes. *American Journal of Psychiatry, 164(*2), 206-214.

Wells, T. (2003). What happens after the high school years among young persons with disabilities? *Social Forces, 82*(2), 803-832.

What Works Transition Research Synthesis Project. Retrieved April 14th, 2007 from http://www.nsttac.org

White Paper: 14-19, Education and skills (2005). British Education statistics. Norwich, UK: Crown. Retrieved November 15th, 2007 from http://www.dfes.gov.uk

Wilson, S. (2006). To be or not to be disabled: The perception of disability as eternal transition. *Psychodynamic Practice, 12(*2), 177-191.

Wittenburg, D.C., & Maag, E. (2002). School to where? A literature review on economic outcomes of youth with disabilities. *Journal of Vocational Rehabilitation, 17*(4), 265-280.

Wong, S.Y., & Wong, T.K.S. (2003). An exploratory study on the needs of parents of adults with a severe learning disability in a residential setting. *Issues in Mental Health Nursing, 24*(8), 795-811.

World Health Organization Bulletin (2004). Current and future worldwide prevalence of dependency, its relationship to total population, and dependency ratios. Retrieved November 7th, 2007 from http://www.who.int/bulletin/volumes/82/4/251.pdf

World Health Organization International Classification of Functioning (2000). Retrieved November 10th ,2007 from http://www.aihw.gov.au/disabilitiy/icf/ddb20/

Appendix 1: Participant Information Sheet

Participant Information Sheet

Date Information Sheet Produced:

27th January 2007

Project Title

Transition to adult life for young adults with complex disabilities – a family perspective.

An Invitation

You are invited to join a research study which is looking at how you and your young adult with complex disabilities experienced the transition period from schooling to adult life. Participation in this study is completely voluntary and if you chose to participate, you may still withdraw from the study at any time prior to the completion of data collection. Please read this information sheet and I will telephone you in a few days time to see if you think you might want to take part in this research.

Who is the researcher?

My name is Pauline Penney. I am a physiotherapist working with children with disabilities and their families. This research study will form the fieldwork for my Masters in Health Science dissertation, which will be completed by December 2007. My supervisor is Dr Antoinette McCallin, who is the Head of Research in the Division of Health Care Practice at AUT University.

What is the purpose of this research?

The purpose of this study is to find out what issues you and your young adult faced when they transitioned from school to adult life. As a researcher I am trying to identify recurring factors that families and their young person experienced, felt or thought during the transition period. The focus of this study is on the families' experiences and perspective of this transition period. Little has been written about this topic and families have not had a chance to tell their stories. This study will give you a chance to discuss these issues with other families in similar situations, with the aim of publishing the findings so that other families, schools and funding providers may learn more about this important time.

The young adults with disabilities in this study all have complex and severe needs, which usually include severe communication and intellectual difficulties. I have therefore

asked for family members to participate in the study rather than the young adult themselves, as you represent the voice of your young adult and will have also experienced your own challenges as your young person transitioned from school. Your young adult is of course welcome to attend the groups with you if you wish. I would ask that you discuss this study with your young adult at their level of understanding to gain their assent and bring any views they are able to express to the discussion.

How was I chosen for this invitation?

You have been approached by an intermediary who knows that you are part of a family which includes a young adult with a complex disability who has left school within the last five years. I have asked intermediaries from the Complex Carers network, the Special Schools Principals Association and a Maori Board of Trustees member to approach families they know would fit these criteria.

Participants in the focus group sessions will therefore be adults who have an immediate family member with a complex disability who has left school within the last five years Participants will need to speak English and live in the greater Auckland area. Maori participation will be encouraged.

What will happen in this research?

I invite you to be involved in my research by volunteering to take part in a focus group discussion. If you decide to join this study, you will be involved in one group discussion involving four to seven participants. The discussion will be led by myself and will take 60-75 minutes. The focus group will be held in a community room at a central North Shore location. Prior to the focus group commencing I will provide you with a few guideline questions of things we will be discussing to allow you to gather your thoughts. The questions will focus on two different areas:

1. As a family, what factors have supported or hindered <u>you</u> as your young person transitioned from school to adult life.

2. What factors do you think have supported or hindered <u>your young adult</u> in the transition process?

The focus group discussion will be audio taped and later transcribed by an independent typist. An assistant will help me at the focus groups with basic housekeeping tasks and audio taping the session, but will not take part in the discussions. Whanau members, support people and the young people with disabilities may be present at the groups, but will not take part in the actual discussion. At the end of the focus group I will summarise what was understood to have been said by the group and offer you the opportunity to make corrections or further contributions. At the end of the study your audiotape will be destroyed. When the study is completed you can receive a copy of the research report, if you so wish. The study will be written up for my Masters dissertation and the findings will be submitted for publication in a national and/or international journal. The findings may also be discussed at seminars or conferences.

What are the discomforts and risks?

I do not anticipate any discomfort or risk to you or your family from participating in this study. However, occasionally such discussions may raise issues that are distressing or stressful. You do not have to answer all the questions and may withdraw from the discussion at any point. You may bring a support person or whanau member to the focus group if that would make you feel more comfortable. Should issues arise directly related to the research I will ensure that a counsellor from the AUT University counselling centre is available to discuss your concerns.

What are the benefits?

As a family there will be no direct benefits to you or your young person from participating. However, some people who have participated in this type of research have found it helpful to have an opportunity to tell their story and discuss issues with others in similar situations. I also hope that this study will improve our knowledge of what factors impact on families and young adults' experiences of the transition period. This information may be of use to other families about to experience this period of life and also to those planning transition services.

How will my privacy be protected?

To ensure privacy and confidentiality you will be asked to choose a false name or pseudonym that will be used on all tapes, transcripts and reports. Both the focus group assistant and the typist will sign a confidentiality form. Any identifying information such as location, institutions, or people will be removed from the transcript. The only exception to confidentiality would be if the researcher had significant concerns about the safety of yourself and/or others.

All study data will be kept in a secure place, and the audiotapes will be destroyed after transcription. The consent forms will be kept with the study supervisor in a secure location, separate from the study data. All data will be destroyed after six years.

What opportunity do I have to consider this invitation?

If you choose to be involved you can contact me, either by phone, email or by writing to the attached contact details. If I do not hear from you, I will telephone you within a week to see if you are interested in taking part in the study. At that stage I can answer any further questions you may have. If you consent to take part you will need to sign a consent form which I will give to you prior to the focus group discussion. You have the right to withdraw from the study at any time and decline to answer any questions. While you may withdraw at any stage, there can be no guarantee that the data can be erased, as there are points beyond which the data cannot be withdrawn without affecting the validity of the study. If you choose to withdraw you do not have to give a reason and this will in no way affect you or your young adult's future care. I will respect your decision and not try to persuade you otherwise.

Will I receive feedback on the results of this research?

You may receive a summary of the research findings if you wish. On the consent form there will be a section to fill in if you would like a summary of the final report sent to you.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified in the first instance to the Project Supervisor, Dr Antoinette McCallin   ph 921 9999 extn 7884 Antoinette.mccallin@aut.ac.nz

If you have any concerns regarding your rights as a participant you may wish to contact a Health and Disability Advocate ph 0800 555050

Concerns regarding the conduct of the research should be notified to the Executive Secretary, AUTEC, Madeline Banda, *madeline.banda@aut.ac.nz* , 921 9999 ext 8044.

Whom do I contact for further information about this research?

Researcher Contact Details:
  Pauline Penney
  Wilson School
  1 St Leonard's Rd, Takapuna, Auckland
  Work phone: 489-5071

Project Supervisor Contact Details:
  Dr Antoinette McCallin Antoinette.mccallin@aut.ac.nz   work ph: 921 9999extn 7884

  Division of Health Care Practice, Faculty of Health and Environmental Sciences

  Auckland University of Technology

  Private Bag 92006, Auckland 1020

Appendix 2: Ethics Approval Letter

M E M O R A N D U M

Auckland University of Technology Ethics Committee (AUTEC)

To: Antoinette McCallin
From: **Madeline Banda** Executive Secretary, AUTEC
Date: 2 April 2007
Subject: Ethics Application Number 07/08 **Transition to adult life for young adults with complex disabilities - a family perspective.**

Dear Antoinette

Thank you for providing written evidence as requested. I am pleased to advise that it satisfies the points raised by the Auckland University of Technology Ethics Committee (AUTEC) at their meeting on 12 February 2007 and that as the Executive Secretary of AUTEC I have approved your ethics application. This delegated approval is made in accordance with section 5.3.2.3 of AUTEC's *Applying for Ethics Approval: Guidelines and Procedures* and is subject to endorsement at AUTEC's meeting on 16 April 2007.

Your ethics application is approved for a period of three years until 2 April 2010.

I advise that as part of the ethics approval process, you are required to submit to AUTEC the following:

*   A brief annual progress report indicating compliance with the ethical approval given using form EA2, which is available online through *http://www.aut.ac.nz/research/ethics*, including when necessary a request for extension of the approval one month prior to its expiry on 2 April 2010;

*   A brief report on the status of the project using form EA3, which is available online through *http://www.aut.ac.nz/research/ethics*. This report is to be submitted either when the approval expires on 2 April 2010 or on completion of the project, whichever comes sooner;

It is also a condition of approval that AUTEC is notified of any adverse events or if the research does not commence and that AUTEC approval is sought for any alteration to the research, including any alteration of or addition to the participant documents involved.

You are reminded that, as applicant, you are responsible for ensuring that any research undertaken under this approval is carried out within the parameters approved for your application. Any change to the research outside the parameters of this approval must be submitted to AUTEC for approval before that change is implemented.

Please note that AUTEC grants ethical approval only. If you require management approval from an institution or organisation for your research, then you will need to make the arrangements necessary to obtain this.

To enable us to provide you with efficient service, we ask that you use the application number and study title in all written and verbal correspondence with us. Should you have any further enquiries regarding this matter, you are welcome to contact Charles Grinter, Ethics Coordinator, by email at charles.grinter@aut.ac.nz or by telephone on 921 9999 at extension 8860.

On behalf of the Committee and myself, I wish you success with your research and look forward to reading about it in your reports.

Yours sincerely

Madeline Banda
Executive Secretary
Auckland University of Technology Ethics Committee

Appendix 3: Consent Form

Project title: ***Transition to adult life for young adults with complex disabilities – A family perspective.***

Project Supervisor: **Dr. Antoinette McCallin**

Researcher: **Pauline Penney**

○ I have read and understood the information provided about this research project in the Information Sheet dated 27 January 2007.

○ I have had an opportunity to ask questions and to have them answered.

○ I have discussed this study with the young person concerned at their level of understanding and they have given their assent to my sharing of their experiences in the focus group.

○ I understand that identity of my fellow participants and our discussions in the focus group is confidential to the group and I agree to keep this information confidential.

○ I understand that the focus group will be audio-taped and transcribed.

○ I understand that I may withdraw myself or any information that I have provided for this project at any time prior to completion of data collection, without being disadvantaged in any way.

○ If I withdraw, I understand that while it may not be possible to destroy all records of the focus group discussion of which I was part, the relevant information about myself including tapes and transcripts, or parts thereof, will not be used.

○ I agree to take part in this research.

○ I wish to receive a summary of the research findings (please tick one): Yes○ No○

Participant signature:

....……………………………………………………

Participant name:

....……………………………………………………

Participant's E-mail details:

……………………………………....……………………………………………………

Participant's Contact Details: (Please complete if you wish to receive a copy of the research summary):

………………………………………………………………………………………..

………………………………………………………………………………………..

………………………………………………………………………………………..

Date:

Appendix 4: Confidentiality Agreement

Confidentiality Agreement

Project title: **Transition to adult life for young adults with complex disabilities – a family perspective**

Project Supervisor: **Dr. Antoinette McCallin**

Researcher: **Pauline Penney**

For a typist transcribing audiotapes.
○   I understand that all the material I will be asked to transcribe is confidential.
○   I understand that the contents of the tapes or recordings can only be discussed with the researchers.
○   I will not keep any copies of the transcripts nor allow third parties access to them while the work is in progress.

Transcriber's signature: ....………………

Transcriber's name: ....……………

Transcriber's Contact Details (if appropriate):
……………………………………………………………………………..
……………………………………………………………………………..
……………………………………………………………………………..
Date:

Project Supervisor's Contact Details (if appropriate):
……………………………………………………………………………..
……………………………………………………………………………..
……………………………………………………………………………

Approved by the Auckland University of Technology Ethics Committee on 02/04/2007
AUTEC Reference number 07/08
Note: The transcriber should retain a copy of this form.

Appendix 5: Question Guide

Focus group Question Guide

Research Title:
Transition to adult life for young adults with complex disabilities – a family perspective.

The Question guide:

Because participants will come to the focus groups representing both the young adult and themselves as individual carers and family members, questions will be structured into two categories. An initial set of questions will concentrate on the family perspective of the transition process. In the second set of questions the family member will be questioned about the young adult's transition experience.

Set 1:
- As family members and carers, how has your young adult leaving school impacted on you as a family?
- What factors supported you as your young adult transitioned from school to adult life?
- What factors hindered you?

Set 2:
- What changes in lifestyle has your young person experienced since transitioning from school?
- What has supported him/her in this transition?
      What barriers has he/she encountered in transitioning to adult life?

Appendix 6: Data Analysis – examples of initial coding

Other parents

School – positive

      -negative

Funding

Lack of services

Lifestyle changes

      -young person

      -family

Societal attitudes

Post school options

      -residential care

      -day care programmes

Funding – Bureaucracy

      -service agencies

Family impact

      -emotions

      Parental mental health

      Burnout/stress

      -disempowerment

Health transition

Advocates

Transition supports

Transition barriers

Agency control over families

Agency accountability

Carers

Appendix 7: Research Journal Excerpts

August 28th

? Social discrimination – is this the underlying message…

.What are people saying about transition barriers? Maybe they are influences rather than

barriers. Many barriers seem to be around resource constraints and services. This could be

a coding stem, rather than a tail maybe.

Sept 12th

'Social Discrimination – a situation of loss shaped by societal attitudes, parental

disempowerment and social isolation'.

Hmmm, as Antoinette would say, 'can I tell the story' from this? Doesn't quite fit yet.

Maybe it's more about Parental Disempowerment as the main concept.

Need to look up disempowerment synonyms and go back to the literature.

Oct 2nd

Got it! It's parental LOSS. Where loss= the disadvantage or deprivation resulting from loss.

Can now tell the story, with service or funding mismanagement, loss of control/ or maybe

care giving problems and perpetual childhood management as the themes underlying loss.