THE SILENT REVOLUTION

DISABLED PEOPLE DISCUSS REGAINING POWER AND CONTROL IN THEIR LIVES

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ABSTRACT

Since the 1960s, a silent revolution has occurred, brought about by disabled people taking control of their lives. This thesis attempts to gain an understanding of this process, particularly in the area of disability residential services in Aotearoa New Zealand. A qualitative methodological design is used. This relies heavily on the social model of disability and Foucault's ideas, to carry out an explorative interpretative study. The stories of five disabled people, who moved from provider-supplied accommodation to their own homes, form the heart of this treatise. Participants explain how they achieved this transition. Three predominant themes were noted in participants' biographies – factors which enabled the move out, features that hindered such a move, and elements that support their new lifestyles.

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CHAPTER ONE
INTRODUCTION

> *I successfully ended up moving into the community and stayed there, and kept well, didn't need supported housing anymore and I thought that I could contribute to your survey. I was speaking to a good psychiatrist and said: "Why don't you actually study those people and find out what moved them on, what steps they took?" He said: "Oh well, they just have moved into the community and we don't hear from them again over a period of time." I thought to myself: Why didn't you get in contact with the people that have actually succeeded in leaving the services and find out what they did differently than the people who stayed?* (Caleb, 2008, research participant)

Caleb's words, spoken in response to being asked why he wanted to participate in this research, provide an apt summary and introduction to the thesis. This project originated from my experience working in the Non-Government Organisation (NGO) sector. I noticed that some disabled people moved out from the cluster homes or group homes[1] they lived in and others did not. I became intrigued that a number of people focused their energy on leaving provider homes whilst others were content to remain there for the very long-term.

This dichotomy so interested me that I decided to use the subject of people leaving provider homes as a research topic for this thesis. This is in light of

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[1] Cluster home: An accommodation option for disabled people comprising two to ten houses of one to four bedrooms on one site. The residents of the home receive daily support from staff that normally live on site.
Group home: A dwelling for four to six disabled people located in a residential neighbourhood usually supervised by live-in professionals.

literature which finds that "residential care further disables impaired individuals" (2006, p. 26). This support can be delivered in ways that create dependency when support staff exercise "power over" the users of these services (Peter, 1999, p. 811). Many disabled people who live in cluster or group homes in Aotearoa have very little power and control over their lives (National Advisory Committee on Health and Disability, 2003b). It is hoped that the focus of the research will contribute to a better understanding of this issue.

Research focus

My research aim is to identify factors that have enabled some disabled people to transition from an environment, where support and accommodation are supplied by the same provider, to a situation where the accommodation and support are supplied by separate providers, or the support has terminated. To achieve this aim, five people who made such a transition agreed to be interviewed. The research is viewed as an explorative interpretative study, and may provide the catalyst for a larger and better-resourced research project to investigate, analyse, identify and promote factors that have enabled some disabled people to move into a position of greater power and control over their lives.

The information in the stories of these participants may be beneficial for the self-empowerment of disabled people living in similar situations. Any empowerment gains for disabled people will potentially benefit, not only individuals, but groups, communities, institutions, social policy, and society as a whole. Individual participants may potentially benefit from the research in terms of knowing that their stories may have helped others take greater control over their lives.

Personal statement

I identify myself as a Survivor[2]. I have personally experienced the disabling effects of institutional practice, having been a recipient of institutionalised, supported accommodation at the former Porirua Hospital in the very early 1980s. With some effort, I quickly managed to leave this monolith, but the experience instilled me with a passion for disability issues. Since that time I have rarely experienced disability as social oppression, but have spoken to disabled people who have. Many of these people experience oppression in the context of professional intervention, especially in the area of residential services. Some of their stories are disconcerting and continue to remind me of the existence of structural and attitudinal barriers that need dismantling. Ideally, the removal of these barriers must be carried out under the direction of disabled people. With this in mind, the thesis looks at the narratives of the participants to better understand self-empowerment.

Format and structure of the thesis

The thesis avoids using justified text. The text is formatted with a left alignment because the uneven spacing of justified text is difficult to read for both dyslexics and those with sight problems (Evett & Brown, 2005).

When expressing my own ideas and thoughts I use the term "disabled people", as this is preferred terminology from the disability movement (Oliver, 1990). "Disabled people" are not people with disabilities, but rather they are those who are disabled by the environment – the economic, political, social and cultural barriers found in society (Oliver, 1996).

To give the thesis a structural clarity, several theoretical perspectives and discourses are examined in Chapter Two. A study of the medical model

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[2] A term to indicate a person's "survival through the discrimination, exclusion and prejudice that they often experience in society because of the label of mental illness, as well as their survival through everyday emotional and mental struggles" (Ellix & Subbuswamy, 2008, p. 55).

shows that this discourse originated from the development of technology and sciences, and did not include the voices of disabled people. This perspective associated disability with pathology and disease, and placed power and control in the hands of medical professionals and associated service providers. They expected disabled people to be changed using techniques of isolation, repairs, improvement and amelioration, in a similar manner to disease interventions.

The medical model was rejected by disabled people who developed an alternative discourse – the social model of disability. This discourse separates disability and impairment, positing that disability is caused by the economic, social, political and cultural barriers that impaired people encounter in society, and suggests that the removal of these barriers will result in disabled people having greater control over their lives.

Michel Foucault's post-structural ideas and concepts regarding power, knowledge and discourse provide another perspective for the thesis to understand power and control (Foucault, 1978, 1980). This perspective emphasises that power is linked with discourses from particular fields of knowledge. Resistance is also associated with discourse and often leads to alternative discourses based on subjugated knowledge. The alternative discourse developed by disabled people has provided the foundation for self-empowerment, leading to the transferring of some power and control into the hands of disabled people. Finally, the chapter reviews factors conducive to the self-empowerment of disabled people.

An historical review of important thoughts, trends, events, government policies and social perspectives regarding disability support and service provision, especially in regards to accommodation disability supports, is presented in Chapter Three. The review shows that there have been several distinct phases, ranging from individual and community, medical and institutional, through to community and rights-based approaches in Aotearoa

New Zealand. These phases reflect transition from a medical-based discourse to a response based on the social model of disability. It is also apparent in the review that the process of deinstitutionalisation has not been complete, and the transition of disabled people from large institutions to provider homes requires the final step of "community membership" (National Advisory Committee on Health and Disability, 2003a, p. 19).

Chapter Four details the methodology used for the project. A participatory research approach provides the research with a focus aimed at benefiting disabled people. An ecological perspective ensures that factors outside of participants are included in the research. The methodology, combined with the social model of disability and Foucault's concepts, provides a basis for the underlying principles of the thesis:

- Research is to be beneficial to disabled people
- Research to focus on the strengths, abilities, resources and attributes of disabled people
- Research to have a self-empowering orientation
- Researcher to be reflective.

Five disabled people were recruited and qualitatively interviewed in their homes during the period May to July 2008. These interviews were transcribed by the researcher and inductively analysed for patterns, themes, categories, causes, consequences and relationships associated with factors enabling participants to leave provider homes for more independent accommodation. The result of the analysis is presented in Chapter Five. The three themes that were evidenced in the data of the participants' stories are arranged under the titles of:

- Enabling factors
- Disabling factors
- Support factors.

Chapter Six is dedicated to a discussion of the analytical findings as stated in the previous chapter. The social model of disability and Foucault's (1978) account of power provide a basis for the discussion. The participants' narratives provide an insight into self-empowering activities seen in their transition to their new homes. The discussion explores external factors of support and assistance identified by participants in their accounts. Also discussed in the chapter are various disabling factors that participants found had the potential to hamper their transition.

The thesis concludes with Chapter Seven. This chapter reviews the research aims. Tentative recommendations are extrapolated from the research and explored.

I see this thesis as a small exploratory project, but one which involves a big topic which has huge implications for disabled people who live in provider homes. Some people view provider homes as a halfway stop in the journey from institutional services towards community membership for disabled people (National Advisory Committee on Health and Disability, 2003a). The five participants who have transitioned from provider homes now enjoy benefits of community membership. Their stories give some insight and awareness into how this process can occur. It is hoped their knowledge and this thesis will become drops in the pool of knowledge that contribute to the self-empowerment of disabled people.

CHAPTER TWO

DISABILITY CONCEPTS

DETERMINING THE PERSPECTIVE

The perspective from which disability is viewed plays a pivotal role in how disabled people are treated. An extreme eugenic example of this was seen in Nazi Germany during the early 1940s when over 200,000 disabled people were murdered (Morris, 1991). There have been two important discourses around disability. The medical model, which has been associated with medical expertise and institutions, views disabled people as passive recipients of care. The model was challenged and resisted by disabled people, who developed an alternative counter discourse – the social model of disability. This is characterised by a power shift from professionals to disabled people, deinstitutionalisation, and the development of the disability movement.

To provide the research with a theoretical basis in understanding disability and disability supports, this chapter will: (a) use Michel Foucault's work relating to discourse and power to seek an understanding of how power and control have influenced the discourse of disability; (b) define and examine the medical and social models of disability; (c) undertake an ecological examination of the factors conducive to the self-empowerment of disabled people.

Discourse and Power

Michel Foucault's (1926-84) writings help to make sense of our modern social existence. He has been associated with post-structuralism, but described his work as a "critical history of thought … of the present" (Smart, 2002, p. p.xiii). A post-structuralist approach posits that individuals create their own meanings based on past experiences and interactions with others around them. There is no single truth, but multiple truths based on subjected knowledge created from the dominant discourses found in society at a particular period (Smart, 2002). This perspective contrasts with a structuralist approach, which believes objective laws govern all human activity. Human activity can be explained and understood by scientifically studying concepts, actions, classes of words, and the laws which govern these (Dreyfus & Rabinow, 1982).

Foucault's work is useful in understanding the current circumstances of disabled people, how history has led to the current situation, and how this situation can be perceived differently (Tremain, 2005). The situation of disabled people is often determined by power relationships embedded in their social life. These are connected to discourse, "the general domain of all statements, sometimes as an individualised group of statements, and sometimes a regulated practice that accounts for a certain number of statements" (Foucault, 1972, p. 80). Traditionally the discourse regarding disability was dominated by the medical discourse, which subjugated disabled people's knowledge.

Discourse

Discourse is the mechanism linking power and knowledge (Foucault, 1980) and "functions to regulate the way individuals think about the world and live their lives" (Munford & Sullivan, 1998, p. 87). "There can be no possible exercise of power without a certain economy of discourses of truth" (Foucault, 1980, p. 93). For disabled people it has been the disciplines of psychiatry, psychology and medicine which have developed professional discourses on disability and disabled people. Through the use of observations and pathologising classifications, medicalised discourses have developed that centre disability inside a person. These factors have all contributed to an idealised concept of a service user (Hugman, 1991; Munford & Sullivan, 1998). People outside of this idealisation are identified and controlled by professionals through the use of a medicalising discourse (Masterson & Owen, 2006).

However, dominant discourses can be challenged and used as a focus of resistance to undermine and thwart:

> Discourses are not once and for all subservient to power to be raised up against it, any more than silences are ... discourses can be both an instrument and an effect of power, but also a hindrance, a stumbling-block, a point of resistance and a starting point for an opposing strategy. Discourse transmits power and produces power, it reinforces it, but it also undermines and exposes it, renders it fragile and makes it possible to thwart it. (Foucault, 1978, pp. 100-101)

Foucault's writings regarding power and biopower provide an insight into how power operates and works, particularly regarding many disabled people who often have been, and continue to be, in a position of powerlessness.

Power

Foucault's post-modern analysis of power explains how, through the exercise of institutional power, certain knowledges have been marginalised in favour of select economic and cultural groups. An analysis of power helps to explain how disabled people have been subjected to the control of particular forms of knowledge and power, as well as explaining those factors that have facilitated emancipatory processes for disabled people.

As a historian of the present, Foucault sees truth not as an objective law or observable fact, but rather as "the ensemble of rules according to which the true and false are separated and specific effects of power are attached to the true" (Foucault, 1984, p. 74). According to Foucault, power is not centrally located within individuals, institutions or communities for:

> Power must be analysed as something which circulates, or rather as something which only functions in the form of a chain. It is never localised here or there, never in anybody's hands, never appropriated as a commodity or a piece of wealth. Power is employed and exercised through a net-like organisation. And not only do individuals circulate between its threads, they are always in the position of simultaneously undergoing and exercising this power. They are not only its inert or consenting target. They are always the elements of its articulation. In other words, individuals are the vehicles of power, not its points of application. (Foucault, 1980, p. 98)

An important idea developed by Foucault is biopower, which is useful to analyse how systems such as the medical model, society, and institutions affect the lives of disabled people. According to this concept, power works through various methods into a single machinery of power operating on individual subjects, and allows for the control of entire groups and populations. "Biopower is the increasing ordering of all realms under the guise of improving the welfare of the individual and the population" (Dreyfus & Rabinow, 1982, p. xxvi). It can be used as a mechanism of discipline, of surveillance, and to regulate populations (Castel, 1991).

Such control and regulation has been especially evident with intellectually disabled people who, during deinstitutionalisation, were moved out into group and cluster homes. Here they were scrutinised by Ministry of Health-funded Needs Assessment Service Co-ordination (NASC) agencies, who collected detailed information used to classify and categorise. Also, within these provider homes, most disabled people are subjected to intense surveillance. Daily notes are made by staff and stored for the perusal and study by health professionals, whose quest for what is desirable has often been shaped by the medical model. The power inherent in this process can enable or disable an individual's access to certain levels of funding and services, which often determines the quality of their lives.

According to Foucault, the state does not occupy the whole field of power relationships, as these occur at a micro-individual everyday level. Individuals are used both as the vehicles of power operation and as the points of application. Therefore an analysis of power requires that:

> One must rather conduct an ascending analysis of power, starting, that is, from its infinitesimal mechanisms, which each have their own history, their own trajectory, their own techniques and tactics, and then see how these mechanisms of power have been - and continue to be - invested, colonised, utilised, involuted, transformed, displaced, extended, etc., by ever more general mechanisms and by forms of global domination. (Foucault, 1980, p. 99)

Scientific medical knowledge facilitated medical power, which led to the development of the medical model – a discourse which continues to negatively impact on disabled people.

Medical Model

As science became more sophisticated and refined in the late nineteenth century, so did the system of inspections, treatments, classifications and judgements (Oliver, 1993). The emergence of a medical discourse of disability was closely connected to the development of technology and advances in science. Sullivan (1995, p. 17) states:

> Thus the paralytic, the cripple and the deformed were increasingly subjected to the medical gaze, diagnosed with greater precision into various categories and for the sake of convenience became known quite simply as the disabled. More importantly, disabled people became subject to the curative regimes of the hospital and the medical profession, and disability became synonymous with pathology and disease requiring medical intervention. In short, disability had become medicalised.

It did not take long for pathology, deficit, disease and disability to become connected. "By defining disability as a pathological medical condition, it inevitably individualises the causes of socio-economic disadvantage: impaired individuals cannot function appropriately within society" (Longmore, 2003, p. 20). Over time, illness and disability became separated from everyday life and were seen as forms of individual pathology. The medical discourse on disability became hegemonic, and subjugated the collective knowledge which grew from the lived experience of impairment and disability.

The medical model expanded to include impairment as an individual tragedy for disabled people and is now known as the individual model.

> The individual model for me encompassed a whole range of issues and was underpinned by what I called the personal tragedy theory of disability. But it also included psychological and medical aspects of disability ... In short, for me, there is no such thing as the medical model of disability, there is instead, an individual model of disability of which medicalisation is one significant component. (Oliver, 1996, p. 31)

The individual model views disability as a personal tragedy and an individual failure. Disabled people are treated as victims, requiring the care and support of more capable people (Barnes, Mercer, & Shakespeare, 1999).

Impacts of medical model

The use of the medical model portrayed disabled people as "pathetic victims of some tragic circumstance" (Sullivan, 1991, p. 255). This perspective placed power and control of resources and decision-making firmly in the hands of medical professionals and service providers.

Stibbe (2004, pp. 27-31) states that if society will not change, then, according to the medical model, there is an expectation for disabled individuals to change in the following five areas: (a) by being cured; (b) by stoically putting up with the disadvantages caused by barriers; (c) by battling to overcome barriers; (d) through psychological adjustment to disability; and (e) by submitting to the "protection of a non-disabled person".

The medicalisation of disability has had, and continues to have, a huge impact on disabled people, viewing them as deficient, not normal. This view has resulted in disabled people being excluded from education and employment, leading to a dependence on welfare benefits (Barnes & Mercer, 2005). Impairment is seen as an individual problem, to be repaired, improved, removed or ameliorated by professionals using medical intervention and technology in much the same way as with a disease.

But since the early 1970s, the medical model, with its individualised, pathologised and medicalised interpretation of disability, has been resisted and rejected by disabled people and their advocates in favour of one that views disability as a repressive social creation. Using "subjugated knowledge" or "popular knowledge" – knowledge developed by disabled people "running parallel to the formal knowledge" (Allan, 2005, pp. 101-102) - disabled people challenged the dominant medicalising discourse of individual deficit and pathology. They developed the social model – an alternative discourse, countering the hegemony of the medical model.

Social Model of Disability

The social model has its origins from disabled people and is a reactive response against the medical model. This alternative discourse was first developed by Britain's Union of the Physically Impaired Against Segregation (UPIAS) in 1976. UPIAS provided its analysis of disability in *The Fundamental Principles of Disability* (1976) document. The paper posited that it is society that disables people with impairments:

> In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society. (UPIAS, 1976, p. 5)

The Union's (1976) view of a disabling society clearly separates biological impairment from social disability. It defines impairment as: "Lacking part or all of a limb, or having a defective limb, organ or mechanism of the body" (ibid., p. 14). Disability it describes as: "The disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities" (UPIAS 1976 quoted in Oliver, 1990, p. 11).

The UPIAS methodology was adopted by other disability organisations in the early 1980s, such as The British Council of Organisations of Disabled People and Disabled People's International, and extended its use to include all impairment whether physical, sensory or cognitive (Thomas, 1999).

Concepts of the social model

The social model developed academically through the publications of Vic Finkelstein (1980), Michael Oliver (1990), Colin Barnes (1991) and "successive waves of disability studies scholars" (Shakespeare, 2006a, p. 33). The model is centred on the separation of *disability* and *impairment,* impairment being related to the human body and disability the negative societal reaction to impairment (Sullivan, 2006). The model explores the economic, political and cultural barriers encountered by people with impairments. The social model posits that change is required to dismantle the barriers found in society exclusive of the disabled person (Barton & Oliver, 1997; Oliver, 1990, 1996; Oliver & Sapey, 2006). Barton and Oliver define these barriers as cultural, social, physical, attitudinal, economic, and political. They suggest the removal of these barriers will provide a foundation whereby people with impairments have greater power and control over their lives. The social model places emphasis on the collective, structural and social origins of disability, in diametric opposition to the individual/medical approach (Barnes, 1998; Oliver, 1990, 1996).

Thomas (1999, p. 17) states that, originally, the social model emphasized "economic concerns and independent living", but began to encompass other hurdles, such as: physical barriers in structures and transport systems, "organizational and attitudinal barriers in education" (ibid.), barriers to leisure activities, barriers that thwart "participation in civic and political structures and processes" (ibid.) – in fact, "socially excluded in every realm of social life" (ibid.). Disability is seen as a "collection of socially created restrictions, which are discriminatory because they limit opportunity for full and equal participation" (ibid., pp. 15-18). This movement away from affixing blame on the individual to factors outside of the disabled person is at the heart of the model. Munford states:

> In a social model of disability the principal cause of disability is situated in restricted environments and disabling barriers wherein disability represents a complex system of social constraints imposed upon people by a highly discriminatory society. (Munford, 1994, p. 6)

The social model has now become the "touchstone" (Bickenbach et al. 1999, p. 1176) and symbol for the "collective identity" (Goodley, 2001, p. 219) of the disability movement. It has been instrumental in developing a political strategy for a movement of social change for disabled people. This has helped to bring about an agenda for liberating disabled people through barrier removal and the creation of a non-disabling society. Psychologically, it has improved the esteem disabled people feel. It has built a sense of collective identity insofar as it is now society that has to change, not disabled people (Shakespeare, 2006b; Sullivan & Munford, 2005). The model has also played an important role in determining policies of non-government organisations, government departments and official agencies in the United Kingdom (Thomas, 1999) and New Zealand.

Despite its strengths, some have more recently found the social model to be outdated and to have deficiencies.

Limits of the social model

The historical importance of the social model and its contribution to disability awareness and rights has not been questioned, particularly in its role as a platform for political, social, cultural and environmental change. But many writers have expressed concern with the model, and have called for it to be refined, expanded and developed, rather than for it to be abandoned (Thomas, 1999).

From the early 1990s, writers from a feminist or postmodernist framework have criticised the social model. They believe its Marxist and materialistic perspective on the social and structural barriers has been too simplistic and has failed to take into the account the cultural and personal experiences of disabled people (Corker & Shakespeare, 2002; Lee, 2002; Richardson, 2000; Shakespeare, 2006a). The model does not allow for the subjective personal experience of impairment to be acknowledged, leading to criticism of a narrow-minded approach (Morris, 1991; Shakespeare, 2006a).

> ...there is a tendency within the social model of disability to deny the experience of our own bodies, insisting that our physical differences and restrictions are entirely socially created. While environmental barriers and social attitudes are a crucial part of our experience of disability – and indeed disable us – to suggest that this is all there is, is to deny the personal experience of physical or intellectual restrictions, of illness, of the fear of dying. (Morris, 1991, p. 10)

Shakespeare (2006a, pp. 29-53) argues that since the social model does not allow disabled people to "share a common experience of oppression" on the basis of impairment, responses to individual-based issues of impairment become difficult. Thomas (1999, p. 25), who defends the model, states that those disabled people with "particular forms of impairment, or pathologised difference" are not having their "experiences and needs" met by the model in its present form, and suggests developing it to include psycho-emotional dimensions.

The view that impairment be separated from disability is at the heart of the social model as developed by Oliver (1990; 1996). It strongly rejects individual and medical perspectives, and therefore downplays the role of impairment. Such a separation for many is not possible on feminist and post-structuralist grounds (Corker & Shakespeare, 2002; Thomas, 2007; Tremain, 2002).

Shakespeare (2006a, pp. 34-38) argues it is not possible to separate impairment and disability because they "interpenetrate" each other:

- To experience disabling barriers it is necessary to have an impairment, otherwise disability becomes a broad way of expressing social barriers for all people
- Impairments may be caused or aggravated by "social arrangements" such as war and poverty.
- What is regarded as impairment is a "social judgement", as meanings and definitions of impairment are socially and culturally determined.

If all barriers were to be removed in the environment of an impaired person, there would still be restrictions and disadvantages caused by their impairment, but under the social model he or she would not be disabled (ibid.).

According to Richardson (2000, p. 1384), the social model fails to satisfactorily include "other forms of oppression such as racism, sexism and ageism". The disability movement has been accused of being dominated by men acting as both theorists and organisational leaders. This gender imbalance has led to the development of a weak model of disability, lacking the personal experience of disability (Morris, 1991; Thomas, 1999, 2007). Further, Thomas (p. 25) suggests the social model is inherently weak or has been overly influenced by "men/straight people/white people/young people".

Response to critique

Oliver has responded to criticism by explaining that the model is not a theory of disability, but rather a practical tool to identify and bring about positive changes for disabled people, and states that the social model has had "... unparalleled success in changing the discourses around disability, in promoting disability as a civil rights issue and developing schemes to give disabled people autonomy and control in their own lives" (Oliver, 1996, p. 39). There has been much debate and criticism of the social model, and Oliver warns that division and conflict may weaken the gains brought about from the model:

> ... engaging in public criticism may not broaden and refine the social model; it may instead breathe new life into the individual model with all that means in terms of increasing medical and therapeutic interventions into areas of our lives where they do not belong. (Oliver, 1996, p. 52)

According to Barnes (1998, pp. 76-78), the social model has achieved huge changes for disabled people. It is easy to forget that the model "emerged from the direct experience of disabled people themselves", and that much of the work produced in the 1980s by disabled people about their experiences of impairment has not been available in libraries and public institutions. A considerable body of literature dealing with the experiences of disabled people has been overlooked, and Barnes believes many critics of the social model are repeating a debate that has been previously covered.

Both the medical and social models of disability have their origins in European values, semiotics and perspectives, and the word disability appears to have no lexical equivalent under a traditional Maori perspective. There is little documentary evidence that portrays a traditional Maori view of disability, and notably very little literature from Maori authors.

Maori Views Regarding Disability

Sullivan (2001) examines a study in 2000 by Kingi and Bray who found the Maori view of disability to be an effect of colonisation. British settlement in Aotearoa resulted in the dominance of European hegemony. Assimilationist and discriminatory policies were developed, which in turn has disabled Maori. What has been particularly disabling for Maori has been a loss of identity caused by the dispossession of land, culture, language, whakapapa, and the effects of poverty (ibid.).

Bevan-Brown conducted a study in the early 1990s and concluded there was no equivalent term for disabled in the Maori language, but the words "poorangi" and "wairangi" have been discussed in relation to intellectual disability (1994, p. 207). A wide range of attitudes towards disabled Maori were discovered by Bevan-Brown's research, including, "being revered as taonga [treasure], being shunned, being accepted with amusement, and being valued as an integral part of the community" (ibid.). The majority of people interviewed in her project showed acceptance towards disabled people – "whanau support, aroha and the total acceptance of the intellectually disabled person both by the individual and Maori community ... having value and mana" (ibid., p. 209). Bevan-Brown believed disability (intellectual) and attitudes associated with it are "intertwined with other Maori concepts, beliefs and values such as whanaungatanga [kinship], aroha-ki-te-tangata [love for others], wairua [spirit/soul], awhinatanga [assistance] and manaakitanga [kindness/hospitality]" (ibid.). Tihi and Gerzon (1994, p. 139) described attitudes that are not so supportive towards disabled people: "Not all lead valued lives, not all are embraced by their whanau."

Te Whare Tapa Wha model

An important Maori contribution to viewing disability and health has been Mason Durie's (1985) Te Whare Tapa Wha model, which became known as the four cornerstones of Maori health: te taha wairua (spiritual), te taha hinengaro (mind and emotions), te taha whanau (family) and te taha tinana (body). This perspective integrates spirituality with the body, mind and family. It provides a holistic method of viewing disability and disabled individuals in a diametric juxtaposition to the medical model of disability, which locates disability as a personal and internal problem. The Te Whare Tapa Wha philosophy views the individual as being collectively connected with the wider extended family, and notions of individuality dissipate into the collective whanau and hapu grouping. The spiritual corner post of the model adds a dimension to disability, rarely mentioned in Eurocentric academic literature, and provides a connection for Maori to ancestors of the past, through whakapapa, and to the cosmos and world of mythology from whom many Maori trace descent (Marsden, 1985).

Today's Maori live in a world dominated by a European social, political and economic system (Humpage, 2004). This system, historically influenced by the medical model, has viewed both disabled Maori and non-Maori in terms of individual deficit and pathology. The development of the social model countered this view, and set the scene for the self-empowerment of disabled people.

SELF-EMPOWERMENT

Change for disabled people (in residential services) requires a change in power relations, so that disabled people can empower themselves. It necessitates an understanding of the nature of power and how power relationships can be altered (Munford & Walsh-Tapiata, 2001). Empowerment, according to Mosedale (2003), has four factors: (a) someone must be disempowered; (b) empowerment is an ongoing process, not a product; (c) empowerment requires people to make decisions on matters which are important in their lives; and (d) empowerment cannot be bestowed by a third party, it must be claimed – this is self-empowerment.

Self-empowerment is evidenced when disabled people developed a counter hegemonic discourse to the medical model in the 1970s. The social model is an example of resistance to the dominating medical-based discourses of pathology and deficit. According to Foucault, where there is such power, emancipatory forces are always present in the form of resistance:

> Where there is power, there is a resistance, and yet, or rather consequently, this resistance is never in a position of exteriority in relation to power. (Foucault, 1981, pp. 96-97)

The notion of resistance by disabled people has been discussed by Munford and Sullivan (1997). Disabled people created resistance to the historic and traditional discourses held by western societies, which is evidenced by the development and growth of the disability movement since the late 1960s. This resistance reflects the self-empowerment of disabled people as they formed disability support organisations as an alternative system of support (Barnes & Mercer, 1995).

Centres for Independent Living

The development of Centres for Independent Living (CIL) is an example of alternative service provision developed by the self-empowering activities of disabled people. The CILs became established overseas by disabled people in resistance to a lack of community-based support services. First introduced at Berkley, California, 1972, to provide support for disabled people attending mainstream university courses, the CILs evolved in the USA to provide information on: community resources, housing advice, peer counselling, training in independent living skills, staff screening and training, and political advocacy at over 500 locations (Barnes & Mercer, 1995; Eustis, 2000; Scotch, 1989).

In the United Kingdom the CILs developed in the early 1980s, and their initial focus was to oppose discriminatory attitudes and practices generated by the "excessively paternalistic" state welfare system (Barnes & Mercer, 1995, p. 36). A primary outworking of the United Kingdom independence movement was the action of disabled people organising their own way out from institutions such as group and cluster homes. This direction was spearheaded by a group known as "Project 81", a number of disabled people living in a group Cheshire Home in Hampshire who used principles and expertise from the USA's Independent Living Movement to agitate for change. They eventually organised a financial agreement with local government that enabled them to move out of the group home and into their own accommodation, along with their own personal assistants (Evans, 2003). This project laid the foundation for the Independent Living Fund – government money for disabled people to live independently in the community – and the Direct Payments scheme – funding for disabled people to employ their own support staff (ibid.).

Aotearoa New Zealand Initiatives

Here, in Aotearoa New Zealand, resistance has led to the formation of disability advocacy groups, initially with the Dominion Association of the Blind, and then the New Zealand Council for the Disabled, which became the precursor for the current Disabled Persons Assembly. These groups have contributed to the process of deinstitutionalisation with many moving into group homes, as outlined in Chapter Three (pp.41-47). Unlike the United Kingdom there has not been a strong move in Aotearoa New Zealand from the cluster/group home model to supported living.

Brook (1999) believes the group home has become the final stopping point, not a stepping stone for further independent living options in Aotearoa New Zealand. It is "vital" (p.88) that further options are explored. There is a perception that control of residential support services continues to remain with non-disabled government officials, service providers and health professionals. Power and control appears to be located in the structures outside of disabled people, who are underrepresented in positions of power (Barton & Mercer, 2001).

There needs to be change in the way residential services are provided, but the change must be as a result of the self-organisation and self-empowerment of disabled people. Otherwise any efforts to improve support and housing will be likened to the phoenix bird which, when destroyed by fire, was reborn from ashes into its former state.

Factors Promoting Self-Empowerment

To provide a framework for analysis, Bronfenbrenner's (1979) ecological perspective (Chapter Four, p.52) is used for the thesis to undertake a review of the factors that promote self-empowerment for disabled people, particularly in relation to residential services for disabled people. The thesis begins with a macro view to further ideas related to the self-empowerment of disabled people at a national and policy level.

At the macro view

The rise of the disability rights movement and the creation of the social model have significantly contributed to the ideological climate that fuelled disability policy development. In line with this direction, Oliver (1996, pp. 145-152) believes returning power and control to disabled people requires an approach of "collective empowerment", whereby organisations are formed, controlled and run by disabled people in their struggle against the "oppression of others". The aim of this struggle is for political and social change to bring about full rights and entitlements of citizenship for disabled people (ibid.). Collective empowerment involves social change achieved by "legislative, policy, financial and organisational processes" (Masterson & Owen, 2006, p. 24).

Since the 1970s, there has been a trend towards normalisation in an attempt to empower intellectually disabled people (Cullen, 1991; MacArthur, 2003; Mirfin-Veitch, 2003). This theory contributed towards the process of deinstitutionalisation internationally and in Aotearoa New Zealand. The principle of normalisation originated in Denmark and Sweden with Bengt Nirje during the 1960s, and was refined by W. Wolfensberger, as an attempt to establish life for intellectually disabled people as "close to normal living conditions as possible" (McIntosh, 2002, p. 67).

Normalisation posits that disabled people have the opportunity to participate in conditions of daily living which correlate as closely as possible to normal situations, circumstances and opportunities experienced by all citizens (Wolfensberger, 1972). When utilised, the normalisation model leads to greater community acceptance and inclusion of disabled people. The aim is to improve the role, status and experience of disabled people. The model was further refined to become Social Role Valorisation (SRV), after taking into account criticisms that normalisation, as implemented, was more for organisations than disabled people. SRV proposes, by participating in society, disabled people will be viewed as valued members of that society (Wolfensberger, 1983). Valued members of society means having a valued social role, such as being a friend, relative, worker, colleague, student or sports team member to others (O'Brien, Thesing, Tuck, & Capie, 2001).

Normalisation has been criticised for not taking into account the complexities of human services and human behaviour (McIntosh, 2002). It has failed to empower disabled people, and has kept them powerless through observations, interventions and monitoring, in the Foucaultian sense "which examines and judges the lifestyle needs of individuals within subjective practices and legislative frameworks, both professional and government" (McIntosh, 2002). There is a danger that in attempting to enable disabled people to become like those of the dominant groups, some desirable characteristics of disabled groups may be lost or devalued, and a strengthening in the power of the dominant groups may also occur (Fook, 2002). Normalisation has failed to take into account the economics of poverty, social and economic restrictions, and is too grounded in values and attitudes (Chappell, 1992). Wolfensberger's theory of normalisation views disabled people as being dependent on non-disabled people, and fails to allow for disabled people as being equal to non-disabled (Sullivan & Munford, 2005).

Equality does not equate to the ability of disabled people to carry out tasks that non-disabled people can perform, but to the way discourses, perceptions and actions are undertaken by people in society, especially by those professionals and staff involved with supporting disabled people. The thesis uses a meso view to best understand how support around disabled people can be optimised for maximum self-empowerment.

A meso view

Community-based residential services developed in response to pressures brought about at the macro level by the disability rights movement. The pressure to deinstitutionalise and promote independent living meant that residential services were developed at the meso level within the community. The staff who work in these residential homes are important to disabled people and act as a "safety net" (Levitz, 2003, p. 455), providing a wide range of services ranging from physical work to emotional labour (Georgeson, 1994; Yamaki, 2004). Support should not mean control. A large body of literature highlights the need for a shift in power from those who support disabled people to the service users, disabled people themselves (Drinkwater, 2005; Georgeson, 2000; Levitz, 2003; O'Brien & O'Brien, 1996; Peter, 1999; Tremain, 2002). It was hoped deinstitutionalisation and the move to community-based services would achieve this shift in power (Bigby & Ozanne, 2001; MacArthur, 2003), but this has not occurred. Professional staff and organisational structures still act as a disabling force for many disabled people (Levitz, 2003; Oliver & Sapey, 2006; Peter, 1999).

Models of power sharing and partnership between disabled people and support staff and service providers have been suggested as a solution to these power imbalances. Collaboration would allow people with impairments to benefit as partners in the "design and presentation of services" (National Advisory Committee on Core Health and Disability Support Services, 1993, p. 5), and enable greater input and control to occur in their own lives (Georgeson, 1994; National Advisory Committee on Core Health and Disability Support Services, 1993).

Power sharing as an alternative approach to service delivery has been intensively explored by Hugman (1991), and requires a complete reorganising of organisational and professional hierarchies (ibid., O'Brien & O'Brien, 1996). Power sharing is a "process of shared learning ... because it has to respond to changing circumstances around the person and to growth in the person" (ibid., p. 10).

Power sharing is also dependent on competent and able staff. A recent study has shown that staff often work in a paternalistic manner (Taggart & McConkey, 2001). The quality and training of the staff who provide support for disabled people, is critical (Bray & Gates, 2003; MacArthur, 2003). There is a correlation between the extent an individual can control aspects of his or her life, and the quality of life experienced by the service users (Treece, Gregory, Ayres, & Mendis, 1999). For power sharing to occur, staff must be highly trained, not only on physical needs but "on philosophies, concepts, attitudes and values which affect clients' lives" (Horner, 1994).

One key-empowering factor for shifting control and power to disabled people is the separation of support from housing services (MacArthur, 2003). Macro pressures from the disability rights movement have contributed to a policy response, at the meso level, for the separation of support and housing services. Individualised funding provides a model for this separation to occur (Centre for Housing Research Aotearoa New Zealand, 2005; MacArthur, 2003; Mirfin-Veitch, 2003; National Advisory Committee on Health and Disability, 2003; Ontario Federation for Cerebral Palsy, 2000). Individualised funding (also known as consumer-directed care, independent living model or direct-payments system), has been described by the Roeher Institute (1993) as:

> An arrangement that seeks to promote self-determination by maximizing individual choice. Individualised funding also promotes the recognition of individual differences. In fact, it is predicated on the assumption that each person is unique and requires a different set of responses to personal circumstances. Finally, it seeks to achieve equality by helping to redress inadequacies in the goods and services to which persons with disabilities have access. (p.7)

Internationally, individualised funding has been available as a support option for nearly two decades in Austria, Canada, France, Germany, the Netherlands, the United Kingdom and the United States (Bartavia, 2002; Kodner, 2003; Ministry of Health, 2003; Mirfin-Veitch, 2003; Oliver & Sapey, 2006; Ontario Federation for Cerebral Palsy, 2000). Kodner (2003) has identified three models regarding individualised funding. Firstly, the professionally monitored model, where clients receive advice and monitoring services from staff; secondly, the professionally assisted model where staff determine programme eligibility and service hours; and finally, the cash model, where clients receive money without structural advice and support.

Research has identified considerable benefits with the individualised funding approach. The model promotes independence and control; is cost effective; allows for support to be tailored to an individual; and encourages community involvement (Bartavia, 2002; Kodner, 2003; Lord & Hutchison, 2003; Mirfin-Veitch, 2003; Oliver & Sapey, 2006; Ontario Federation for Cerebral Palsy, 2000; Yamaki, 2004).

A critique of individualised funding indicates that without professional support, guidance and overview, the model can fail to deliver quality assistance to some disabled people (MacArthur, 2003; Mirfin-Veitch, 2003; Ontario Federation for Cerebral Palsy, 2000). Disabled people and their families can find it difficult to meet compliance requirements such as bookkeeping, budgeting, and managing staff (Mirfin-Veitch, 2003; Ontario Federation for Cerebral Palsy, 2000).

Aotearoa New Zealand is lagging behind international developments and trends regarding the availability of individualised funding. The model has been operating since 1998 in a very limited manner. In 2003 there were only 250 people accessing this service which the Ministry of Health (2003) described as "not a positive option but as a last resort ... only limited consistency and sometimes a lack of safeguards in its provision ... lack of choice ... ad hoc development" (p.4). Since 2001 there has been a moratorium on any further individualised funding occurring for disabled people (ibid). Significant work is required before individualised funding can be an option for assisting disabled people to take control of their support in Aotearoa New Zealand.

Individualised funding would provide an option for some disabled people to move from cluster/group homes into supported accommodation. There is very little research comparing supported living with provider homes. A study by Mansell 2006 describes two research projects which compared supported living with group homes, one in the USA and another in the United Kingdom. Mansell reported, the USA study found that disabled people in supported living situations undertook a greater range of preferred community activities more often than those living in group homes. They also engaged in a greater number of activities with more people. There was no difference between the costs of supported living and group homes in Oregon USA. The UK study found there were few differences between both types of accommodation, but those in supported living had more choice "about where they lived, with whom they lived, and day-to-day issues". Conversely, those in supported living were more likely to have their homes vandalised and "were perceived to be more at risk of exploitation by people in the local community" (Mansell, 2006, p. 70).

Much of the previous discussion has been on decisions and factors that often lie outside the locus of many disabled people. An important sphere for emancipatory change is in promoting an environment where disabled people are able to make free and un-pressurised decisions, especially inside their own homes – the micro view.

A micro view

Many have argued, disabled people are not involved enough in the decision-making processes in their lives (Bray & Gates, 2003; Kitchin, 1998; MacArthur, 2003; Munford & Sullivan, 1998; Treece et al., 1999). There needs to be a shift away from service providers making decisions, to disabled people being in control (Ontario Federation for Cerebral Palsy, 2000).

Michael Levitz (2003), a disabled person living independently in the United States, has written that, "To be responsible and make good choices, we need information that is written or explained to us in a way that we can understand" (p. 455). Some people with impairments may require support with decision-making processes (O'Brien & O'Brien, 1996). This support can come through advocacy groups and families. Tufail and Lyon (2004, pp. 60-73) have identified "self-advocacy" as the best form of support for disabled people, and describe it as "being strong for yourself and for others". Self-advocacy requires an environment and the opportunity for disabled people to make choices.

Self-empowerment at all levels of disabled people's lives is necessary and must be based on disabled people taking action themselves. Fook (2002, pp. 46-55) cautions about potential pitfalls regarding empowerment:

> the paradox of empowering, without doing people's empowering for them ... one person's empowerment may be another's disempowerment ... (the) dangers of dilution ... (the) dangers of addressing too many target groups and addressing none adequately ... (and the) ambiguous relationship between self-help and empowerment.

Self-empowerment for disabled people in Aotearoa New Zealand is occurring, but control of government-funded disability support remains in the hands of the disability industry. If disabled people's goal of total emancipation is to advance, further changes are required (Sullivan & Munford, 2005).

The social model of disability is a materialist account, and a post-structural perspective presents the research with a platform to further understand power and self-empowerment for disabled people. Michel Foucault's ideas provide concepts and a framework for understanding how historical and current discourses have influenced support and housing for disabled people in Aotearoa New Zealand. This review of the medical and social models, power and self-empowerment, shows there are many factors that have impacted positively on the lives of disabled people. These forces can range from government policy to self-empowered decision making.

There is no golden goose or single simple solution to bring about an overnight improvement in the sphere of disability support. But there are multitudes of potentialities that can bring about conditions conducive for the self-empowerment of disabled people. Focusing on a single government policy initiative or an academic disability model is likely to be unhelpful for the average disabled person living in the community. What is more important is to take the time to listen to what disabled people are saying and to understand what has happened to them historically. The following chapter undertakes an historical review of disability support in Aotearoa New Zealand with a focus on residential services.

CHAPTER THREE

DISABILITY DISCOURSES

SETTING THE CONTEXT TO DISABILITY IN AOTEAROA NEW ZEALAND

The past influences today's steps on the path of our future directions (A Maori saying).

The previous chapter outlined several theoretical perspectives to provide some understanding and insight into the situation of disabled people. To complement the theoretical dimension and to further understand the current state of affairs of disability in Aotearoa New Zealand, it is useful to be aware of the historical context, the discourses of yesteryear.

Munford and Sullivan (1998, p. 187) state that "Discourse functions to regulate the way individuals think about the world and live their lives. Lived practices are, in turn, regulated through ideas, language, institutional behaviour, rituals and social relationships...[these have] determined the way services, resources and interventions are organised, and delivered to disabled people." Historical disability-related discourses have impacted harshly on disabled people and their echo continues to be heard today.

As support for disabled people in Aotearoa New Zealand has evolved from the 1800s to the present day, remnants from the past remain and continue to influence current forms of support. This chapter will examine important historical thoughts, trends, events, government policies and social perspectives regarding disability support and service provision, particularly in regards to accommodation. There will be a focus on government policy, which is integral to the quality of life for disabled people, as it is government which ultimately determines the levels and types of support for many disabled people. This chapter will show that there have been several distinct phases and trends in the social and governmental response to disability, ranging from individual and community, medical and institutional, through to community and rights-based approaches.

The Discourse of Deserving Poor

In Aotearoa New Zealand, newly arrived colonialists came seeking a new life and an egalitarian society, but brought with them moral attitudes of care for the deserving poor based on Christian values (Beaglehole, 1993; Nash, 2001; Oliver, 1977; Tennant, 1996). Settlers looked to families, communities and "benevolent societies" to provide support for disabled people in a spirit of individualism and independence (Beatson, 2001; Tennant, 1996, pp. 7-10). This approach contrasted with Maori models of support based on a "social system of responsibilities and rights" within the extended family and was known as whakawhanaungatanga (McDonald, 2001; Nash, 2001, pp. 33-34).

From its early colonial origins, the state lacked a wealthy class that could provide capital to fund health, poverty and education. Instead it promoted individual responsibility. For example, the 1846 Ordinance and 1877 Destitute Persons Act made relatives of destitute persons liable for family support (Koopman-Boyden, 1985; Tennant, 1996). But there was an exception for "lunatics" and the 1846 Lunatics Ordinance provided for publicly funded asylums (Tennant, 1996). As the economy grew in the 1860s, local provinces began to provide support for those who by their moral behaviours were "deserving" of support – orphans, widows, and disabled people. For others of low moral standing (undeserving) such as prostitutes, drinkers of alcohol and solo mothers, aid was less forthcoming (Oliver, 1977, p. 9).

Beginnings of institutionalised care

Government funded asylums were established nationally from the 1890s. The first "lunatic" asylum was established in Karori in 1854 (Phillip, 2001). Many others were soon established around the country – Otago and Canterbury, 1863; Nelson, 1864; Auckland, 1867; Westland, 1872; and Ashburn Hall (a private facility), Dunedin, 1882 (Tennant, 1996). These new asylums continued the policy of incarceration and confinement used previously in prisons against those mentally unwell (Hunter, 1957a, 1957b, 1957c).

During the late 1800s hospitals and charitable organisations became established, and in 1885 provincial hospital services were organised into a national system of health provision using Hospital Boards, via the Hospitals and Charitable Institutions Act (Tennant, 1989). The Act also incorporated the term "charitable aid" into national law, which became the precursor to the welfare system. In 1880 the Sumner Deaf and Dumb Institution was established as the world's first government funded school for the deaf. In 1891, a residential institution for the blind was set up by the Jubilee Institute for the Blind (Mitchell & Mitchell, 1985) which would later become the Royal New Zealand Foundation for the Blind. The first facility for severely physically disabled, the Home of Compassion, was established by Mother Mary Aubert and her Sisters of Compassion on the banks of the Wanganui river in Jerusalem in 1886, moving to Wellington in 1899.

Much of the support provided for disabled people in the early and mid nineteenth century was based on a Christian discourse centred on morality. This was about to change as the eugenics movement initiated a new class of deserving poor.

Eugenics and the Medicalisation of Disability

Darwinian ideas of evolution, natural selection and survival of the fittest led to the development of Social Darwinism, which spawned the eugenics movement. Eugenics, based on a racial standard connecting disability with "degeneracy, inferiority and low morality" (Tennant, 1996, p. 14), furthered the segregation of disabled people.

The Eugenics Education Society (New Zealand) was formed in 1910 and its members included prominent academics, leading politicians and important government officials (ibid). The influence of eugenics contributed towards segregation, stigmatisation and the medicalisation of disability and, according to Ford (2004, pp. 12-13), led New Zealand governments between the late 1890s to early 1930 to pass "discriminatory and segregationist legislation." For example, the Immigration Restriction Act 1899 banned mentally and intellectually impaired individuals from immigrating to New Zealand (Tennant, 1996). The Mental Defectives Act 1911 officialised terms such as, "lunatics", "feeble-minded", "idiots", "imbeciles", and required those deemed "mentally defective" to live in sexually segregated mental hospitals from the age of five (Beatson, 2001, p. 452). As New Zealanders entered the Twentieth Century, disabled people had been cast as abnormal and the scene was set for the isolation, containment, discrimination and segregation of disabled people.

Increased government involvement

The world first Old-age Pension Act of 1898 heralded the faltering beginnings of the welfare state, but rigorous character and asset-testing limited the numbers of those eligible to a "small minority" (Tennant, 1996) of people over the age of 65. In 1908 a special government school for mentally retarded boys was opened in Otago (Mitchell & Mitchell, 1985, p. 15). The Mental Education Amendment Act 1907 became the first legislation detailing government responsibility for the provision of services for disabled people.

The Act provided for the compulsory education of "defective or epileptic children" between the ages of 6 and 21 years (ibid.).

During the 1920s, intellectually disabled people had the choice of living at home, without funding, or at the following psychiatric institutions: Seaview, in Hokitika; Seacliff, near Dunedin; Tokanui, near Hamilton; and Kingseat, in Auckland (National Advisory Committee on Health and Disability, 2003b). In 1929 the Templeton Farm School was opened for "high-grade imbeciles and low-grade feeble-minded" (Beatson, 2001, p. 455). Polio epidemics in 1916, 1925-25, 1936-37, 1947-49 and 1952-53 increased government involvement and furthered the medicalisation of disability. Hospitals for returned soldiers were used for polio victims, and the need for extensive long-term treatments put pressure on government to develop children's wards in hospitals (Tennant, 1996).

Before the 1940s, Maori were "actively discouraged from using such [disability] services" and support was expected to be provided by the extended family. But because of urbanisation in the mid twentieth century, Maori came in greater contact with specialised disability agencies (National Advisory Committee on Health and Disability, 2003a, pp. 30-31).

By the late 1940s, more than 3000 intellectually disabled people were living in large psychiatric or psychopaedic institutions at rural locations, isolated from society (National Advisory Committee on Health and Disability, 2003a). During this period disabled people were viewed as passive and grateful receivers of the charitable support and care provided by medical specialists and non-disabled people. Power and control were firmly in the hands of the non-disabled, and there was little consideration for disabled people to have input into the decisions affecting their lives (Tennant, 1996).

Both World Wars I and II created conditions for a change in attitude towards disability and impairment in New Zealand society, as large numbers of service personnel returned home disabled (Beatson, 2001; Tennant, 1996). Services to returned soldiers after World War II were "more comprehensive and efficient" than those provided after World War I, with service provision being by way of multi-agency support, rather than by one agency coordinating the effort (1996, pp. 20-21). Governments also began to show commitment to civilian rehabilitation. The 1954 National Government established an interdepartmental committee to advise Cabinet on civilian rehabilitation (ibid.).

Institutionalisation

The 1950s marked the apogee in exclusionary policies in New Zealand. The last of the large institutions for accommodating disabled people out of the sight and mind of the public, and even their own families, was built (Beatson, 2001). During the 1950s and 60s, parents were encouraged to permanently place their disabled children into these institutions from age five (Georgeson, 2000; National Advisory Committee on Health and Disability, 2003a). A consultative committee to the government released the Aitken Report in 1953, recommending that intellectually disabled people be placed into large residential institutions from the age of five.

The Levin Farm and Mental Deficiency Colony (Later known as Kimberley Hospital and Training School, and then Kimberley Centre), began operating, in an attempt to provide a facility in the North Island similar to Templeton in the South. Here the number of residents peaked in the 1970s with over 700 disabled people (Hunt, 2000). The name changes of the Kimberley Centre are symbolic markers of societal attitudes.

The name, "Levin Farm and Mental Deficiency Colony", reflected the discriminating and segregative ideologies gleaned from the influence of eugenics, whereby people were isolated and separated from the "healthy" and "normal" able-bodied in an attempt to prevent reproduction and "contamination" of the human species (Olssen, 1981, p. 6). The title change to "Hospital and Training School" underpinned the development of medical influence by giving the impression that medical professionals were rebuilding and improving impaired bodies, whilst at the same time using disabled people as a resource for teaching and experimentation. Finally, the name change to the prosaic "Kimberly Centre" in 1987 was an effort to normalise, camouflage and deny the fact that 540 people were living in conditions of isolation and seclusion.

The Discourse of Reaction: The Development of Independent Providers and Consumer Groups

Post World War II, consumer groups representing disabled persons and their families began to develop. The Dominion Association of the Blind was established in 1945 as a reaction to the autocracy and paternalism of the New Zealand Institute for the Blind (Sullivan, 2001; Tennant, 1996). Soon after, in 1949, the Intellectually Handicapped Children's Parents' Association (later to become the IHC New Zealand Incorporated) was formed, and began to resist institutions in favour of community-based support (Beatson, 2001).

The IHC has developed into a large organisation providing targeted vocational and residential services. With an operational budget in excess of two hundred million dollars, the IHC is a quasi bureaucracy[3]. Its role as an advocate, seeking change in government policy and ideology, has diminished as it is difficult to advocate when nearly fully funded by government. The focus of the organisation is now as a service provider, but an active advocacy unit has been retained. This strong relationship between government and IHC replicates a pattern found between government and charitable organisations since the late 1800s, whereby the voluntary sector, driven by

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[3] Figures ending June 2007 show an income of over $210,000,000 ($184,000,000 from government contracts), 6260 staff, 3674 residential and vocational service users, and 2800 family/whanau service users.

strong individual philosophies, decides on what services to provide, and the government helps with financial aid. The strong philosophical ideologies inherent within IHC and other organisations helped to influence government policy regarding deinstitutionalisation (Roberts, 2000).

According to Sullivan (1991, p. 265) the non-government sector has played a pivotal role in "the structuring of disability and the lives of disabled people in Aotearoa New Zealand", and cites the example of the Crippled Children's Society, founded in 1925. The society was set up by medical experts in an attempt to improve services for children affected by polio. The organisation "presented and viewed disability from a medical perspective which defines and objectifies individuals in terms of functional impairment" (ibid.). Such a view was typical of the non-government sector as these organisations were dominated by an expert, professional medical perspective:

> These were inevitably organised along medical lines, under-funded and largely dependent upon charity for operating costs. This ethos not only associated disability with poverty and inferiority but also penetrated the cultures with disastrous consequences for residents. On the one hand it inevitably attracted some staff and volunteers alike who, motivated by the "do-gooder mentality", came to work in the organisations where they could help the "pitiable" and "tragic" victims. (Sullivan, 1991, p. 265)

In 1957 the Pukeora Home for the Disabled was opened. The opening was significant, as the state "accepted responsibility for the direct care of physically disabled people" (1995, p. 21). But the institution was run "more like a hospital than a residential home" (ibid.), with strict rules and regulations that placed power and control firmly in the hands of staff. Alcohol consumption, sexual relationships amongst residents and friendships between staff and residents were banned (Sullivan, 1995).

Winds of Change: Deinstitutionalisation and the Social Model of Disability

The Burns Report of 1959 was a seminal document in that it recommended a change of government policy, away from the use of large institutions for isolating and supporting disabled people, towards deinstitutionalisation which did not occur until the late 1970s. The report was critical of the government provision of residential services for people with intellectual impairments and received considerable publicity (Beatson, 2001; Millen, 1999). As human rights became debated during the 1960s, this change of direction grew and by the 1970s deinstitutionalisation had become a driving force in many areas of social policy for disabled people (Tennant, 1996).

From the mid 1970s, the government approach to services for people with disabilities became increasingly community and rights based. Two Royal Commissions of Inquiry contributed to this shift. The 1972 Royal Commission of Inquiry into Social Security led to significant changes in social welfare benefits, and in 1972 the Department of Social Welfare (DSW) was established (Mitchell & Mitchell, 1985). A second Royal Commission to investigate psychopaedic hospitals in 1972 resulted in a change of government policy, preferring the use of small residential facilities to large institutions (Ministry of Social Development, 2002).

Pressure continued to mount towards the process of deinstitutionalisation, and Weber (2008) describes these forces as follows: Firstly, sociological forces reflected a change in negative public opinion towards large institutions. Secondly, the introduction of new anti-psychotic medication enabled some disabled people to be treated outside of hospital settings. Thirdly, legal forces such as the Burns Report 1959 and two Royal Commissions of Inquiry provided an impetus for change. Finally, political and financial forces contributed to the discharge of people into the community, which many saw as being driven by cost cutting factors.

ACC Legislation

As an attempt to centralise and coordinate rehabilitation policy, the Accident Compensation Act of 1972 is seen as a significant milestone and catalyst for change (Pirie, 1977). The passing of this Act and its full implementation in 1974 provided a coordinated programme for non-means tested medical and vocational rehabilitation for persons incapacitated as the result of injury or accident. The significance of the Accident Compensation Act was that for the first time in Aotearoa "a central coordinating body responsible for the complete rehabilitation of a distinct portion of the handicapped population now, in fact exists" (Pirie, 1977, p. 503). Critics of the scheme say it places "little emphasis on the concept of social rehabilitation" (ibid., p. 499), creating "an elite among the disabled" (Neuman, 2006, p. 10). Those injured prior to 1972, the ill, and the congenitally impaired, are disadvantaged when compared with those incapacitated by accident.

Disabled Persons Community Welfare Act 1975

The second centralised approach to the problems of New Zealand's rehabilitation policy was the passing of the Disabled Persons Community Welfare Act 1975. Pirie saw the Act as a response to a fragmented historical past: "The moving force behind the Bill was not a Royal Commission but the one hundred and thirty five year history of rehabilitation in New Zealand" (1977, p. 504). The Act was significant, as this was the first time legislation was formulated with the input of disabled people using the social model of disability (Beatson, 2001). This Act provided (by way of a means tested system) funding for specific services, appliances, aids, vocational training, respite care, home help/care and loans to individuals who were not covered by the provisions of the Accident Compensation Act. In an attempt to remove barriers which hindered disabled people from the public space, the Act requires all new public buildings and those undergoing extensive renovation to have walkways accessible for disabled people. The legislation granted financial aid to both voluntary and private sector organisations that provide disability services. These requirements were radical and opened the way for a new era in public policy for disabled people based on the social model of disability.

Community Care Scheme

In the mid 1970s the Community Care Scheme was set up by government to establish residential facilities in the community. They were usually cluster or group homes, which have been called "mini-institutions" (Schalock, Baker, & Croser, 2002, p. 101). These homes heralded the development of community-based residential services for disabled people during the 1970s and 1980s (National Advisory Committee on Health and Disability, 2003b). The intention of this shift from large institutions was to promote community assimilation and participation, but this largely has not occurred (National Advisory Committee on Health and Disability, 2003b). Sullivan (1995, p. 21) states that "while the aim of establishing these homes in the community was to facilitate integration, these aims have remained largely unfulfilled".

Normalisation

An important theoretical driving force in the process of deinstitutionalisation was the theory of normalisation as expounded by Wolfensberger in the 1970s (see pp.25-26 in Chapter Two). This ideology became influential in Aotearoa New Zealand in the 1980s and became an important driving force for the government policy of inclusion and normalisation (Ballard, 1994; Lemon, 2001). At this time the disability rights movement began in the United Kingdom with publication of the *Fundamental Principles of Disability* (1975) by the Physically Impaired Against Segregation (UPIAS) and led to the development of the social model of disability (pp.14-19 in Chapter Two.).

The 1989 Education Act was a significant milestone in the move to community integration, giving the right for disabled children to be educated at their local schools. Previous to this, most disabled children were forced to be enrolled in special schools and segregated from the majority of schools in Aotearoa New Zealand. A further positive development for disabled people occurred when the Office of the Health and Disability Commissioner was established through the Human Rights Act 1993. The Act prohibits all forms of discrimination on the grounds of disability.

New Deal Initiative

An attempt to transfer all services for disabled people from a number of government departments to one, under an initiative called New Deal,[4] was promulgated in the early 1990s. The proposal resulted in disability support services shifting to the Ministry of Health with a capped and ring-fenced budget within Vote: Health. This change was legislated for in the Health and Disability Services Act 1993, which repealed the Disabled Persons Community Welfare Act, but retained most of its provisions. Sullivan described the introduction of this Act as "a severe body blow. It marked a retreat from legislation based on the social model of disability to legislation based firmly in the medical model" (2000, p. 41). The new department became known as Disability Services Directorate, and came under the responsibility of Regional Health Authorities, and is now currently funded by government from Vote: Health. Between 1993 and 1995 all disability support services were transferred from the Department of Social Welfare to Health, with the exception of vocational services, which was transferred from the Department of Social Welfare to the Department of Work and Income in 1999.

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[4] The New Deal: Support for Independence for People with Disabilities, Ministers of Social Welfare and Health, 1992.

New Deal introduced free market principles of competition and tendering for disability services that were previously funded by the state (Tennant, 1996). This major shift in funding resulted in criticism regarding fragmented decision-making and an over reliance on financial accountability, as opposed to the over-all quality of provider performance (National Advisory Committee on Health and Disability, 2003b).

Closing of Institutions

More than 10,000 disabled people moved out of institutions and into the community over the period 1990 to 2000 (National Advisory Committee on Health and Disability, 2003b). The closures of Templeton and Porirua Hospitals were announced in 1996. At the end of 1997 Mangere, Kingseat and Cherry Farm were closed, and very few people were left in Porirua Hospital. Tokanui in the Waikato closed in 1998 and Ngawhatu Hospital in Nelson closed in 2000.

Deinstitutionalisation and the shift into the community gave the impression of empowerment for disabled people, but the process for many was only a change of language. Patients became clients, the doctors and nurses were now called professionals, and hospitals devolved into service providers. The shift to community care was characterised by inadequate funding and under-resourcing of limited services (Tennant, 1996).

New Zealand Disability Strategy 2001

A portfolio of Minister for Disability Issues was established in late 1999, shortly followed by the New Zealand Public Health and Disability Act 2000. This Act required the establishment of an Office for Disability Issues and the development and implementation of a New Zealand Disability Strategy, which all government departments must include in their frameworks. The New Zealand Disability Strategy was released in 2001 and is significant because it is a rights-based framework based on the social model of disability (National

Advisory Committee on Health and Disability, 2003b). Two key objectives of the Strategy promote "a non-disabling society" (objective one), and rights for disabled people (objective two). The Disability Strategy has become important for disability rights and political change in Aotearoa New Zealand, as all government departments are now accountable to the Strategy, and government policy must reflect its objectives: "Government departments are expected to develop annual New Zealand Disability Strategy implementation work plans that spell out what work they are doing to implement the Strategy" (Ministry of Health, 2001).

To Have an Ordinary Life Report 2003

The National Health Committee's 2003 report: To Have an Ordinary Life, Kia Whai Oranga Noa, reflected three years of research and investigation into how intellectually disabled people are living in the community. The Committee identified three areas where significant change is required. Firstly, the refocusing of needs assessment, service coordination and service purchasing of disability services. Secondly, changing the "custodial ownership model of service delivery" because it currently results in a "collective living" situation where disabled people have very little power and control over their lives (pp. 45-46). Thirdly, changing the current system of disability supports to ensure that the basic health needs of intellectually disabled people are met.

Like Minds Project

A Like Minds project was funded by Ministry of Health in 1997 to reduce discrimination associated with mental illness. National plans have been developed which incorporate the social model of disability. The plans promote "non-discriminatory policies and practices within organisations that are responsible for housing" (Ministry of Health, 2003b, p. 10). One of the aims of the project is to help remove the barriers caused by the "special/segregated provision in ... housing ... [where] people with experience of mental illness are separated socially from other people" (ibid., p. 4). The project uses high-profile media campaigns to promote the inclusion into society of disabled people (ibid).

Closing of Kimberly

The Kimberly Centre in the Horowhenua finally closed its doors in 2006, and the occasion was marked by a government celebration held at the Beehive on 14 November 2006, entitled: "The end of institutionalisation". The Minister of Health, Pete Hodgson, said: "The end of institutionalisation is a milestone for disabled New Zealanders and their families ... a milestone for New Zealand" (Office for Disability Issues, 2006). In claiming the end of institutionalisation, government seems oblivious to the serious situation of isolation and control faced by disabled people living in community-based homes run by charitable organisations and businesses. Disabled Persons Assembly (DPA) Chief Executive Gary Williams (ibid.) drew attention to the reality of the burgeoning growth of mini-institutions in the community at this government celebration:

> ... the massive 400 bed places are empty but the institutions have not closed. We still have many forgotten people who are existing in a world that I call Staffville. Staffville is where disabled people provide staff with jobs; Staffville is an isolating place. There are lots and lots of such places where disabled people live together simply because they are disabled people. By their very nature, they are institutions.

CURRENT SITUATION

In 2001, it was estimated that 27,300 disabled people were living in residential facilities (Centre for Housing Research Aotearoa New Zealand, 2005). These residential services are being supplied by a matrix of providers ranging from central government, small volunteer organisations and businesses. Many of these have developed and function in an unorganised, ad hoc, fragmented manner (Moore & Tennant, 1997; Moore, 1995). Horner states, "it is quite possible to create all of the limitations of a large institutional environment in the smaller setting of a community home" (Horner, 1994, p. 168). Cluster and group homes can "solidify staff-client roles, lend themselves to group routines ... limit the control that individuals have over their lives, and inhibit community integration" (ibid.).

Many disabled people are dissatisfied with the group homes model which, in many cases, has replicated the institutional milieu that it was meant to replace (MacArthur, 2003). A recent Australian report into the quality of life for disabled people who have transitioned from a large institutional setting to community-based living, has found that there was no change in the relationship dynamics between staff and residents as a result of the move. Residents were "constrained in what they were allowed to do: freedom of choice was diminished, along with independence" (Borbasi, Bottroff, Williams, Jones, & Douglas, 2008, p. 846). The experience for many disabled people is of care and support arrangements "orchestrated and driven by others" (ibid.).

Research has identified support staff as exercising undue power and control over disabled people (Borbasi et al., 2008; Horner, 1994; McGill & Emerson, 1992; Ministry of Health, 2004; National Advisory Committee on Health and Disability, 2003b). A 2004 Ministry of Health survey of disabled people found:

> "Choice and control" was a major recurring theme and service users commented that they had none or very little control over their lives. For example, what they would like to wear and when they want to go to bed. (Ministry of Health, 2004, p. xiii)

In many ways it is not surprising that some professionals and service providers continue to act in a patronising and paternalistic manner, as history continues to shape today's society and structures. This historical review has been undertaken to gain an understanding of the factors of the past which have the ability and potential to influence today's disability support services.

The focus of the thesis will now turn to its own inquiry – a study into the stories of five independent disabled people who have moved from supported residential services to a situation where support is separate from accommodation, or where support is no longer provided. A crucial factor in the success or failure of this research is the methodological structure of the inquiry. The next chapter undertakes to explain the theoretical underpinnings, principles and methodology of the research, focusing on qualitative interviews and the specific research procedures.

CHAPTER FOUR

METHODS OF DOING

THE RESEARCH DESIGN

The research experience must serve to validate, politicise and make visible the disability rights perspective. This inevitably empowers people as it identifies the non-disabled world as the source of oppression, facilitates understanding of the experience of disability and rejects oppressive ideologies applied to the individual with an impairment. (Boyles, 1994, p. 39)

The previous chapters on history, the social model of disability, power and self-empowerment have laid a foundation for the research. This foundation feeds into the methodology: the subject of Chapter Four. Such a framework is designed to capture the voices, understand the strengths and abilities of disabled people, and identify enabling structures. The purpose of the framework is to contribute to the self-empowerment of disabled people in Aotearoa New Zealand, as outlined by Boyles in the above quotation.

Theory provides a lens through which to clarify events and behaviours that might otherwise seem clouded. It informs our decisions and actions relative to our observations. For the purposes of this research the social model of disability and Foucault's post-structural concepts (as previously discussed) will inform the theoretical dimension of the investigation. The project will avoid scrutiny of individual impairment. Instead it will focus on the external factors of oppression and control emanating from institutions, professions and discourses, often originating from the medical discourse on disability.

METHODOLOGY

Methodology can be confined to rules, procedures and methods used in research, but it is more than that. It includes "the analysis of the principles or procedures of inquiry in a particular field" (Merriam-Webster Online Dictionary, 2008). Therefore methodology consists of the principles and philosophical foundations at the heart of a research project and provides the vehicle to propel the study forward (Bloor & Wood, 2006, pp. 381-382).

Originally, an emancipatory research method was considered (Barnes, 1992; Oliver, 1992), as collaboration with the participants is an important feature of the approach. With this method the participants are involved in the entire research process ranging from the original inception, design, data collecting, analysing and finally reporting (Neuman, 2006; Schutt, 2004). Those interviewed are mutual participants, able to influence the methodology and act as "researchers" in the "joint process of data creation" (Fook, 2002, p. 29). Participants assist with "formulating, designing and carrying out the research ... the researcher takes the role of a consultant or collaborator" (Neuman, 2006, p. 28).

But upon reflection, and in line with current debate regarding the difficulties of actually being able to achieve emancipatory research (Campbell & Oliver, 1996; Sullivan, 2006), a participatory research approach was chosen. Sullivan (2006, p.189) states, "the goals of participatory research are not too removed from those of emancipatory research".

Participatory research

Participatory research has emerged from the work of Brazilian educationalist Paulo Freire. The two main characteristics of participatory research are, according to Stoecker: "increasing participation in the research process and making social change" (1999, p. 841). Key to participatory research is the principle that research is with participants, not on participants. Participants may be involved in any of the following stages: research design, data collection and analysis, and dissemination of the results. The research must include an emancipatory focus that aims to benefit the group being investigated through changing the structures of society (Stoecker, 1999). The participant's knowledge is regarded as meaningful and important, and ownership of the results is shared between the researcher and participants. Emphasis during the research is on process rather than outcomes (Cornwalla & Jewkesb, 1995).

Ecological perspective

The research uses an ecological perspective (1979) to inform "about the nature of the person-environment interrelatedness and the person-situations transactions" (Compton & Gallaway, 1994, p. 118). Rather than focus solely on the person, the ecological perspective provides a methodology for seeing a person and his or her situation as a whole entity, with each part related to all other parts in a complex way through multifarious processes where "each element is both cause and effect" (ibid.).

Individuals and families in the environment are at the heart of the perspective, and it is important to identify and connect people to other systems and sub-systems (Jack, 2000). These relationships are identified, studied and analysed, looking for enabling and disabling discourses. Used correctly, the model becomes both a reflective tool and a framework for analysis which can identify strengths and weaknesses in the entirety of an individual's ecology. The ecological model can consist of up to several levels of scrutiny: ontogenic, micro-system, meso-system, exo-system and macro-system (Belsky, 1980).

The theoretical perspectives as stated above have helped to inform the principles of the research.

PRINCIPLES FOR THE RESEARCH PROJECT

For the purpose of giving guidance, direction and an orientation to the research, four principles have been developed under the over-arching umbrella of the social model of disability, and combining the theoretical approaches of participatory research:

1 Research to be beneficial for disabled people

Historically, research has been exploitive (Cram, 2001; L. Smith, 1999). Past researchers have achieved knowledge, prestige, power and economic benefits, while those researched gained little. To counteract the negative effects of the past, this research must have demonstrable and practical benefits for disabled people and there must be no possibility of exploitation. Perspectives that emphasise the need for self-reflection and empowerment for participants will determine the research, rather than an uncritical acceptance of facts and data inspired by researcher biases and agendas (Hewitt, 2007).

2 Research will focus on the strengths, abilities, resources and attributes of disabled people

Under the guise of the medical model, disabled people have been introspectively examined with an undue focus on deficits, needs, weaknesses, and pathology (Oliver, 1990, 1992, 1993; Rapp & Goscha, 2006; Saleebey, 1997, 2002). This approach has led to a helpless victim mentality perception of disabled people to creep into society. The research will engage with disabled people with the view to understanding their resilience, strengths and abilities. These attributes will be explored, identified and documented and, hopefully, others will read their accounts and be inspired.

3 Research will have a self-empowering orientation

In the previous chapter the literature showed disabled people have, through several discourses, been oppressed in various ways, including isolation, discrimination, prejudice and injustice. Many disabled people continue to be a powerless group in society. Therefore the research will have a self-emancipatory orientation underpinned by the principles set out in the social model of disability.

4 The researcher will be reflective

The values, beliefs, and life experience of the researcher influence the construction of research questions, data collection, and interpretation of findings. Factors such as age, appearance, social class, culture, inequalities of knowledge and power, environment, and gender all impact on investigative process (Denzin & Lincoln, 1994, 2006). Reflection focuses on how the preconceptions and assumptions of the researcher influence the research's design, information gathering and data analysis. Being reflective gives consideration to the potential effects of these variables on the data (Hewitt, 2007).

The principles as stated will provide a fundamental framework to guide the specific methods and procedures used in the research, which will be based on qualitative means.

Qualitative Method

A qualitative methodology using semi-structured interviews with five disabled people will form the basis of the inquiry. Denzin and Lincoln state:

> Qualitative research is a situated activity that locates the observer in the world. It consists of a set of interpretive material practices that make the world visible. These practices transform

> the world. They turn the world into a series of representations including field notes, interviews, conversations, photographs, recordings, and memos to the self. At this level, qualitative research involves an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them. (Denzin & Lincoln, 2008, p. 4)

Qualitative research has its roots in sociology through the influence of the "Chicago School" in the 1920s and 1930s, along with anthropology, in the same period, and the work of Boas, Mead, Benedict, Bateson, Evans-Prichard, Radcliffe-Brown and Malinowski. In a short time, qualitative research became used by other social sciences such as education, social work, and communications (Denzin & Lincoln, 1994, p. 1).

Strengths of the qualitative approach

A qualitative investigation is inductive and naturalistic, allowing participants to express themselves in their own terms, and allows for research be undertaken in an environment familiar with and comfortable to the participants (Patton, 2002). Qualitative research is characterised by themes and categories that emerge from the culturally specific perspective of the participants, and it "produces knowledge claims about one or very few individuals, groups, or institutions" (Morrow & Smith, 2000, p. 200). The approach is useful for gaining an understanding and meaning of events and situations, and for finding "concepts, problems and interpretations" from the collected data (Glasser, 1998, p. 67). This method provides "illumination, understanding and extrapolation, rather than the casual determination, prediction and generalisation" (Patton, 1990, p. 424), and is involved with the social view of a value-based world.

Qualitative researchers stress the socially constructed nature of reality, the intimate relationship between the researcher and what is studied, and the situational constraints that shape inquiry. Such researchers emphasise the value-laden nature of inquiry, seeking answers to questions that stress meaning (Denzin & Lincoln, 1994, p. 4)

Such an approach links the research process to morals and ethics, and requires the research to have an orientation and an emancipatory focus that will benefit disabled people.

Critique of qualitative research

Qualitative methods of research have been criticised for not addressing the power imbalance that exists between the researcher and participant. The researcher is still considered the "expert' and there is the potential for exploitation of those people being researched. Analysing and interpreting the data is determined by the researcher, and participants have little input into any of the research processes (Barnes, 1992; Oliver, 1992). These points are addressed, to some extent, by the reflexive nature of the research.

Qualitative Interviews

Qualitative interviews using a "general interview guide" will be the chosen format for the planned inquiry (Patton, 2002, pp. 342-345). This form of questioning relies on open-ended questioning to "develop a picture of the interviewee's background, attitudes and actions, in his or her own terms; to listen to people as they describe how they understand the worlds in which they live and work" (Schutt, 2004, p. 298). Interviews are likened to a conversation between partners, rather than between a researcher and interviewees (Kaufman, 1986, pp. 22-23). This method honours the knowledge, strengths and resilience of disabled people and it avoids the impersonal and mechanical effects associated with questionnaires and surveys (Patton, 2002).

Benefits of the qualitative interviewing method

The purpose of qualitative interviewing is to gather data not easily obtainable through other methods such as observation, surveys and questionnaires. Qualitative interviews allow the researcher to enter into the world of disabled people and gather their stories, experiences and feelings. Interviewing starts with the premise that "the perspective of others is meaningful, knowable, and able to be made explicit" (Patton, 2002, pp. 340-341). The interview format has the advantage of addressing complex issues, clarifying questions and responses, observing the person for non-verbal information, and allowing for flexibility in questioning (Steinburg, 2004, p. 107).

Unlike rigid surveys and questions, qualitative interviewing gives flexibility to the interviewer to shape future questions based on the reply from previous ones. Questions can be framed and reframed to "delve" into areas rich in information and knowledge (Babbie, 2001, p. 292).

The use of qualitative interviews provides an ideal platform to enter the world of disabled people, hear their stories, and collect data explaining their strengths, resiliencies and skills utilised when moving from a cluster or group home setting to a more independent environment.

Empathetic interviewing approach

The interview process of the project is informed by an empathetic-interviewing approach, which premises that it is not possible to interview objectively using pure positivist procedures. In fact the interviewer "is a person, historically and contextually located, carrying unavoidable conscious and unconscious motives, desires, feelings and biases" (Fontana & Fry, 2008, p. 116). Since it is not possible to be a neutral objective interviewer, taking a stance is natural, and it is better to "interact as persons with the interviewees and acknowledge that they are doing so" (ibid.). The empathetic interviewing approach posits that the researcher takes an ethical position in favour of the person or group being studied (ibid.). This approach is used, as the results of the research are intended to benefit disabled people by promoting policies, ideas and actions that contribute towards the self-empowerment of disabled people.

SPECIFIC PROCEDURES

The specific procedures involved with the collection of interviews, the analysing of data and the publishing of results has potential to inflict harm on the participants. To protect participants, the interviews were guided by ethical criteria and boundaries.

Ethical Concerns

Research is a political act involving power, and has the potential to exploit those being studied (Foucault, 1980, pp. 109-133). There is a possibility for harm to occur if the interviews are undertaken inappropriately, as participants placed themselves in a position of vulnerability when they shared their life stories. Therefore, the research has a responsibility to protect the respondents and ensure their wellbeing.

Before the research could commence, ethics approval was sought (Appendix 1) and gained from the Massey University Human Ethics Committee (Appendix 2). This helped to ensure that the research met required ethical standards for the participants, the researcher, and the University.

Participants were told they did not have to answer any questions that they felt uncomfortable with and the questions were presented in a sensitive and respectful manner. A disabled person was used as a third party to ask potential participants if they were interested in being involved in the research. This avoided the possibility of disabled people feeling pressurised by the presence of the researcher to become participants. An information sheet summarised the research process and informed participants about their rights to withdraw at any stage of the process. This right was reinforced at all face to face meetings the researcher had with the participants. Verbal consent was obtained in the initial phone call with the researcher. Before the interviews, the researcher clarified details on the information sheet and asked if the participant wanted the original tape recording of the interview returned. One participant requested and received the tape-recording of the interview.

Interview records are kept confidential by keeping them in a locked cabinet, and the computer used in the research is password protected (Wilkinson, 2001). These guidelines for ethical research were followed: avoiding harm, guaranteeing confidentiality and anonymity, using informed consent, promoting rights of withdrawal, using supervision, and ensuring participants have access to material.

The Wellington branch of the National Assembly of People with Disabilities (DPA) was contacted by letter informing them of the research and invited their comment. The researcher was contacted by Wellington DPA, who requested that a copy of the findings be forwarded to them.

Who will benefit from the research? This is an important question for ethical reflection. The author will benefit from the research, as it will contribute towards gaining further knowledge and a post-graduate qualification, and therefore greater power in our hierarchical society. Disabled people will also benefit, as the research will give voice to their experiences, and be listened to and respected.

Recruiting participants

Five disabled people who have transitioned from a cluster or group home situation into their own accommodation were required for the research. When recruiting participants, the research did not segregate disabled people according to disability. Rather, participants who had lived in a group or cluster home for their accommodation and support needs over a period greater than six months, were chosen. The researcher collaborated with a third party (a local disabled person) to informally make inquiries to ascertain potential interest and involvement in the research from disabled people living in the lower half of the North Island.

An information sheet was given to people interested in the research by the local disabled person. This explained the research details and requirements, participants' rights, confidentiality details, study aims and time required (Appendix 3). Telephone numbers were given to the researcher, who phoned to explain and clarify research details and processes. Once availability and interest in participating were verified, the researcher arranged times for the interviews to be conducted in a place of the interviewee's choosing.

Initially, seven disabled people were interested in participating in the research project. This number was narrowed down to five, as two people did not meet the criteria, having only lived in a group home setting for a period of less than six months. Partway during the interviews, two people withdrew from the research, stating to the person who had originally approached them that they had changed their minds. This set the research back over one month and it was initially difficult to find two replacements. Several individuals and a disability consumer organisation who originally said they could help find participants were unable to do so. But a recommendation to speak with a Wellington based community worker, who provides vocational services for disabled people, led to three respondents being located. After contacting the three people, two were interviewed.

The interviews

The respondents were contacted by phone and were given the opportunity to meet with the researcher to discuss the project. Of the five participants, four took part in a pre-interview meeting to gather further information and present questions. The participants were given the choice of being interviewed at a location of their choosing.

Before the interview, another information sheet was presented. Participants were briefed on the ethical details of the research, particularly the confidentiality arrangements. After ensuring the participants understood the process, written consents were obtained using the consent form (Appendix 4) and the authority for the release of transcripts form (Appendix 5).

All the participants were interviewed in their homes during the period May to July 2008. How each individual participant experienced their transition from group or cluster homes was explored during one interview of up to one and a half hours' duration, using open ended questions. A prompt sheet was used (Appendix 6) to guide the inquiry. The interviews were recorded using a Sony TCM-5000EV interview magnetic cassette tape record loaned from Massey University. At the end of the interview, annotations were made to capture any non-recorded information noted by the researcher.

The interviews were transcribed by the researcher. Participants received a draft transcribed copy of their interview for additions or alterations to be made. No changes were asked for. The tapes were inductively analysed for patterns, themes, categories, causes, consequences and relationships. A draft copy of the analyses was given to the participants for input into the research process. Three participants met with the researcher to discuss and provide additional analyses of the data. This additional information contributed to the final findings of the thesis. A summary of the research was given to each participant upon completion of the research.

Data analysis

The act of interpretation is a subjective experience, and is both an "artistic and political" act, for there is no one "interpretive truth" (Denzin & Lincoln, 2006, p. 37).To aid analysis, *Transana:* a computer software programme, developed by the University of Wisconsin, Madison Centre for Education Research for researchers to analyse digital video or audio data[5], was used. This software allowed for the simultaneous analysis of both audio and transcribed data. According to Kvale (1996), such a method avoids most of the pitfalls associated with the loss of intended meaning when conversation is transcribed to "verbatim interview transcriptions", which he describes as "artificial constructs that are adequate to neither the lived oral conversation nor the formal style of written texts" (p. 166). Care was taken to use the transcripts in conjunction with the actual recordings, as the tone of voice, pitch, rising or falling articulation, laughter and strength of delivery add significant evidence to the intended meanings of participants' stories (Kvale, 1996).

The interview transcriptions were analysed using Patton's three-fold process. Firstly, the large amount of information was reduced to smaller detailed amounts; secondly, themes and patterns were identified; and lastly, a framework was constructed to display the results that have been gleaned (Patton, 2002). Once again this process was carried out using the *Transana* software, which allowed for the coding to be carried out and recorded, alongside the transcripts and sound recordings.

Any quotes used in the thesis have been rendered in a readable written style to facilitate comprehension. Digressions, pauses and fillers such as "ah", "eh" and "mmm" have been removed and the text edited for ease of reading and understanding (Kvale, 1996).

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[5] For further information see http://www.transana.org/

In this chapter, the choice of research methods and design has been stated. Ethical pitfalls and a method to prevent these occurring have been discussed. This methodology, combined with a review of history, the use of the social model of disability and Foucault's post-structural account of power and bio-power, as set out in the previous chapters, have provided the framework for the stories of five disabled people to be heard and studied. The following chapter introduces the five people who were interviewed, analyses their stories, and identifies themes and patterns found in their accounts. Each person presented a unique and remarkable biography with a plethora of information which this thesis attempts to capture.

CHAPTER FIVE

THE STORIES OF FIVE PEOPLE

The participants and their stories are a vital part of this research. They are five disabled people who have successfully moved out from a cluster home setting. These people provide a knowledge base from which to gain some understanding of self-empowerment, displayed when participants organised their own accommodation in the community.

This chapter will introduce the participants. The organisations mentioned, geographical locations described, street names and participants' names have been changed to ensure confidentiality. The factors, themes and patterns which emerged during analysis will be examined and discussed in detail.

The Participants

Five disabled people participated in the research – four male and one female. Two participants were Pakeha, two were Maori and one person described himself as part Samoan. Four of the participants were mental health survivors and one was physically disabled. Table 1 (p.67 below) summarises the details of each participant.

Alan

Alan is a 41-year old Pakeha male mental health survivor who lives alone in a family-trust home and is not employed. He has experienced mental health support since his early 20s and had three admissions to institutions: Porirua Hospital, Ngawatu at Nelson and Sunnyside near Christchurch. The longest admission was for two and a half years at Porirua Hospital. When in his mid 30s, Alan lived at group home in the South Island for eight months. After "rehabilitation" from Porirua Hospital, Alan was referred in 1999 to an NGO residential provider in the lower North Island. He shared a three-bedroom home, one of nine, two-and-three-bedroom cluster houses. At the NGO, provider staff were on site 24 hours per day. He left to stay with his parents for six months, and then went flatting locally, in various houses from the private sector. In 2005 he moved into a nearby family-trust home organised with family support where he pays minimal rent. Alan receives support in his home through monthly visits from a local community mental health nurse.

Caleb

Caleb is a 37-year old part Samoan male who first experienced psychiatric support at Porirua Hospital in 1993. After spending two and a half months there, he went to live with family. Seven months later Calebwas referred to a Wellington NGO provider. He lived in a two-bedroom cluster home in a setting of seven, two-and-three- bedroom homes which had onsite support staff 24 hours per day. In 1994 Caleb left the provider and went to family in Samoa for 9 months, returning to his Aotearoa New Zealand family home in 1996. After a short period, Caleb went flatting for two years, then because of isolation returned to the same cluster home in 1998 for one year. In 1999 Caleb left the provider to flat locally with a friend for 5 months. Caleb now has his own flat which is rented cheaply from a locally based landlord, near to family. Currently Caleb works part-time and receives support from a community-based mental health support worker who visits monthly.

Elliot

Elliot is a 42-year old Pakeha male who, because of muscular dystrophy, regularly spent three to four week respite breaks with the Crippled Children's Society (CCS) from an early age. In the late 1980s, Elliot went flatting near his parent's home in the Wellington region. After one and half years, Elliot returned to his family and in 1991, with the support of a social worker, moved to an NGO setting of seven, two-bedroom cluster houses close to his family.

Staff were on site here for 24 hours per day. In 1999, Elliot moved into a granny flat located close to his mother's property. In 2007, Elliot left his mother to move into a family-trust home. Here he pays cheap rent and the house will become Elliot's when his mother dies. Elliot is seeking work and gets support twice a week for domestic cleaning from an NGO community support worker.

Jack

As a 47-year old male Maori mental health survivor, Jack was first admitted to Lake Alice in 1985, where he experienced "many admissions". After his family moved to the Wellington area in 1991, Jack had several admissions to Porirua Hospital. In 1994, Jack first experienced supported living when hospital rehabilitation staff directed him to move into a large Wellington Council block of flats that had a floor dedicated to former Porirua Hospital survivors. Daily support was provided by NGO workers. After another admission to Porirua Hospital Jack was sent, in 1995, to a nearby NGO provider who had twelve, two-bedroom cluster homes with support staff on site 24 hours per day. In 1999 Jack successfully applied to the provider to live at a nearby single-roomed cluster home setting of four houses managed by the same NGO provider, where support staff visited on a daily basis. Because the local District Health Board withdrew funding for level one and two mental health services, the NGO provider withdrew support and landlord services from the cluster home. This resulted in Jack commencing a tenancy agreement for the home with Housing New Zealand 2000, where he continues to reside. Jack works full time and receives monthly support from a local community mental health nurse.

Nancy

Nancy is a 42-year old Maori female who was first admitted to Porirua Hospital in 1989. During the next 11 years, Nancy was regularly in and out of Porirua Hospital and her parent's or boyfriend's homes. Her longest admission was for four and a half months. After a stay at the hospital in 1999, she was directed by the Court to live six months with a community-based NGO provider of supported accommodation. Whilst waiting for a vacancy, Nancy spent one month with her parents and then moved into the NGO provider's three-bedroom home, part of a clustered setting of four houses. After 11 months with the providers, Nancy moved into a Housing New Zealand one-bedroom house in 2000. Nancy continues to live here and a community mental health nurse visits her twice per week. Presently Nancy works one day per week.

TABLE 1: Participant details, part A

Person	Interview length (hr:min)	Gender	Age (yrs)	Ethnicity	Disability	Time (years) spent at large institutions
Alan	1:14	Male	41	Pakeha	Survivor	3
Caleb	1:07	Male	37	Samoan	Survivor	0.25
Elliot	1:03	Male	42	Pakeha	Physical	0
Jack	0:46	Male	47	Maori	Survivor	>7
Nancy	0:47	Female	42	Maori	Survivor	>5

TABLE 2: Participant details, part B

Person	Number of occasions living at institution/s	Lived in a group or cluster home	Time (years) in cluster homes	Year left cluster home	Current employment status
Alan	3	Cluster	3.25	1999	Not working
Caleb	1	Cluster	2	1999	Not working
Elliot	0	Cluster	8	1999	Not working
Jack	>10	Cluster	6.5	2000	Full time
Nancy	>15	Cluster	0.9	2000	Part-time

Differences and similarities regarding background information

Criterion for eligibility to participate in the project was not based on impairment, but rather the decisive factor was the disabled people's previous experiences of group or cluster type housing. All the participants had transitioned from cluster homes to their new community homes, and one person had previously experienced group home accommodation. Four of the participants had a mental health background and one was physically disabled. This ratio does not reflect recent data on impairment types in Aotearoa New Zealand, where 65 percent of people reported a physical impairment, 41 percent sensory, 15 percent psychiatric or psychological and 5 percent intellectual (Statistics New Zealand, 2002). The research was not intended to replicate these ratios. Rather, the information gained from the research is seen as promoting thought, discussion and a starting point for a larger and better resourced project.

All the participants lived within 50 kilometres of Wellington and had significant family members living within 30 kilometres of both their former provider homes and their current accommodation. Those spoken to were enthusiastic to share their stories, and after completing two interviews, patterns and themes began to emerge.

Presentation of data

The stories of participants were analysed and studied to find themes and patterns which explained how they were able to transition from provider homes. A large part of their stories was about the reasons that provided the impetus for leaving provider homes. These reasons are noted and identified under the category of "enabling factors". It became apparent from the narratives that other factors were also connected with their moves out from provider homes. There were forces which hindered the participants from leaving, and this theme is described as "disabling factors". Finally, a third theme was also identified and called "support factors". This determinant is used to describe the features that have assisted the participants to remain living in the community and not return to a provider home situation.

1 ENABLING FACTORS

After transcribing the interview, a thorough analysis of the data revealed a number of enabling factors which contributed to the participants' experiences of moving out from the cluster homes. These are labelled as *enabling factors*, and were pivotal to providing the impetus for participants' moves from provider accommodation. These factors will now be examined in order of importance as discussed by participants, beginning with personality clashes.

Personality clashes

Conflict and disagreement with other people is an inevitable part of human existence, and all participants recounted situations of indirect or direct conflict and disagreement with flatmates and staff at the provider homes. These pressures and conflicts led to dissatisfaction with their accommodation, which contributed to participants seeking alternative living arrangements. This process is clearly exemplified by Nancy's experience in a three-bedroom cluster home with two other flatmates:

> *But then in the end some people, I knew, weren't going to move on and I just said to myself; they're not going to move on, we've been here for months, this is not a happy situation. They're not going to move on; I'm going to have to move on. That was it, it was like, "You win I'm going to move. Yeah you two win." It was a struggle. In the end there were two of them and they're vegetarian. I'm not a vegetarian. They'd buy all these vegetables, but then they couldn't cook. And then they'd want me to cook it. Sometimes when you look at people it's not the big things, it's just the little things that drive you up the wall. In the*

> *end it was, "You win, you can stay and I'm going to move." That was it, and then I went to my father and I told him how unhappy I was, and he said, "Okay, okay calm down", and then we went down to Housing Corp and they gave me the choice of three flats, and I chose this one.* (Nancy)

Nancy had previously lived with three different flatmates over an eleven-month period and recounted, earlier in the interview, how when she found two of these flatmates incompatible to live with, she would "move them" on by being "nasty to them". This strategy did not work in the above illustration because the person involved stood up to Nancy and did not move out. Finally, it was Nancy who moved out and ended up living in a Housing Corporation flat, where she continues to reside today.

All the participants had little or no choice in deciding who would live in their former homes. Most NGO providers have a policy of a trial period when a person enters the provider's service. The newly arrived person lives with other flatmates for a time period of up to four weeks. This process often does not take into account the viewpoints and feelings of those who are already living in the house. Nancy recounts her experience when staff organised a two-week trial for a person to live in her home, which she shared with a flatmate:

> *It was just a farce. We said, "We don't want you", and they just said, "Well that's just too bad, because she's been given notice where she's staying, and she's coming. That's it". And we said, "Then why are you at telling us there's a two-week trial. There's not a two-week trial". And they said, "Well that's it, if you don't like it, lump it."* (Nancy)

The person involved in the trial period eventually ended up staying in the home. This led to conflict and disagreements with Nancy, which contributed towards Nancy leaving.

Elliot's experiences of stress and conflict led to him becoming socially isolated from his fellow residents:

> *I felt like going as I was a little bit under pressure* [from] *the people I used to flat with and of course the staff* [Several minutes later] *I thought enough is enough. I was thinking of moving out anyway and how would I cope with moving out. Everybody was blaming everybody else, and I made it worse really ... even my friend was. So I thought, the best thing for me is to get out of there.* (Elliot)

For the participants in this research, the move from the provider homes to their own homes resolved any issues associated with personality clashes with staff and fellow residents, as they now live alone with neither flatmates nor partners.

Provider dissatisfaction

A common theme with all the participants was dissatisfaction with some aspect of the provider's policies and procedures. The most common complaint was of provider rules, which went beyond the normal expectations of homeowners and were perceived as unreasonably imposed on them. Alan's account clearly demonstrates his dissatisfaction with the provider's policies:

> *Well you start to get bored with people in that time. You don't like being told what to do and you're certainly very aware of how your life is supposed to be going ... They didn't like you just sitting around watching television and smoking cigarettes. You had the Board or the Trustees or there was the staff for sure. I mean you couldn't lie in bed until 1 o'clock in the afternoon because that wasn't getting you anywhere ... They starting coming in, they got one chap, they actually*

> *got Charles to come in and wake us: "You got to get out of bed now, there's things to be done, you got to be down the road at 7 o'clock or you're going up there today."* (Allan)

Alan's comment – "You're certainly very aware of how your life is supposed to be going" – is revealing. It indicates that staff were giving feedback regarding how the residents should be behaving in their own homes.

Other participants were unhappy with being told what time to be home in the evenings, having money deducted from their bank accounts by the provider without the resident's permission, and being "forced" to undertake activities. But for most, having regular routines and procedures imposed on them by the provider was the major source of discontent.

The participants' stories of the NGO providers were not always negative. There were accounts which demonstrated positive experiences, particularly around staff support, which will be examined later in the chapter. Another factor spoken about positively by all the participants was family support. Families play an important unpaid role supporting disabled people, often complementing the work that professionals in the disability services sector undertake.

Family support

All the participants had stories to tell of family support, which contributed directly and indirectly to their moving out from the provider homes. Elliot's mother provided both moral and practical support for Elliot to move from the cluster home he had lived in for eight years:

> *My mother was quite ... keen for me to move out ... she showed me a couple of houses ... we went to look at the land agent of course, just around the road from Bridge Road ... It was really to buy a place and*

> *of course it had to be done up, something cheaper. So when mum was doing it, we actually got one of those houses, what you got built in the backyard and it worked out cheaper to build a place there.* (Elliot)

Without the backing of his mother, Elliot would have found it difficult to secure his own home. A granny flat was purchased and moved onto the back of his mother's property and Elliot spent six years there before moving to his present family-trust home.

Alan's parents provided a room in their home for six months until Alan found a flat which he shared with his friend. Caleb's mother gave him money to join his father in Samoa. Nancy's parents helped to find a Housing Corporation flat and assisted with decorating it. These examples of practical support to assist in leaving provider home settings were meaningful for the participants.

It was also important for the participants to receive moral and emotional encouragement from their families. All the participants spoke of continued, regular contact and back-up from significant family members, particularly parents and siblings. Family support assisted participants to achieve their goals and aspirations.

Goals and aspirations

Four of the participants spoke strongly of their personal goals when recounting how they left the residential provider. Their vision was not to live long-term at provider homes but to leave for a more independent accommodation.

Nancy was placed with the NGO disability provider by Court order and always believed she would eventually find her own home:

> *You don't want to think,* [that] *"I want to stay here for the rest of my life." ... I never thought I was going to be there like for years and years and years. It was never the plan.* (Nancy)

Caleb recounted clinging to the memory of his previous lifestyle before going into hospital. He sought to return to that way of living by setting goals:

> *Goals that I'd set for myself – live in the community, in my own flat, work, lose some weight, stop smoking stuff –* it *was a goal of mine. I'd lived independently before I went into hospital. I wanted to gain that life again, of looking after myself, cooking and cleaning. It was me wanting to change, but could achieve more if I was out of the place.* (Caleb)

Another force which enabled the participants to leave their former accommodation was the help of NGO staff.

Staff positive support

The participants spoke of both negative and positive experiences of NGO staff in relation to their moving out of the provider homes. Over twice as many positive experiences compared with negative were outlined. The staff role in the transition covered a wide ground. Jack talked about experiential training in independent living skills, and recounted that staff originally had provided intensive support, including: cooking, cleaning, shopping, transportation and the paying of bills. But when the NGO provider decided to close several cluster homes, staff provided training for the residents to carry out their daily life skills independently. Jack recounts:

> *They gave us trips and that. We went up to Wanganui and they would take us shopping, start us off ... dental, doctors and GPs. They take us to see our psychiatrists when you first got in there, then they slowed it*

> *down, and tried to make you independent … they would show me how to get the benefit and break that up and show you what to do. Automatic payments and things like that,* [buying] *food. Then they drifted off from taking us shopping and let us catch a taxi.* (Jack)

Elliot found the staff encouraging, which helped him gain a better understanding of himself. This gave him confidence and contributed to him leaving: "*Just finding out who I am and I moved out, yeah. … this was quite good for me … I just got to know other people, get different ideas from other people, so that was good for me and helped me.*"

Nancy recounted that the initial idea to leave the NGO provider and get a flat came from mental health staff after she spent one week in hospital following a suicide attempt:

> [It] *came from the staff at Wellington. Like, "You can do it on your own", and I'm like, "I can't do it on my own". And then it was, "Well what are you going to do, you're so unhappy. You're either going to move to another supervised accommodation, so you will at least, probably, have at least another flatmate. We don't want you to suicide and you're not happy where you are. You can't go back to your parents. You've broken up with your boyfriend, you can't go there. What are you going to do?" And they said, "You can do it, you can get your own flat and you can do it."* (Nancy)

The support Nancy found from the hospital staff was in contrast to the staff at her cluster home who discouraged her from leaving. Determined to go, and with support from her family, Nancy left to set up home in a flat, where she continues to live today.

The positive staff support identified in the research complemented the inner drive and vision that assisted participants to move into new homes where they could have more control over their lives.

Need for greater control

Two of the participants spoke how the need for greater control over their lives was a determining factor in leaving the provider home. Staff-created structures and boundaries were a source of frustration for Nancy and contributed to her leaving:

> *I just got sick of people telling you what to do – "Make sure you're back by 9 o'clock, because we're going to bed at 9 o'clock." They* [the staff] *would look after your medication, so you had to be back by a certain time to have your medication. It's not like, we go out and can go home whenever you like, and take your meds, and go to bed. Because they looked after your medication, there were guidelines like – you had to be there at 9 o'clock in the morning to have your medication, and you had to be there at 9 o'clock at night to have your medication, because the bottom line was, if you didn't have your medication, they wouldn't be awake when you got back to have it. So it was all the little things that drive you up the wall.* (Nancy)

Nancy's frustrations with the support staff were similar to those aired by Elliot. He talked about how the support staff used to visit him daily – "I didn't like them because [they were] too nosey." After the provider lost a funding contract the staff stopped coming. Elliot said he liked "being independent and paying your own rent and paying your own power, knowing budgets, learning how to budget. I know how to do it all now."

The participants indicated it was important to have control over their immediate environments. To be able to decide who could live in their homes and stipulate how people behaved within them is an important issue. Previously it was staff who dictated the norms. Now it is the disabled people themselves who set their own standards, and who ultimately control who comes through the door:

> *If you've got your groceries there and you go away, they [flatmates] eat all your food, go in your room and touch everything. Here, you've got the keys to the door.* (Elliot)

Moving from a situation of powerlessness and lack of control is not easy, and some of the participants suggested that the support of friends helped in this process.

Support of friends

The support of friends helped participants to leave the NGO residence, and provided support for the initial period of living and establishing social networks in the community. Of all the participants, Alan appeared to be the most reliant on the support of friends. On the two occasions he moved from providers' homes, he did so with the intention of sharing a house with a friend, as illustrated by the following example:

> *I was going to get a house with this lady and I had to give notice ...* [but] *it didn't work. I ended up staying between her place and my parents' place.* (Alan)

Alan is presently living alone, but he misses the company of another person and would like a flatmate to live with him.

For Caleb, the offer from a friend in the community helped motivate him to move out from the NGO provider where he had been living for one year, and go flatting.

> *I already had made my mind up I was going to move out anyway. But just when Brian asked, I thought; yeah, I'll put in my notice. Once I've put in my notice and finished my time, I'll move out, and it's community again … but if he didn't ask me I would have done it anyway.* (Caleb)

Caleb lived with Brian for five months, and when Brian left, Caleb found another flat, where he presently continues to reside by himself.

Friends provided the catalyst for some of the participants to make the initial move into the community. Now, in their new homes, friends continue to provide ongoing social acceptance and encouragement, contributing to the participants' overall wellbeing.

Finding a balance between the public and/or private within a person's home is normally determined by the people living there. For many disabled people in provider homes, this balance is determined by the staff who work for the provider.

The need for privacy

For two of the participants the need for privacy was a determining factor in their decision to leave the provider home. Both people spoke of their need for privacy within their homes. Jack talked about his experiences at Bridge Street, in a two- bedroom cluster home, one of twelve on the site, before he moved into his current accommodation, a one-bedroom flat not far away:

> *The lack of privacy that's the only thing that's wrong with it* [Bridge Street]. *Patients would just come in, and clients would just come in and out whenever they liked. We had no privacy … Oh your flatmate, when you go away they eat all the food, there's no food* [laughs].

> *Some things are pretty good though I suppose. I like this place better that's all.*
>
> [One minute later]
>
> *It's a lot more private here* [Jack's present home], *you're left by yourself up here, more or less. Down there you didn't ever know who's coming or not coming.* (Jack)

Similarly, Nancy preferred to live alone, an option not available at her previous cluster home environment. Nancy talked about the economic difficulties of living alone and said it would be cheaper to flat with others:

> *I can get a two-bedroom flat and get someone to move in, but I'd rather just work one day a week and stay here, and not have anyone move in. Different things work for different people.* (Nancy)

To ensure her privacy, Nancy has chosen to supplement her Invalids Benefit by working part-time.

Negative staff experiences

As seen earlier in this chapter, positive staff experiences, such as support and encouragement, were a factor for some participants leaving the provider home environment. Conversely, negative staff experiences were also identified as a contributing factor for two of the participants.

Elliot explained that staff changes had contributed towards a feeling of disillusionment living in his cluster home. Elliot had originally enjoyed living in the cluster home, but things began to change:

> *The President was Mary Brown, yes ...she was interfering. We were forced into it ... and I didn't like that.* (Elliot)

Elliot was reluctant to elaborate on what he was forced to do and indicated he was finding the topic uncomfortable, so the line of questioning was abandoned. Negative staff experiences and personality clashes led to Elliot leaving after eight years' accommodation.

Nancy also found aspects of staff conduct unsatisfactory. She had spoken previously of how the staff used a two-week trial to place another flatmate into her house without her agreement. In the following extract, Nancy discusses how a staff member whom she admired greatly had left and the replacement did not meet her expectations:

> *John Brown, he left, so that was a big part of it ... and the staff, the woman who ran it at the time, all she did care about was, "at the end of the month I have made Support Trust so much money" ... well they are three-bedroom houses and if you haven't got three people in your flat, house, they're not getting the money from that extra person. They want three people in, and at the end of the day they don't care whether you're compatible or not. They just care as long as the house is full. That was the bottom line. They don't care if you're not compatible, that's what happened you know.* (Nancy)

Nancy found the staff member who replaced John Brown motivated by money and not by a quality of life approach, which she had admired in the previous worker. Another factor which helped Nancy to leave the provider's home was the availability of government-provided housing.

Availability of state housing

Two of the research participants had moved into state houses. The availability of state housing was a determining factor in their move from the provider service. Jack was living in one such house, part of a cluster of four homes. When the local District Health Board withdrew funding to the NGO for certain accommodation and support services, the users of the service were offered the tenancy by the Housing New Zealand Corporation (HNZC):

> *They were going to get rid of these places, going back to community houses of Housing New Zealand. They gave us three weeks to move because they didn't know whether we'll be allowed state houses. So we went to a meeting in town and they told us that we had them* [HNZC houses]. (Jack)

In preparation for the changeover, Jack said the NGO prepared him for taking over the house: "They come in and showed me how to do my power, phone, rent."

Similarly, Nancy was also living in a provider's house. Unhappiness and frustration led her to leave this house and find her own flat, with the support of family. "I talked to my father about it and he said; "We'll support you, if you get a flat." So we went to Housing Corp and came here."

Financial resources impact on a person's ability to find suitable housing. This research also established that financial resources played a role in participants' migration from provider accommodation to their own home.

Family financial resources

Access to family financial resources assisted three of the research participants to leave their provider homes. Family finances paid for an airline ticket that enabled Caleb to live with family in Samoa: "My mum had to pay for the ticket to Samoa. I said to her, 'If you could pay for the ticket I'd go to Samoa and try to get well'." Caleb spent nine months with his father and then returned to his mother in Aotearoa New Zealand.

Alan intended to go flatting with a friend, but left the NGO provider and moved to his parent's home for six months. During this time his parents helped to support him financially until he found his own flat. He now lives in a family-trust house that was purchased after his mother died. The family trust also contributes to Alan's household expenses.

Similarly, Elliot has utilised family financial resources. When he moved out from his provider home in 1999, Elliot shifted into a granny-flat that his mother had paid for. The flat was situated at the rear of his mother's house and Elliot paid cheap rent. When his mother moved out of the district to an age-care facility, she organised for Elliot to live in a family-trust house which was paid for by her. Elliot continues to pay rent at a subsidised rate, and when his mother dies he will inherit the house.

Access to monetary sources outside of government transfers conferred an advantage that helped some of the participants to access independent housing options in the community. Similarly, self-educational skills were a factor assisting with the move from provider homes.

Self-educational skills

Self-educational skills were an important factor that assisted Caleb leave the NGO provider. For Caleb, the reading of self-help books, particularly those associated with mental health and well-being, gave him the skills and confidence to leave:

> *I knew that with the book I had the tools now. I didn't stop at that book. I got more and more books out, read more and more; mainly self-help books, learnt more and more. After I had done everything that the book had said to do to get well, I made up my mind to move out within the next three to four months.* (Caleb)

Caleb stressed several times in the interview that the acquiring and the studying of these books was the most important feature for enabling him to move out from the NGO provider. For Jack, government policy was one significant factor that enabled him to achieve his own accommodation.

Government policy, financial disincentive and the stigma of living in a provider home

The literature review in Chapter Three on the history of service provision for disabled people has shown the impact and importance of government policy in determining types and qualities of support. For Jack, government policy led him to take over tenancy of a one-bedroom cluster home from Housing New Zealand when the NGO provider was forced to withdraw support services after the local District Health Board ceased funding levels one and two mental health services.

Two other factors that played a lesser role in Jack's desire to leave the provider home were also evident in his interview. Firstly, Jack found he was financially penalised living with the provider: "They took money off our benefits, paid for our teeth and I never went to the dentist or doctors for six years and they were taking our money for paying that ... over 20 dollars [per week]." Secondly, Jack explained that it was stigma which gave him the motivation to leave his first cluster home for another with the same provider, which was nearby and had a lower community profile:

> *With stigma. They* [the inhabitants of the local community] *really knew who we were down there. So many people would talk about us there.* (Jack)

Jack was reluctant to talk about the stigma he had experienced and the subject was not pursued, even though the factor was significant for Jack. The stigma Jack felt from being associated with the NGO cluster home in a local neighbourhood provided him with the catalyst to move to a lower profile provider home, where there were fewer houses and residents, and staff did not live on site.

Another enabling factor for participants leaving provider homes are their social networks external to the NGO provider accommodation.

External social networks

Social networks were a contributing factor for Alan leaving the home. When asked if staff had helped with the move from the provider home, Alan explained how his involvement with the local sports club assisted him to leave:

> *I had outside people coming and seeing me as well, like that's from rugby. Steve* [from the local rugby club] *used to come and see me down at the Trust ... you need something; it's got to be on a recreational level.* (Alan)

Alan spent time most weeks meeting with rugby players both socially and competitively; they had become important "others" in the community external to his living environment. This network provided a support for Alan to move out to a more independent setting.

As the research progressed and the stories of the participants were analysed and studied, another set of factors emerged from their discussions. Running parallel to the features which enabled the participants to leave their former residences were factors that hindered such a transition.

2 DISABLING FACTORS

The research identified several factors that hindered the participants from leaving their NGO provider homes to a more independent setting, which the research categorises as *disabling factors*. These forces encouraged and promoted dependence, making it harder for the participants to leave. The factors will be discussed in order of importance as stated by the participants, starting with the sense of family and companionship.

Sense of family and companionship

Several participants in the research spoke of how the staff and residents at their former provider homes provided companionship and a sense of family and kin. Their experience of friendship and solidarity with the other disabled people at their former homes was significant to them.

Most of the participants recalled with fondness times of camaraderie and companionship, which served to lighten the sense of isolation and loneliness they sometimes experienced. Elliot identified closely to the other residents of the provider home, enjoying the kinship and social interaction, and spoke warmly about his initial experiences:

> *There's talk, talk and all kinds of laughs, and carry-ons … someone to talk to, we used to talk about politics and fights, and go back, I'd talk nights with them. We used to get on really well. I thought I was one of the boys down there, I thought I was part of something.* (Elliot)

Similar sentiments of camaraderie with fellow flatmates at the provider home were echoed by Allan:

> *There were different people that you could talk to everyday. You could go and see someone different every day. They went on outings; for*

> *weeks, a week away, a weekend away, that was one of the good things. Where the Trust is, that's a very good place down by the river; the river is a nice place to go during the day. Barbecues, barbecues were good there. I never really sat still in any situations.* (Allan)

Allan currently finds living in his present home to be lonely and socially isolating, and he would like one of his former flatmates from the provider home to join him.

Provider homes can provide a sense of family and belonging as stated by Caleb: "Kind of a family feel to the place in some ways, yeah, a feeling of belonging." Paradoxically, these feelings of belonging and family are a strength and resource which provide a powerful incentive to remain living in a provider home environment, and this topic will be explored in more detail in the following chapter.

Similarly, the routines and activities of the NGO provider present an encouragement to remain living in a provider home setting.

Routines and activities of provider

A common thread in the narratives of all the research participants was the presence of staff working on site at the provider homes for 24 hours per day. The staff created and reinforced routines around care, cleaning, cooking, shopping and social excursions.

Jack enjoyed "being independent" after he took over tenancy of his present home when the NGO provider's contract was phased out by the local District Health Board. Initially he found the experience of independence quite difficult.

> *First it was hard ... they used to pick us up everywhere. We went somewhere in town and they'd pick us up, or the hospital they'd pick*

> *us up and take us there. Blood tests; they'd come and pick us up and take us there. Picking me up, taking me to work, bringing me home and taking me shopping.* (Jack)

The impact of the staff and their routines has the potential to hinder disabled people from leaving provider homes. The financial benefits of living in an NGO home has a comparable effect.

Financial disincentive

One of the participants explained the financial disincentive she experienced was a consideration when leaving her former provider home. Nancy observed, "It's expensive to go in the community", as she did not pay for rent at her former home but did pay for the food, power and phone expenses.

After a mental health professional presented her with options, Nancy expressed her reluctance to leave the NGO provider house because it was financially "convenient" to stay:

> *They* [mental health assessors] *come in and assess everyone and after the assessment they just said, "Yeah, you can stay on if you want to." I wanted to move, but it was like to where? And where are you going to get the money from to move? And it was just convenient, I wasn't happy, but it was convenient.* (Nancy)

Eventually pressure from an incompatible flatmate forced Nancy to move to a one-bedroom Housing Corporation flat. But the financial benefits accrued when living in a provider home prevented Nancy from leaving earlier.

For two participants, their desire to leave their NGO homes was discouraged by the staff who worked there.

Staff influence

As noted earlier in the thesis, staff who work in the disability services sector exercise significant influence over disabled people. Overall, the five people interviewed for the research spoke positively regarding their experiences with the staff from the NGO. However, two participants did state that staff attempted to hinder their move from the provider home once they had indicated their intentions to move out.

Nancy got the idea to move out from mental health staff at the local hospital. The staff in her provider home understood that Nancy wanted to move but were not keen to help. Nancy said they were "happy to have me there, because they are getting paid for it. They are happy to have me there because I'm the bum on the bed [laughing]", and did not assist her in any way to shift. Indeed they actually mocked her saying: "Oh yes, yes, yes, yes, we've heard it all before."

Nancy was not disheartened by the staff members' comments and moved out with help from her family. A similar dissenting chord was expressed by Caleb when he told staff of his intention to leave the NGO provider: "They thought that moving in with Brian was a bad move. But I didn't, I knew that it was a good move." Caleb succeeded with his quest to leave and has never returned to supported accommodation.

The above disabling factors may help explain why some disabled people stay in a provider home situation. The third and final theme, running alongside enabling and disabling factors in participants' narratives, is support factors.

3 SUPPORT FACTORS

The research participants appear to be living successfully in the community. All had moved from their former provider homes during the period 1999 to 2000 and all had chosen not to return again to such accommodation. Three participants rented homes and two lived in family owned houses. Participants identified several *support factors* which have enabled them to live independently in the community. Of these, family support was of primary importance.

Family support

The encouragement and practical support of family members was mentioned previously as an enabling factor which helped participants leave the quasi institutionalised setting of the NGO provider. In a similar manner, family support has assisted the participants to maintain their existence in their own homes after making the transition from the NGO provider. This family support falls into two categories: social support, and practical assistance.

Jack explained how his family were currently significant people in his life, and detailed who was important, and some of the activities that they undertake:

> *Sister, brother, my mate over in Aussie. Family over in Aussie. His* [Jack's brother] *family and I went over to Aussie, there are pictures up there* [points to holiday photos on the wall] ... *the Christmas before. I went over there for two weeks. I've got family up in Levin; foster family. But I've got to go up and see them, that's why I bought my last car off Peter.* (Jack)

It was not only social and emotional support that Jack received from his brother's family; they also helped financially and assisted with the costs of the holiday.

The most significant practical assistance received by two of the participants was financial support through the funding of their homes. Both Alan and Elliot lived in houses which had been paid for by family trusts. These had been established by their parents. They can live in the homes for as long they desire. Only Elliot pays a minimal rent. This financial assistance plays an important role in providing a quality lifestyle for Alan and Elliot in their community. Other family members also contributed practically in smaller ways, such as Caleb's mother paying for the furniture in his flat, Nancy's mother making curtains for her home, and Jack visiting his brother for the occasional meal.

Voluntary unpaid family support was not the only important support factor enabling the participants to live in their own homes. Government funded Disability Support Services plays a pivotal role.

Disability Support Services (DSS)

As noted in Chapter Three, government funded disability support in Aotearoa New Zealand has been an ever-changing landscape reflecting the balance between political policies, societal mores and scientific opinion. Government funded DSS delivered through the health and NGO sectors help the five participants to remain in their own homes.

Three of the participants had received government funded support immediately after leaving their former homes. Nancy received regular weekly help from a support worker after she had left her provider home. Apart from going to the community mental health services once a month (where she had a nurse), this was all the support she received. Nancy believed that without this weekly support she would never have been able to remain in her new home as, apart from the domestic help, the social and emotional support the visit provided was crucial to her survival. This support lasted "about a year", when "they said I was well enough, I didn't need it."

Today Nancy and the other survivor participants do not receive any domestic help inside their homes, but all have regular meetings (one to three monthly) with nurses and psychiatrists from their local community or Maori mental health teams. When Elliot left his former provider home to go into a granny-flat situated on his mother's property, he received regular assistance from her. Now Elliot has left his mother's property and receives twice weekly domestic help in his own house from a support worker who works for a local NGO.

Four of the five participants receive a disability benefit. These payments are supplemented by employment (one person) and accommodation benefits (three people).

Caleb told the author that a local drop-in centre, open for all disabled people, was an important support for him when he moved into the community:

> *I'd go there quite often, but there'd be times when I'd miss it, and I wouldn't know why. It was just a social environment I suppose and* (pause) *talking and chatting with people.* (Caleb)

To this day Caleb continues to visit the drop-in centre, where he enjoys the social interaction.

In a similar way to the drop-in centre, the informal social networks of friends and neighbours have also been a maintaining factor for the participants to live successfully in the community.

Social networks

The social networks of friends and neighbours were mentioned by some of the participants as a factor which assisted them in continuing to live in their own homes. Positive relations with neighbours were experienced by three of the participants. This was very evident in Nancy's account regarding her neighbours:

> *Edith comes here ... then there's Ian who lives two doors down, he's an alcoholic, he's good ... I've got Marianne next door, she's, she's a consumer too, she always brings my washing in for me. I love her, I mow her lawn ... people borrow things ... washing powder ... zigzags ... smokes ... we all live in and out of each others' lives, and I like it, so you're not actually isolated.* (Nancy)

Similarly for Alan and Jack, their relationships with neighbours, in time, developed into friendships. Alan would go fishing with a previous neighbour and one of Jack's neighbours has given him wine at Christmas, feeds his cats when he is not there, and stores her spare house keys with him.

The social interaction with neighbours can be a way of increasing social capital. For two of the participants, state housing has been a support factor in assisting them to stay in their new homes.

State housing

State housing was mentioned previously in the chapter as a factor which enabled two participants to leave the provider home. These two people remain in their state rental homes and this factor helps them to maintain their position in the community.

The benefit of living in a state home is, according to Nancy, the reasonably priced rent – "I only pay eighty dollars for rent." Another advantage of state housing is having the security and benefits of a landlord who has the philosophy of providing affordable quality homes to socially disadvantaged citizens (Housing New Zealand Corporation, 2008).

Employment is one way for disabled people to increase their income and, for one of the participants, is a feature enabling her to live in the community.

Employment

Of the five participants, one works full time and one person part-time. Nancy explained working one day per week enables her to live in the community:

> *For me I just work once a week at the recycling centre, sometimes on call occasionally. But just to have enough money to stay here because it's dearer living here than living in supported accommodation.* (Nancy)

Like a torch beam that provides light at night, the stories of Nancy and the other participants have helped provide some insight into how some disabled people have managed to move out from a provider home setting to their own homes. As each participant is unique, so their stories are unique, but their narratives are linked by common threads which have been identified and grouped into the three categories of enabling, disabling and support factors. The factors are complexly connected together. Within the groupings a wide range of reasons associated with the move from provider homes have been discussed, from the micro and personal, such as goals and aspirations, to the wider macro factors such as government policy.

These results gained from the interviews of five participants provide the basis for commentary, and the next chapter will undertake a discussion on these findings.

CHAPTER SIX

DISCUSSION

In the last chapter, data of participants' stories were presented in detail. Each person's narrative showed specific motivations for moving out. Alan left because he believed it would allow him to live and form a partnership with a female friend he knew. Caleb believed living independently in the community was the final stage of his recovery process and a step towards becoming well. Elliot felt picked-on. He became isolated and lonely, and believed leaving would rectify the situation. Jack wanted greater control in his own home and wanted to distance himself from the stigma he had experienced from neighbours. Nancy had incompatibility issues with flatmates and preferred to live alone.

Common features are evident from their individual narratives, and the identification of enabling, disabling and support factors are important findings of the research. This chapter will discuss these findings in light of theoretical perspectives as explained in Chapter Two, and the historical background to disability supports from Chapter Three. The social model of disability and the historical oppression of disabled people help inform this research, requiring that it is to the benefit and to the self-empowerment of disabled people. Therefore this discussion will reflect these concepts, but first, the original research aims will be revisited.

Returning to the research aims

The purpose of this study is to gain an understanding of how some disabled people were able to leave a group or cluster home settings and move into their own homes. It is hoped that the stories of these people may be beneficial for the self-empowerment of disabled people living in comparable situations with similar aspirations. The social model of disability and Foucault's analysis of power supplied the theoretical foundation for the study. A participatory research approach required it to adopt an emancipatory focus, aimed at benefiting disabled people. An empathetic interviewing method allowed the researcher to listen to and identify with the group under investigation.

Three themes of enabling, disabling and support factors were noted in the data, and help explain how these disabled people managed to move from provider homes – "mini-institutions" (Schalock et al., 2002, p. 101), to their own homes in the community.

ENABLING FACTORS FOR CHOOSING TO MOVE

The predominant themes in the stories of participants are the enabling factors – the forces and reasons that facilitated the move away from the provider homes to housing settings where the control on accommodation and support are not held by a single NGO disability provider. Within the theme of enabling factors, the five determinants that stood out in the narratives as being particularly important were, personality clashes, NGO provider dissatisfaction, family support, goals and aspirations, and positive staff support.

Biopower and resistance

Factors of personality clashes and provider dissatisfaction indicate a general dissatisfaction with the participants' former accommodations. This can be understood in terms of Foucault's (1981) assertion that where there is power there is resistance (see Chapter Two, p.9 & p. 22). Using Foucault's rationale, participants' clashes with staff and residents, and dissatisfaction with providers, can be understood as stemming from the power imbalance between the staff and residents.

Continuing with Foucault and his concept of biopower, participants described how a professional discourse is directed at the body in order to produce a particular type of subject (Foucault, 1978). For example, the staff members would wake up Alan's sleeping body every morning at a fixed time in order to bring about changes in the subject, "Alan", so that his "body" may be "used, transformed and improved" (Foucault quoted in Sullivan, 2005, p.29) to the standards deemed satisfactory and normal by provider staff. Such an example of biopower reflects the control of bodies in order to produce a type of subject. Alternatively, populations of disabled people can be the subject of surveillance, record keeping, regular assessments and staff instructions, in order to produce docile subjects (Drinkwater, 2005).

By opposing the dominating knowledge of the provider with their own "subjugated knowledge" (Allan, 2005), participants were able to offer an alternative discourse which became "a point of resistance and a starting point for an opposing strategy" (Foucault in Yates, 2005, p. 70). The power imbalance, discourses and actions associated with the service provider's control over participants in their own homes resulted in the development of an alternative discourse of resistance, which provided the impetus to leave the provider home.

In their transition from provider homes, participants were able to access and use help and support from other people.

Support of others

As participants in human society, the support of other people is related to our overall sense of well-being (Walsh, 2003). Without such support, our position in society can be weakened – an occurrence experienced by many disabled people who have been marginalised in society (Chenoweth & Stehlik, 2004).

The social isolation impacting on disabled people living in institutional settings has been well documented, with special regard to the lack of engagement with people outside of the disability services provider (Marquis & Jackson, 2000; Werner, Horner, & Newton, 1997).

The support of others is a significant and important feature, not only in the transition of the participants from provider homes, but also for their sense of well-being. Participants identified their "supportive others" as family, staff, friends and social networks (external to cluster home).

Families are a natural system of help in complementing and sometimes replacing formal support (MacArthur, 2003). The family support which helped participants leave home was wide-ranging, comprehensive and practical. Two participants were living in homes provided by family. Nancy's father actively encouraged her transition, and together they went in his car searching for suitable flats. When Alan left the provider, he initially lived with his parents before finding a flat. Caleb was given money by his mother to leave and stay with family in Samoa.

The support of families included both practical assistance and emotional sustenance. Such support is often taken for granted by disability professionals and (Carpenter, 2000) recommends the use of a family-centred approach for support services that work with disabled people. Such an approach is useful, especially for children, but some disabled people may prefer to make decisions without reliance on parental support.

Self control

An inability to exercise control inside their homes contributed to participants leaving the provider homes. Personal privacy is a precursory for creating a sense of home (S. G. Smith, 1994). But for many disabled people living in provider homes, this essential human right is compromised (Ministry of

Health, 2004). A vital aspect of what a home means for people is having a sense of security and control over one's living environment (Annison, 2000). Research has shown, however, that support staff have exercised undue power and control over disabled people in the group and cluster home setting (Borbasi et al., 2008; Horner, 1994; McGill & Emerson, 1992; Ministry of Health, 2004; National Advisory Committee on Health and Disability, 2003b).

Staff actions

Two participants were reluctant to talk about their negative experiences with staff, and the line of inquiry was not pursued. Many support staff employed by disability providers are unskilled, lowly paid and poorly trained (MacArthur, 2003; Ministry of Health, 2004). These factors may explain the frustrations experienced by some of the participants which led to their leaving.

Staff also play an important role in determining the quality of life for many disabled people inside provider homes (Bray & Gates, 2003; MacArthur, 2003). Participants spoke positively of certain staff-members. Caleb was impressed with a staff-member who invited him home for several meals and "treated us the same as everyone else" (Caleb). His account verifies the findings of research into the lives of intellectually disabled people, which found a positive relationship between staff and service users to be associated with the "development of personal identity and self-worth" (Marquis & Jackson, 2000, p. 422). Positive staff input assisted all participants in their transition from provider homes.

Social networks

In a similar way to staff, social networks and friendships were identified as important enabling factors. Friendships significantly add to the contentment and overall quality of life for disabled people and provide support for well-being (Boydell, 2002; Trimberger, 2002). However, it is unusual for disabled people living in supported accommodation to have social networks outside provider homes, as their social networks can be dominated by fellow residents, staff and health professionals, leaving few opportunities for social contact with members of local communities (Metzel, 2005; Werner et al., 1997). This was not the case for participants who had strong family ties and links to others in the community.

Self-empowering factors

The social model of disability promotes self-empowerment and self advocacy (Goodley, 1997). An educational study by Anderson (1986) noted that the following criteria were significant in determining self-empowered behaviour: (a) awareness (of self, others and systems); (b) goals; commitments and outcomes; values (respect of others and self); (c) information (of self, others and the world); and (d) life-skills (personal, inter-personal and situational).

Participants who left the provider homes all displayed to some degree the self-empowerment criteria as described by Anderson, and these were seen in the following factors – goals and aspirations; need for self-control; need for privacy; self-education skills; reaction to financial disincentive; and response to the stigma felt at a provider home.

It was noted that the hope of participants for a better home environment provided the drive for goals and aspirations related to the transition into new homes. Goals, and the inner vision that propels the goals, provide a powerful force for personal change and achievement, influencing motivation (Rapp & Goscha, 2006). The goals and aspirations of the participants seem to have provided a framework for energy to be directed towards leaving.

Deegan (1996) says this hope can be diminished by the control of others, but declares this can be rectified by providing opportunities to exercise self-empowerment, via, "choice, options, information, role models, being heard, developing and exercising a voice [and] opportunities for bettering one's life" (p.94). Such advice connects with the social model of disability.

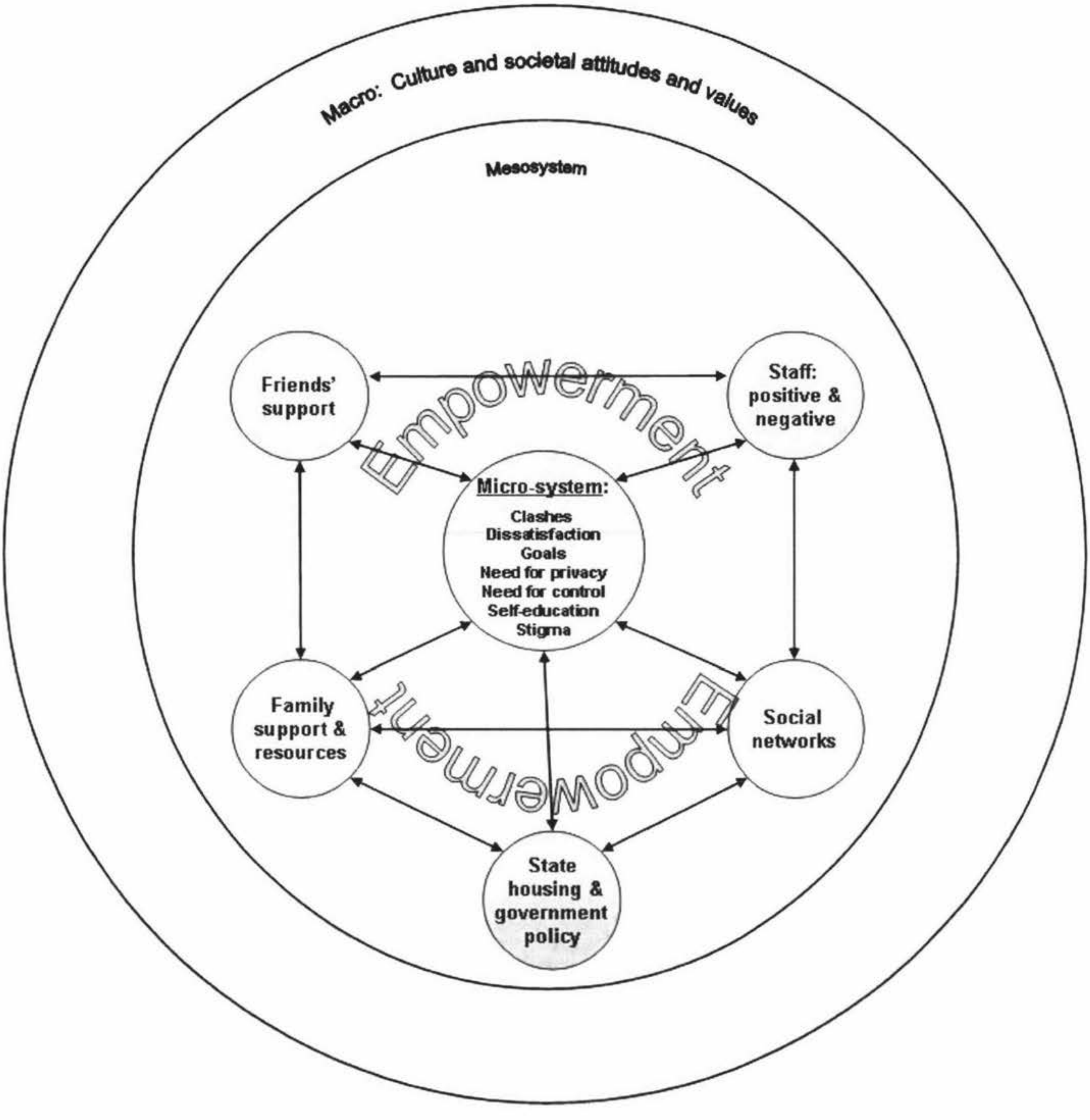
Caleb's quest to undertake a study of self-help books was associated with his aspiration to leave the provider home. The experience of stigma from surrounding neighbours inspired Jack to leave his provider home. Nancy's quest for privacy resulted in a search for state homes with help from her father. These examples illustrate that, by following their dreams, these disabled people were able to form their own alternative discourses rather than conforming to providers' expectations.

Contextual features

The contextual features of state housing and government policy were enabling factors in the participants' stories. Other aspects of government-provided social supports were not spoken about. It is doubtful if participants would have so easily left their former homes without the support of the Invalids Benefit, which all were receiving when they moved into the community.

The above enabling factors identified in this research contributed to participants leaving their provider homes. These factors are presented in Figure 1 on the following page, which shows the connections between the different factors.

FIGURE 1: Wheel of transition
Enabling factors identified in participants' transition from provider homes



Based on Bronfenbrenner's concept of the ecological perspective (Greene & McGuire, 1998), note that the small circles represent enabling factors grouped into micro (individual) and meso (outside, but near the individual) categories of enabling factors. The connecting arrows show a relationship between the categories.

DISABLING FACTORS

This research did not set out to determine what prevented disabled people from leaving provider homes. But when the interviews were analysed, it became apparent that active forces, with the potential to create dependencies and mitigate any attempt to move out, were active in provider homes. Four factors with this potential were identified: a sense of family and companionship; financial disincentives to leave; the routines and activities of the providers; and staff influence.

Sense of family

Group homes provide companionship and peer support for disabled people (Ho, Black, & Andreasen, 2007). This support and company is especially important, as some disabled people continue to be socially isolated in society and, in some situations, actively rejected (Brook, 1999; Chenoweth & Stehlik, 2004; Marquis & Jackson, 2000). Whilst parts of society continue to be antagonistic and hostile to disabled people, provider homes will continue to provide a haven and a sense of security for those who choose to live there. But paradoxically, this sense of family and companionship felt at provider homes has the effect of deterring participants from leaving. While recognising this, the challenge is how to provide it in ways that are not dependency-creating, but empowering. How this might be done is discussed in more detail in the following chapter.

Conversely, living in a group home can be lonely and isolating (1988). Elliot (p.71 above) found himself socially isolated at the provider home. It was this isolation that motivated him to leave.

Financial disincentives to leave

Financial factors also acted as a disabling force, potentially stopping participants from leaving provider homes. Many NGO disability organisations rent houses from HNZC under a Community Group Housing programme (Housing New Zealand Corporation, 2005). They receive bulk government funding from the Ministry of Health's Disability Services Directorate (DSD) to supply both support and accommodation services. This acts as an indirect subsidy for those living in provider homes, which ends once they leave. As a consequence, Nancy, once she had left the provider home, found living in the community more expensive. The additional incurred expenses acted as a deterrent to leave.

This system of provider funding has been criticised by Sullivan and Munford (2005). They argue that when disabled people left the large institutions, the individualised funding of their support needs was to follow each person who left, and be used by them. But because of administrative convenience, individualised funding was replaced by a system of bulk funding to provide support for fixed numbers of disabled people per provider. This produces client capture, and removes much of the power and control disabled people may have over their lives into the hands of disability service providers. Sullivan and Munford go on to argue that the bulk finding system oppresses and disempowers the disabled people who left former institutions, and who now live in provider homes. This is apparent with Nancy, when her disability provider discouraged her transition to the community.

Staff influence and the routines and activities of the providers

The impact of staff and routines in hospitals and older-age homes has been found to encourage dependency on the provider by the users of these services (Goodin, 1985). Oliver states that residential and day-care facilities "all serve to institutionalise disabled people and create dependency" (Oliver, 1993, p. 54). Participants spoke of similar situations at their former provider homes. The five participants described staff practices and provider routines that had the potential to create long-term dependencies and reliance on the NGO provider. These included being woken up every morning by staff, group-outings, group-holidays, group-shopping, and transportation solely by staff using provider-owned vehicles.

There is no mention in participants' narratives about their input into the running of the provider homes. A study in the USA may explain the lack of participation. Hagner and Marrone (1995) found the following factors have hindered disabled people's ability to be involved in disability services' decision-making processes:

- service decisions are based on the convenience and self-interest of the provider
- professionals are cautious allowing disabled people to make decisions
- professionals see themselves as solely having the knowledge and expertise to make decisions and may view disabled people as incompetent decision-makers
- disabled people are compliant because of the power imbalance that exists between disabled people and professionals
- few resources are devoted to help disabled people have decision-making input into services
- professional networking and relationships often take priority over disabled people's needs

Disabling factors described by participants did not present insurmountable barriers preventing them from moving from the provider homes. Why participants overcame these barriers where others have not is an interesting question, partly answered by this research. This recognises that the skills of self-empowerment, the support of others, plus the macro factors of government policy have been instrumental in effecting a transition to new homes in the community. The disabling forces identified in the stories of participants were not weak and easy to surmount, but the participants displayed determination, resilience and self-empowerment when moving from the provider homes to their own homes, where they continue to live today, aided by supporting factors.

SUPPORT FACTORS

Participants successfully remain in their new homes. Two still live in the original state-owned homes they first moved into, two live in family-owned homes, and one person rents his own flat. The participants have not felt the need to return to the provider home setting.

The purpose of this research was not to investigate how disabled people manage to live successfully in the community. However, the participants themselves identified aspects which assisted them to live semi-independently in the community. These are, family support and social networks, disability supports, employment and state housing.

Family support and social networks

Family members are an important element in ensuring successful community living for disabled people (Carling, 1995). All participants receive regular communications and support from family via face to face meetings and the use of telephones. Practical support such as housing provision, help with forms, financial advice and household management techniques, were noted. Participants also receive emotional support and the sense of well-being that families provide by way of family gatherings, family holidays, the sharing of meals, regular telephone calls and celebration of birthdays.

As mentioned previously under enabling factors, family support is a feature that assisted participants to leave provider homes. The sense of family and companionship at their former homes is viewed by participants as an important resource. The participants' stories show that their need for companionship and intimate social relations with family members or pseudo-family members is an important determinant on the ability of disabled people to successfully leave a mini-institutional setting.

Families are part of the social networks of participants, which also includes friends. All participants had friends in the community whom they visited regularly. These networks help to prevent the social isolation and loneliness that contributed to Caleb returning to the provider home he had left two years previously. According to Lin (1986), isolation can occur at four levels: (a) community, the larger social structure of a person; (b) organisational, which includes work, schools, church; (c) confidantes, friends, family and significant others; and (d) the person, who is able to perceive and interpret relationships.

Participants were presently observed to have strong relationships at the confidante and community levels. Four participants communicated and met regularly with family and friends. Only Elliot seemed to have few friends in the community, but had a strong family relationship with his sister and mother. Three participants experienced strong relationships at the organisational level – two worked and one was a member of a rugby club. All participants experienced the isolation that can occur at an individual level in their new homes, but four still chose to live alone. Only Alan is seeking a flatmate.

Disability support

Disability support is important in helping participants to maintain their independent accommodation in the community. Support from both the NGO sector and District Health Board (DHB) level was noted in participants' accounts. This support includes visits by NGO support workers, community mental health workers, visits to a disability community drop-in centre, and the use of respite accommodation. The disability support that participants receive is minimal, and most participants have contact with support staff less than once a month, with the exception of Elliot, who has domestic help two times per week.

The participants do not require labour-intensive personal support. It is unlikely that if the participants did require such intensive support, they would be able to leave a provider home under the current funding model. Alternative models of support will be discussed in Chapter Seven.

Funding by way of the Ministry of Social Development (MSD) also assists participants. Invalids Benefits as an income source help participants to live in the community. This point was not directly mentioned by participants, even though four participants receive the payment, possibly due to the questioning focus of the researcher, or because participants may have considered the payment a basic human right and not a significant factor for them leaving the provider homes.

Employment

The Ministry of Social Development (MSD) is the main funder for the NGO provider to deliver vocational work programmes where Nancy works one day a week. This extra money helps her to pay for the additional costs that she experiences living in the community. Such funding of employment initiatives is helpful, as disabled people are less likely to be employed than non-disabled people (Statistics New Zealand, 2002). Targeted subsidies, vocational training and funding assistance help some disabled people to gain employment and employment skills. The drop-in centre for disabled people which Caleb attends for social networking is also partially funded by the MSD.

State housing

The low income of disabled people has been identified as a barrier to securing adequate housing (National Housing Commission, 1988). There are not enough suitable and accessible houses for disabled people in Aotearoa New Zealand, particularly single houses (Centre for Housing Research Aotearoa New Zealand, 2005). The government funded state housing supplied through Housing New Zealand gives Nancy and Jack the security of a long-term rental home at a reasonable rental based on a percentage of their income.

Government funding for direct and indirect support, family support, and social networks, helps participants to live in the community. The participants' accounts of their transition from provider homes symbolise an important point in the continuum of the self-empowerment of disabled people, a place where they enter a new "era of community membership" (National Advisory Committee on Health and Disability, 2003a, p. 19).

Community membership

For many years some disabled people were locked away in institutions. During the period of deinstitutionalisation, from the 1960s, through to the closing of Kimberly Hospital in 2006, disabled people moved into community-based provider homes. These often replicated the former conditions of little choice and staff control found in the institutions they had left (MacArthur, 2003). The National Committee on Health and Disability (2003) is positing a change from institutional thinking to community membership. The participants' transition to their own homes in the community reflects the final stage in the process of ending institutionalisation. For this to occur, there will need to be a major change in the social, economic and institutional barriers that confront disabled people in Aotearoa New Zealand society.

This discussion based on the presented stories has focused on the enabling, disabling and support factors noted in the participants' narratives. Analysis of their accounts shows that an alternative discourse was developed in response to the dominant discourses found in provider homes, primarily the medical model. This alternative reasoning encouraged resistance, and became a starting point for an opposing strategy which led to participants leaving provider homes for their own accommodation. The self-empowering skills and external supports evidenced in their stories enabled this transition. Participants have moved from being clients and service users, to the experience of citizenship. They now participate in community membership – the final stage in the process of deinstitutionalisation (National Advisory Committee on Health and Disability, 2003a). This transition represents a silent revolution.

It is on the basis of community membership and full citizenship for all disabled people that the next chapter will make recommendations and conclude the thesis.

CHAPTER SEVEN
CONCLUSION AND RECOMMENDATIONS

The intention of this research has been to gain insight into how some disabled people have transitioned from provider homes to their own homes. The intent is to achieve some understanding of the self-empowering skills and knowledge that disabled people manifested when transitioning to new accommodation. Such information may be beneficial to other disabled people contemplating similar transitions from provider homes, and for disability providers and policy-makers connected with accommodation and support services.

To achieve such an aim, the thesis began with an exploration of the theoretical basis that informed this research, viz, the social model of disability and Michel Foucault's (1978) approach to power. Then, historical discourses related to disability supports in Aotearoa New Zealand, ranging from institutionalisation to community care, were investigated. The theoretical perspective outlined and the knowledge gained from the historical investigation laid a foundation to inform the methodological approach, which in turn provided the framework for the interviews with five participants and the analysis of their stories.

The analysis of participants' narratives identified three themes of enabling, disabling and support factors associated with their transition from provider homes, and presented the structure for a detailed discussion of these factors. A Foucaultian perspective suggests that resistance to power imbalances at provider homes contributed to participants' dissatisfaction towards their home environments. This ultimately led to their decision to change accommodation. The support of others, notably families, friends and staff, aided the moving on. Macro factors of social housing and government policy were also a contributing influence.

The research identified, as well, disabling and supporting factors in the narratives, even though these features were not an active focus for the inquiry. Disabling factors that had the potential to hinder the transition from provider homes were identified as: the sense of family experienced at provider homes (which, paradoxically, was also viewed as a strength and resource for those disabled people who chose to live there), providers' activities and routines, financial benefits of provider homes, and staff discouragement. In the community, the participants still live and are supported by the factors of family support (both practical and emotional), government funded disability supports, social networks, state housing, and employment.

A visual overview of the three themes of enabling, disabling and support factors identified in the thesis is presented in Figure 2, the following page. Factors which enabled participants to leave the provider home are found at the bottom of the diagram, and labelled: *Self-Empowerment, Macro* and *Networks*. The *Disabling Wall* identifies the forces which hindered participants' ability to leave. Top of the diagram show the factors which assist the participants to live in the community, under the title of *Community Support*.

FIGURE 2: Enabling, disabling and support factors identified in the research

(Adapted from Rapp, 2006, p.20, and used by permission from the author).

Concluding Thoughts

The participants' stories focused on their journey from provider homes to their own homes in the community. Each person's account is individual and presents a kaleidoscope of people, places, events and emotions. Their motivations may be individual, but a common thread links their stories – a desire to leave their former homes. Notwithstanding this strong desire, the fact remains that many other residents of provider homes choose to stay. This begs an important question – is there a place for group or cluster housing for disabled people who want to live independently in the community?

From the participants' narratives and from literature (Oliver, 1993), it could be argued there is no place for NGO disability service providers who supply group and cluster housing, and that all disabled people should move into their own homes. But this research argues against such a position. Instead, participants recounted positive characteristics of provider homes, particularly in regard to social supports from both the staff and residents. As long as disabled people continue to face hostility, isolation and loneliness in society (Brook, 1999; Chenoweth & Stehlik, 2004; Marquis & Jackson, 2000), such support is important. The National Advisory Committee on Health and Disability believes the use of cluster and group homes should be the exception "rather than the norm" (2003, p.22). The challenge for providers is to make such homes as non-disabling and independence-enhancing as possible for inhabitants. While this current study is small and exploratory in nature, a number of tentative recommendations can be extrapolated from it which may go some way towards meeting these ends.

RECOMMENDATIONS

1 Establishment of alternative models of accommodation and support

From the participants' stories, it is clear they were not happy with their former cluster homes. There is a lack of choice for accommodation other than group and cluster homes for disabled people in Aotearoa New Zealand (1999). The lack of alternative independent accommodation contributed to participants seeking and organising their own flats and houses.

One alternative to the group/cluster home model is the supported living model. An introduction of the supported living model would allow disabled people to live in their own homes with individualised support (Howe, Horner, & Newton, 1998; O'Brien, 1994). Supported living would give disabled people greater choice over:

- Where to live?
- How to live?
- Who provides the assistance?
- Control over who is involved
- How that support is undertaken?

These are concepts developed from the independent living movement (Picking, 2000).

Separating the housing requirements from support needs would give disabled people greater choice and control over their accommodation needs (MacArthur, 2003; National Advisory Committee on Health and Disability, 2003a). Such separation would deliver the following advantages for disabled people:

- Greater focus on support needs
- Wider range of housing options
- Tenancy rights (under group/cluster homes, disabled people have no tenancy rights)
- More interaction with community, family and friends
- The choice of having own home (Brook, 1999).

The full introduction of an individualised model of support for disabled people is also recommended (see Chapter Two, pp.28-30). This funding option was introduced to Aotearoa New Zealand, but its availability ceased in 2001. Only 250 people have accessed this alternative model of support (Ministry of Health, 2003a). Though not suited for all disabled people, individualised funding provides an option for disabled people that complements supported living (Lord & Hutchison, 2003; MacArthur, 2003).

Some of the research participants commented that it was lonely living in society after provider homes, where close social interactions were assured. To help address this need, participants would sometimes visit residents from their former homes, or frequent a local drop-in centre for disabled persons. Residential providers need to actively establish connections with such existing disability organisations and promote these in their service. Providers also need to assist former residents to access and develop naturally occurring social networks in the community, thereby helping them to integrate into their natural surroundings – mainstreaming.

The establishment of disability resource centres is recommended. Such centres need to be independent of government and professional disability support services. These centres would not only provide social networking, but also provide information on support options, advocacy services, peer-support, and benefit advice.

2 *Make group and cluster homes more empowering for disabled people*

For disabled people who desire to live in provider homes, changes are required to make their home environments more empowering. The following conditions will help, encourage and promote more participation and control for disabled people living in provider homes (Hagner & Marrone, 1995; Jenkinson, 1993; Kendall, Buys, & Larner, 2000; Shepherd, 1998):

- Disability service alternatives to provide disabled people with options, choice and control at provider homes
- Use of staff selection and training at cluster/group homes to best meet disabled people's needs
- Use of support for disabled people at provider homes to access, develop and maintain community connections
- Providing assistance with some disabled people's decision-making at provider homes, especially when individuals lack decision-making experience
- Have life-style plans, when used, developed by a service separate from the provider homes providing the support and accommodation
- The funding of support at cluster/group homes to be linked with individual plans that can be used with other providers
- Involving disabled people with the operation and direction of provider homes services by ensuring significant representation in governance and staff roles
- Engaging service users and local disability groups with the cluster/group homes' strategic planning

- Having disabled people involved as evaluators of the provider homes' effectiveness.

It is important to instil a sense of ownership and control for the people living in provider homes. A partnership approach may help to provide a solution to the power imbalance that exists in cluster and group homes for some individuals. Sullivan and Munford (2005, pp. 29-30) suggest the following for the creation of such partnerships:

- "Bringing disabled people's knowledge to the centre" of service provision
- Understanding the systems of service provision for the purpose of benefiting disabled people
- "Disrupting deficit models" that fail to place disabled people in the "central position" of change
- Using "critical evaluation of relationships and processes" to bring about emancipatory change
- Undertaking a "fundamental shift in mindset" on how disability professionals exercise their power.

A shift toward partnership between disability service providers and disabled people living in cluster and group homes could occur relatively easily in Aotearoa New Zealand because of the centralised system of funding that operates under the Ministry of Health. But what is required, and what is lacking, is the political will for such a change to occur.

3 Further research

The thesis is an explorative interpretative study and has been limited by time, resources and the use of a small sample size. Further research into how disabled people have managed to leave a group or cluster home setting to live in their own homes will add a greater reliability and validity to the findings of this research.

It is clear that some disabled people wish to live in a cluster or group home setting. The research does not recommend that these people leave their current homes. Rather, it would be useful for further research to be undertaken to explore how the current accommodation model can be reconfigured to transfer power and control from NGO providers to the disabled people they support. Such research will add to the knowledge base regarding disabled people and disability groups, and can be used to promote reform in government disability policy.

Final Words

Participants' stories formed the basis of these recommendations, and supplied much of the knowledge for this thesis. Their narratives regarding leaving provider homes show many individual inner strengths and abilities. Evident also is the support of others significant in their lives, as well as supporting macro-factors. Disabling forces identified by the participants at their former homes did not stop them moving out. Now, participants live out their dream of a new home in the community, which is not always an easy place to live, supported by family, friends, and government supports. The fact that they continue to live in their own homes today is a testament to their self-empowerment skills and the support of others, which could form the basis for further research.

This thesis began with the words from one of the participants and will end in the same way:

> *The bottom line about living here you have to work one day a week, but that's okay. But whether I would go back to supervised accommodation and sleep in every day? Its better living here. You have control … I like it here. I've never had a suicide attempt here – so that really sums it all up … The people down the fish and chip shop know me. Everyone knows me, it's like a little community, everyone. Tomorrow I'm going to a birthday party, one of the girls down the road. We live like this and I like it – yeah.* (Nancy, 2008)

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APPENDIX 1: Massey University Human Ethics Committee Application

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Massey University

Te Kunenga ki Pūrehuroa

Application No: ___08 / 07_______

This number is assigned when your application is accepted.
Quote on all documentation to participants and the Committee.

Human Ethics Application

FOR APPROVAL OF PROPOSED RESEARCH/TEACHING/EVALUATION INVOLVING HUMAN PARTICIPANTS

(All applications are to be typed and presented using language that is free from jargon and comprehensible to lay people)

SECTION A

1. **Project Title** The silent revolution: disabled people talk about housing and taking control of their lives.

Projected start date for data collection 01 April 2008 **Projected end date** 01 June 2008

In no case will approval be given if recruitment and/or data collection has already begun.

2. **Applicant Details** *(Select the appropriate box and complete details)*

ACADEMIC STAFF APPLICATION (excluding staff who are also students)

Full Name of Staff Applicant/s

School/Department/Institute

Campus *(mark one only)* **Albany** ☐ **Palmerston North** ☐ **Wellington** ☐

Telephone **Email Address**

STUDENT APPLICATION

Full Name of Student Applicant Guy Patrick Oskar Burns

Employer (if applicable) N. A.

Telephone *021 2624645* **Email Address** guy@hapu.co.nz

Postal Address 226 Main Road South. Raumati South 5062. Kapiti Coast

Full Name of Supervisor(s) Dr Martin Sullivan

School/Department/Institute Massey University. College of Humanities and Social Sciences.

Campus *(mark one only)* **Albany** ☐ **Palmerston North** ☒ **Wellington** ☐

Telephone 6 356 9099 ext: 2833 **Email Address** m.j.sullivan@massey.ac.nz

GENERAL STAFF APPLICATION

Full Name of Applicant ....

Section ....

Campus *(mark one only)* **Albany** ☐ **Palmerston North** ☐ **Wellington** ☐

Telephone .... **Email Address** ....

Full Name of Line Manager ....

Section ....

Telephone .... **Email Address** ....

3. **Type of Project** *(mark one only)*

Staff Research/Evaluation:	☐	**Student Research:**	☐	**If other, please specify:**
Academic Staff	☐	**Qualification**	☒	
General Staff	☐	**Credits Value of Research**	☐	

4. **Summary of Project**
Please outline in no more than 200 words in lay language why you have chosen this project, what you intend to do and the methods you will use.
(Note: all the information provided in the application is potentially available if a request is made under the Official Information Act. In the event that a request is made, the University, in the first instance, would endeavour to satisfy that request by providing this summary. Please ensure that the language used is comprehensible to all)

The researcher is familiar with the disabling effects of-institutional practice, having been a recipient of institutionalised, supported accommodation at the former Porirua Hospital. Subsequent to this I have had over 20 years of social service experience in the non government sector and noticed that many service providers exerted undue power and influence over disabled service users in their own homes. Most service users who live in cluster or group homes do not have power and control over their lives, but the staff that support them do. It is significant that some disabled people have silently and quietly broken free from the bondage of this institutionalised care. The planned enquiry will use semi-structured, in-depth interviews, by way of an informal conversational approach with open-ended questions to collect data.

5. **List the Attachments to your Application**, e.g. Completed "Screening Questionnaire to Determine the Approval Procedure" (compulsory), Information Sheet/s *(indicate how many)*, Translated copies of Information Sheet/s, Consent Form/s *(indicate of how many)*, Translated copies of Consent Form/s, Transcriber Confidentiality Agreement, Confidentiality Agreement *(for persons other than the researcher / participants who have access to project data)*, Authority for Release of Tape Transcripts, Advertisement, Health Checklist, Questionnaire, Interview Schedule, Evidence of Consultation, Letter requesting access to an institution, Letter requesting approval for use of database, Other *(please specify)*.

- Information sheet
- Consent form
- Authority for the release of transcripts
- Interview guide

Applications that are incomplete or lacking the appropriate signatures will not be processed. This will mean delays for the project.

Please refer to the Human Ethics website (http://humanethics.massey.ac.nz) for details of where to submit your application and the number of copies required.

SECTION B: PROJECT INFORMATION

General

6 **I/we wish the protocol to be heard in a closed meeting (Part II).** **Yes** ☐ **No** ☒
(If yes, state the reason in a covering letter)

7 **Does this project have any links to other MUHEC or HDEC application/s?** **Yes** ☐ **No** ☒

If yes, list the MUHEC or HDEC application number/s (if assigned) and relationship/s.

8 **Is approval from other Ethics Committees being sought for the project?** **Yes** ☐ **No** ☒

If yes, list the other Ethics Committees.

9 **For staff research, is the applicant the only researcher?** **Yes** ☐ **No** ☐

If no, list the names and addresses of all members of the research team.

Project Details

10 **State concisely the aims of the project.**

The proposed research project aims to identify factors that have enabled some disabled people to transition from an environment where support and accommodation have been provided by the same organisation, to a situation where the accommodation and support are separate, or support has been terminated.

11 **Give a brief background to the project to place it in perspective and to allow the project's significance to be assessed.** *(No more than 200 words in lay language)*

As a social work practitioner who has been involved with disadvantaged and powerless groups for over twenty years and who has experienced institutionalised care, I have been intrigued by the fact that some disabled people have far greater power and control over their environment than other disabled people. The National Advisory Committee on Health and Disability (2003, p.43) found most service users who live in cluster or group homes do not have power and control over their lives, but the staff who support them do. This research will gather stories of those people who have most recently transitioned from an institution or provider who supplied both accommodation and disability support services, to a situation of living in their own homes or flats, where support and accommodation are separated, or the support had ceased.

12 **Outline the research procedures to be used, including approach/procedures for collecting data. Use a flow chart if necessary.**

The planned enquiry will use semi-structured, in-depth interviews, by way of an informal conversational approach with open-ended questions to collect data. Five people who have lived in an environment where support and accommodation services have been supplied by the same provider for a period longer than 6 months and who have transitioned to a position where support and landlord services are separate, or support is terminated, will be invited to participate in the project. Through networks on the Kapiti Coast, and standing relationships with people with impairments, the researcher will use a third party (a local disabled person) to informally make inquiries to ascertain potential interest and involvement in the research. An information sheet will be given to any potential participants explaining the research details and requirements, participants' rights, confidentiality details, study aims and time required. A consent form, confidentiality statement and interview guide will also be offered. Data will be collected from each participant by the use of one interview of two hours' duration. The interviews will be audio-tape recorded, transcribed and inductively analysed for patterns, themes, categories, causes, consequences and relationships. The Wellington branch of the National Assembly of People with Disabilities will be contacted by letter informing them of this research and invite comment.

13 Where will the project be conducted? Include information about the physical location/setting.

The interviews will be conducted in the Wellington, Kapiti, Horowhenua or Manawatu areas .at locations chosen by participants.

14 If the study is based overseas, specify which countries are involved. Outline how local requirements (if any) have been complied with.

15 Describe the experience of the researcher and/or supervisor to undertake this type of project?

The researcher has a limited experience of qualitative research through a Massey of University Bachelor of Social Work Degree (lst Class Honours). Dr Martin Sullivan (supervisor) is an experienced disability researcher and currently a senior lecturer at Massey University Palmerston North. He has published widely on disability both in Aotearoa and internationally.

16 Describe the peer review process used in assessing the ethical issues present in this project.

The ethical implications and impacts of the proposed research have been discussed with Dr Sullivan (who served on the National Ethics Advisory Council 2000-07).

Participants

17 Describe the intended participants.

The intended applicants will be disabled individuals who have lived in an environment where support and accommodation services have been supplied by the same provider for a period of greater than 6 months, and who have transitioned to a position of living in their own homes or flats, where support and landlord services are separated, or support has been terminated. If participants will be interviewed in their own home the researcher will inform Dr Martin Sullivan of the time and place of visit, and will ring Dr Sullivan upon completion of the interview. The researcher will carry a mobile phone when interviewing.

18 How many participants will be involved?

Five.

What is the reason for selecting this number?

(Where relevant, attach a copy of the Statistical Justification to the application form)

After consultation with Dr Sullivan, the supervisor, it was decided the stories of five information rich participants will provide sufficient data for a study of this size.

19 Describe how potential participants will be identified and recruited?

I intend to draw upon the networks and relationships with service providers and disabled people I built up during my 20 years in social services on the Kapiti Coast. A third party individual will make informal inquiries to ascertain potential interest and involvement in the research. An information sheet will be given to any potential participants explaining the research details and requirements, study aims, time required and participants' rights. A consent form, confidentiality statement and interview guide will also be available. The Wellington branch of the National Assembly of People with Disabilities will be contacted by letter informing them of the research and invite comment.

20 **Does the project involve recruitment through advertising?** **Yes** ☐ **No** ☒

(If yes, attach a copy of the advertisement to the application form)

21 **Does the project require permission of an organisation (e.g. an educational institution, an academic unit of Massey University or a business) to access participants or information?** **Yes** ☐ **No** ☒

If yes, list the organisation(s).

(Attach a copy of the request letter(s), e.g. letter to Board of Trustees,PVC,HoD/I/S,CEO etc to the application form. Include this in your list of attachments (Q5). Note that some educational institutions may require the researcher to submit a Police Security Clearance)

22 **Who will make the initial approach to potential participants?**

A third party individual.

23 **Describe criteria (if used) to select participants from the pool of potential participants.**

Those who have most recently transitioned from an institution or provider who supplied both accommodation and disability support services, to a situation of living in their own homes or flats, where support and accommodation are separated, or the support had ceased, will be chosen.

24 **How much time will participants have to give to the project?**

A total of three hours. One interview of two hours' duration and one hour for receiving feedback from each participant regarding their individual transcribed data.

Data Collection

25 **Does the project include the use of participant questionnaire/s?** **Yes** ☐ **No** ☒

(If yes, attach a copy of the Questionnaire/s to the application form and include this in your list of attachments (Q5))

If yes: i) indicate whether the participants will be anonymous, (i.e. their identity unknown to the researcher). **Yes** ☐ **No** ☐

ii) describe how the questionnaire will be distributed and collected.

(If distributing electronically through Massey IT, attach a copy of the request letter to the Director, Information Technology Services to the application form. Include this in your list of attachments (Q5))

26 **Does the project involve observation of participants? If yes, please describe.** **Yes** ☐ **No** ☒

27 **Does the project include the use of focus group/s?** **Yes** ☐ **No** ☒

(If yes, attach a copy of the Confidentiality Agreement for the focus group to the application form)

If yes, describe the location of the focus group and time length, including whether it will be in work time. *(If the latter, ensure the researcher asks permission for this from the employer).*

28 **Does the project include the use of participant interview/s?** **Yes** ☒ **No** ☐

(If yes attach a copy of the Interview Questions/Schedule to the application form)

If yes, describe the location of the interview and time length, including whether it will be in work time. *(If the latter, ensure the researcher asks permission for this from the employer).*
The interviews, of two hours' duration will be conducted at a location of the participants' choosing, at a time most convenient to them.

29 **Does the project involve sound recording?** **Yes** ☒ **No** ☐

30 **Does the project involve image recording, e.g. photo or video?** **Yes** ☐ **No** ☒

If yes, please describe.

(If agreement for recording is optional for participation, ensure there is explicit consent on the Consent Form)

31 **If recording is used, will the record be transcribed?** **Yes** ☒ **No** ☐

If yes, state who will do the transcribing.
The researcher.

(If not the researcher, a Transcriber's Confidentiality Agreement is required – attach a copy to the application form. Normally, transcripts of interviews should be provided to participants for editing, therefore an Authority For the Release of Tape Transcripts is required – attach a copy to the application form. However, if the researcher considers that the right of the participant to edit is inappropriate, a justification should be provided below)

32 **Does the project involve any other method of data collection not covered in Qs 25-31?** **Yes** ☐ **No** ☒

If yes, describe the method used

33 **Does the project require permission to access databases?** **Yes** ☐ **No** ☒

(If yes, attach a copy of the request letter/s to the application form. Include this in your list of attachments (Q5))

(Note: If you wish to access the Massey University student database, written permission from Director, National Student Relations should be attached).

34 **Who will carry out the data collection?**
The researcher.

SECTION C: BENEFITS / RISK OF HARM (Refer Code Section 3, Para 10)

35 **What are the possible benefits (if any) of the project to individual participants, groups, communities and institutions?**
The planned research can be seen as a pilot study that may provide the catalyst for a larger and better resourced research project to investigate, analyse, identify and promote factors that have enabled some disabled people to move into a position of greater power and control over their lives. This data will provide valuable clues and information to benefit and help those living in cluster or group homes, whom the National Advisory Committee on Health and Disability (2003, p.43) have found to be oppressed by service providers and their staff. Any empowerment gains for disabled people will potentially benefit not only individuals, but groups, communities, institutions, social policy and society as a whole. Individual participants will potentially benefit in terms of knowing that their stories have helped others take greater control over their lives.

36 **What discomfort (physical, psychological, social), incapacity or other risk of harm are individual participants likely to experience as a result of participation?**
Anonymity and confidentiality will help to ensure there is no risk of harm to participants.

37 **Describe the strategies you will use to deal with any of the situations identified in Q36.**

To prevent potential harm the researcher will ensure any information, that may identify the individual and place of residence or former residence, will be anonymised. For example, personal names, geographical locations, personal relationships and provider names will be changed. Importance will be placed on sensitivity and tact during the interview process and participants will be informed of their right to decline answering any question, or part of question and to withdraw at any stage.

38 **What is the risk of harm (if any) of the project to the researcher?**

There is no envisaged risk of harm to the researcher.

39 **Describe the strategies you will use to deal with any of the situations identified in Q38.**

The researcher will regularly meet with Dr Sullivan, the chief supervisor, to discuss any issues and areas of stress, harm and discomfort that may unexpectedly arise during the research.

40 **What discomfort (physical, psychological, social) incapacity or other risk of harm are groups/communities and institutions likely to experience as a result of this research?**

While no service provider or agency will be named or identifiable, some may be embarrassed by the information discovered in the research.

41 **Describe the strategies you will use to deal with any of the situations identified in Q40.**

Any information that may identify any service provider or agency revealed during the interviews will be disguised or removed.

42 **Is ethnicity data being collected as part of the project?** **Yes** ☐ **No** ☒

If yes: i) will the data be used as a basis for analysis? **Yes** ☐ **No** ☐

ii) justify this use in terms of the number of participants.

(Note that harm can be done through an analysis based on insufficient numbers)

If no: i) justify this approach, given that in some research an analysis based on ethnicity may yield results of value to Maori and to other groups.

Since this is not intended to be a representative sample from which generalisations can be made, a small number of participants will be involved of which some might be Maori.

43 **If participants are children/students in a pre-school/school/tertiary setting, describe the arrangements you will make for children/students who are present but not taking part in the research.**
Not applicable.
(Note that no child/student should be disadvantaged through the research)

SECTION D: INFORMED & VOLUNTARY CONSENT (Refer Code Section 3, Para 11)

44 **By whom and how, will information about the research be given to potential participants?**

Printed information regarding the research will be mailed by Guy Burns to the potential participants.

45 **Will consent to participate be given in writing?** **Yes** ☒ **No** ☐

(Attach copies of Consent Form/s to the application form)

If no, justify the use of oral consent.

46 **Will participants include persons under the age of 16?** **Yes** ☐ **No** ☒

If yes: i) indicate the age group and competency for giving consent.

ii) indicate if the researcher will be obtaining the consent of parent(s)/caregiver(s). **Yes** ☐ **No** ☐

(Note that parental/caregiver consent for school-based research may be required by the school even when children are competent. Ensure Information Sheets and Consent Forms are in a style and language appropriate for the age group)

47 **Will participants include persons whose capacity to give informed consent may be compromised?** **Yes** ☐ **No** ☒

If yes, describe the consent process you will use.

48 **Will the participants be proficient in English?** **Yes** ☒ **No** ☐

If no, all documentation for participants (Information Sheets/Consent Forms/Questionnaire etc) must be translated into the participants' first-language.

(Attach copies of the translated Information Sheet/Consent Form etc to the application form)

SECTION E: PRIVACY/CONFIDENTIALITY ISSUES (Refer Code Section 3, Para 12)

49 **Will any information be obtained from any source other than the participant?** **Yes** ☐ **No** ☒

If yes, describe how and from whom.

50 **Will any information that identifies participants be given to any person outside the research team?** **Yes** ☐ **No** ☒

If yes, indicate why and how.

51 **Will the participants be anonymous (i.e. their identity unknown to the researcher?)** **Yes** ☐ **No** ☒

If no, explain how confidentiality of the participants' identities will be maintained in the treatment and use of the data.

Anonymity cannot be guaranteed given the small population of potential participants but confidentiality can. Original information will only be seen by the researcher & supervisor if necessary. Names, places and any distinguishing characteristics will be removed and/or changed to preserve-confidentiality.

52 **Will an institution (e.g. school) to which participants belong be named or be able to be identified?** **Yes** ☐ **No** ☒

If yes, explain how you have made the institution aware of this?

53 **Outline how and where:**

i) the data will be stored, and

(Pay particular attention to identifiable data, e.g. tapes, videos and images)

Tapes and printed transcripts will be kept in a locked cabinet at the researcher's home at 226 Main Road South, Raumati 5032. Electronic copies will be kept on a password protected computer at this address. Only the researcher will have access to the cabinet & computer.

ii) Consent Forms will be stored.

Consent Forms will be stored separately in locked draw at the researcher's home 226 Main Road South, Raumati 5032.

(Note that Consent Forms should be stored separately from data)

54 **i) Who will have access to the data/Consent Forms?**

The researcher and supervisor.

ii) How will the data/Consent Forms be protected from unauthorised access?

The data and forms will be kept separate in a locked drawer and cabinet. The researcher will be the only person with copies of the keys.

55 **Describe arrangements you have made for the disposal of the data/Consent Forms when the minimum five-year storage period (ten years for health-related research) is up?**

The data and consent forms will be destroyed or erased after five years by the supervisor.

(For student research the Massey University HOD Institute/School/Section / Supervisor / or nominee should be responsible for the eventual disposal of data)
(Note that although destruction is the most common form of disposal, at times, transfer of data to an official archive may be appropriate).

SECTION F: DECEPTION (Refer Code Section 3, Para 13)

56 **Is deception involved at any stage of the project?** **Yes** ☐ **No** ☒

If yes, justify its use and describe the debriefing procedures.

SECTION G: CONFLICT OF ROLE/INTEREST (Refer Code Section 3, Para 14)

57 **Is the project to be funded in any way from sources external to Massey University?** **Yes** ☐ **No** ☒

If yes: i) state the source.

ii) does the source of the funding present any conflict of interest with regard to the research topic?

58 **Does the researcher/s have a financial interest in the outcome of the project?** **Yes** ☐ **No** ☒

If yes, explain how the conflict of interest situation will be dealt with.

59 **Describe any professional or other relationship between the researcher and the participants? (e.g. employer/employee, lecturer/student, practitioner/patient, researcher/family member). Indicate how any resulting conflict of role will be dealt with.**

N/A

SECTION H: COMPENSATION TO PARTICIPANTS (Refer Code Section 4, Para 23)

60 **Will any payments or other compensation be given to participants?** **Yes** ☒ **No** ☐

If yes, describe what, how and why.

(Note that compensation (if provided) should be given to all participants and not constitute an inducement. Details of any compensation provided must be included in the Information Sheet)

To cover transportation costs and inconvenience $25 will be available per participant for each interview.

SECTION I: TREATY OF WAITANGI (Refer Code Section 2)

61 **Are Maori the primary focus of the project?** **Yes** ☐ **No** ☒

If yes: Answer Q62 – 65

If no, outline: i) what Maori involvement there may be, and

It is possible Maori may be involved as a research participant/s.

ii) how this will be managed.

If one or more Maori are involved in the research process the researcher will contact Mr Ron Lake, a Kapiti based Kaumatua, to seek cultural input and advice regarding the interview process and related matters.

62 **Is the researcher competent in te reo Maori and tikanga Maori?** **Yes** ☐ **No** ☒

If no, outline the processes in place for the provision of cultural advice.

See Q61

63 **Identify the group/s with whom consultation has taken place or is planned and describe the consultation process.**

(Where consultation has already taken place, attach a copy of the supporting documentation to the application form, e.g. a letter from an iwi authority)

See Q.61

64 **Describe any ongoing involvement of the group/s consulted in the project.**

N/A

65 **Describe how information resulting from the project will be shared with the group/s consulted?**

N/A

SECTION J: CULTURAL ISSUES (Refer Code Section 3, Para 15)

66 **Other than those issues covered in Section I, are there any aspects of the project that might raise specific cultural issues?** **Yes** ☐ **No** ☒

If yes, explain. Otherwise, proceed to Section K.

67 **What ethnic or social group/s (other than Maori) does the project involve?**

68 **Does the researcher speak the language of the target population?** **Yes** ☐ **No** ☐

If no, specify how communication with participants will be managed.

69 **Describe the cultural competence of the researcher for carrying out the project.**

(Note that where the researcher is not a member of the cultural group being researched, a cultural advisor may be necessary)

70 **Identify the group/s with whom consultation has taken place or is planned.**

(Where consultation has already taken place, attach a copy of the supporting documentation to the application form)

71 **Describe any ongoing involvement of the group/s consulted in the project.**

72 **Describe how information resulting from the project will be shared with the group/s consulted.**

73 **If the research is to be conducted overseas, describe the arrangements you will make for local participants to express concerns regarding the research.**

SECTION K: SHARING RESEARCH FINDINGS (Refer Code Section 4, Para 26)

74 **Describe how information resulting from the project will be shared with participants.**

(Note that receipt of a summary is one of the participant rights)

All participants will receive a draft transcribed copy of their interview for them to edit and make any additions or alterations. A summary of the research will be given to each participant upon completion of the research.

SECTION L: INVASIVE PROCEDURES/PHYSIOLOGICAL TESTS (Refer Code Section 4, Para 21)

75 **Does the project involve the collection of tissues, blood, other body fluids or physiological tests?** **Yes** ☐ **No** ☒

(If yes, complete Section L, otherwise proceed to Section M)

SECTION M: DECLARATION (Complete appropriate *box)*

STUDENT RESEARCH

Declaration for Student Applicant

I have read the Code of Ethical Conduct for Research, Teaching and Evaluations involving Human Participants and discussed the ethical analysis with my Supervisor. I understand my obligations and the rights of the participants. I agree to undertake the research as set out in the Code of Ethical Conduct for Research, Teaching and Evaluations involving Human Participants.

The information contained in this application is to the very best of my knowledge accurate and not misleading.

Student Applicant's Signature **Guy Burns** Date: 19/02/2008

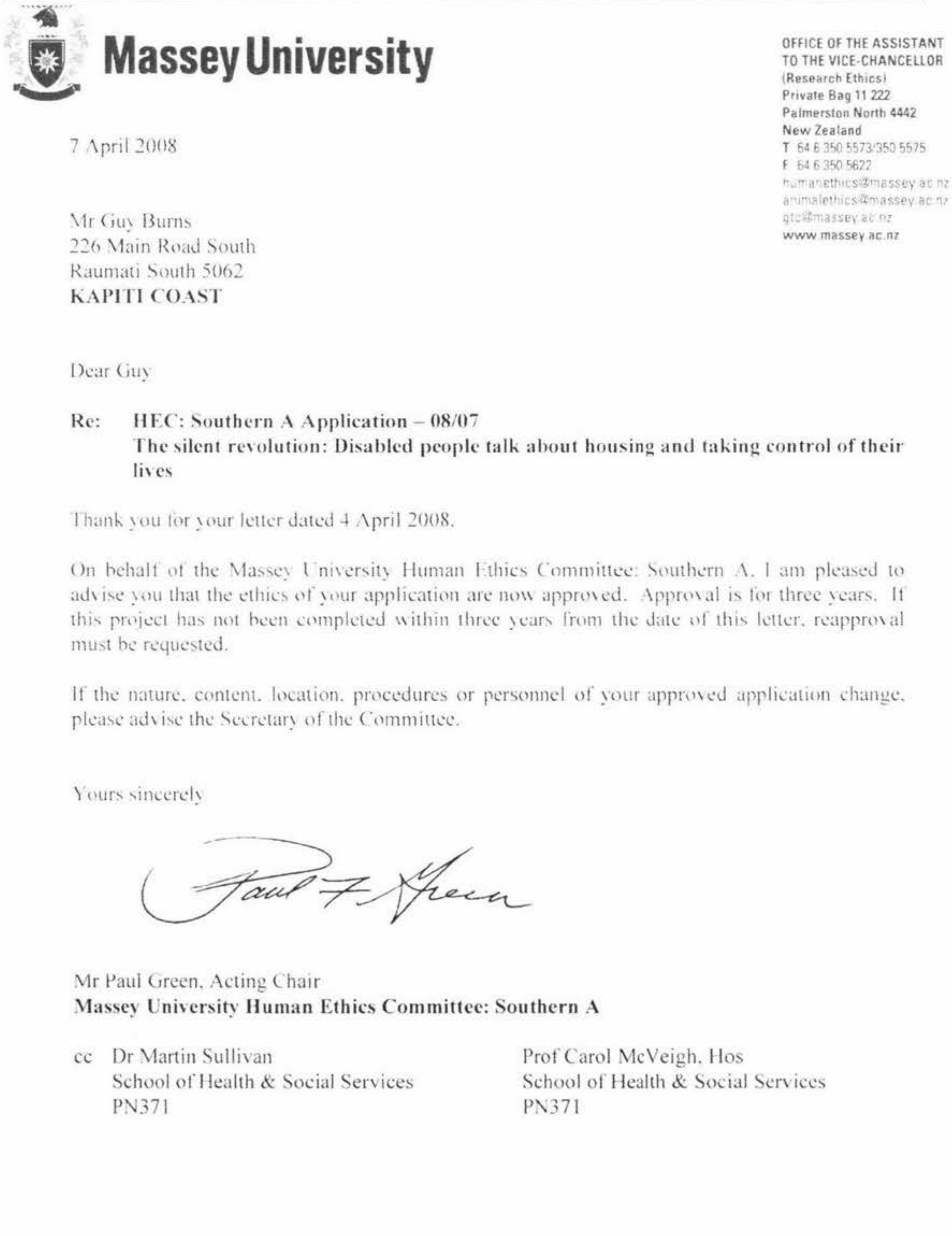
Declaration for Supervisor

I have assisted the student in the ethical analysis of this project. As supervisor of this research I will ensure that the research is carried out according to the Code of Ethical Conduct for Research, Teaching and Evaluations involving Human Participants.

Supervisor's Signature .... Date: 19/02/2008

Print Name **Dr Martin Sullivan**

APPENDIX 2: Massey University Human Ethics Committee Approval



Massey University

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7 April 2008

Mr Guy Burns
226 Main Road South
Raumati South 5062
KAPITI COAST

Dear Guy

Re: HEC: Southern A Application – 08/07
The silent revolution: Disabled people talk about housing and taking control of their lives

Thank you for your letter dated 4 April 2008.

On behalf of the Massey University Human Ethics Committee: Southern A, I am pleased to advise you that the ethics of your application are now approved. Approval is for three years. If this project has not been completed within three years from the date of this letter, reapproval must be requested.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

Yours sincerely

Paul F. Green

Mr Paul Green, Acting Chair
Massey University Human Ethics Committee: Southern A

cc Dr Martin Sullivan
School of Health & Social Services
PN371

Prof Carol McVeigh, Hos
School of Health & Social Services
PN371

Massey University Human Ethics Committee
Accredited by the Health Research Council

APPENDIX 3: Information Sheet

INFORMATION SHEET

Researcher Introduction

My name is Guy Burns. Currently I am engaged full-time on a Masters of Social Work research project. My supervisor for the research project is Dr Martin Sullivan, Senior Lecturer, Massey University.
Our contact details are:

Researcher	Supervisor
Guy Burns	Dr Martin Sullivan
Kapiti Coast	Senior Lecturer
Phone: 04 9042002	School of Health and Social Services
Email: guy@hapu.co.nz	Massey University
	Private Bag 11-222
	Palmerston North
	06 356 9099, extension 2833
	Email: m.j.sullivan@massey.ac.nz

I have experienced first-hand the disabling effects of institutionalised, supported accommodation (at the former Porirua Hospital). Subsequent to this, I have had 20 years of social service experience in the non government sector. During this time I noticed many service providers exerting undue power and influence over disabled service users in their own homes. It seemed that disabled people who received housing and support from the same provider did not have the same power and control over their lives as others living in situations where the landlord and support functions were separated. The National Advisory Committee on Health and Disability in 2003 stated that most service users who live in cluster or group homes do not have power and control over their lives, but the staff that support them do.

This research project, which forms the foundation for my Masters of Social Work thesis, will gather the stories of those who have most recently transitioned from an institution or provider who supplied both accommodation and disability support services, to a situation of living in their own homes or flats, where support and accommodation are separated, or the support has ceased.

Participant Recruitment

This information sheet explains to you the research details and requirements, study aims, time required and your rights. Also enclosed are a confidentiality statement, an interview guide and a consent form for you to sign if you would like to participate in my research. Please take your time to read this information, and if you are unsure about anything regarding the research please ring myself and/or the supervisor of the research project. Our contact details are on top of the first page. The Wellington branch of the National Assembly of People with Disabilities has been contacted by letter informing them of this research.

Five people will be interviewed. This number was chosen after consultation with Dr Sullivan, my supervisor, who indicated that the stories of five participants will provide sufficient data for a study of this size. To cover transportation costs and inconvenience, $25 per person will be available.

Project procedures and involvement

The interviews will be at a place of your choosing and conversational in nature. I will use an interview guide to steer the interview of approximately two hours. Your interview will be audio-taped and transcribed. The transcript will be sent to you to check out and make changes if necessary. It is anticipated this process will take about one hour. At any time you can pull out from the process.

Your consent form, audiotapes, notes and printed transcript will be kept locked at my home. Electronic information will be stored on a password protected computer. After five years this material will be destroyed or erased

All the information that you have provided will be completely confidential to me and my supervisor. No one else will have access to the information. Names, locations, institutions and other identifying information will be changed or removed to maintain confidentiality. It will not be possible to identify yourself in the final research report.

A summary of the research findings will be presented to you upon completion of the research project by me.

Participants' Rights

You are under no obligation to accept this invitation. If you decide to participate, you have the right to:

- Decline to answer any particular question
- Withdraw from the research at any time
- Ask questions regarding any aspect of the research during participation
- Alter any information, data or material that you have provided
- At any time ask for the audiotape recorder to be turned off during the interview
- Expect all information provided by you to be completely confidential to the researcher only. No other person will have access to the raw data (recorded interviews). All information will be collected carefully and anonymously and it will not be possible to identify you in the final research report
- A summary of the research finding

Project Contacts

Please contact the researcher and/or supervisor at any time if you have any questions regarding the project. Guy Burns, phone: 04 9042002, email: guy@hapu.co.nz. Dr Martin Sullivan, phone: 06 356 9099, extension 2833, email: m.j.sullivan@massey.ac.nz.

Committee Approval Statement

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 08/07. If you have any concerns about the conduct of this research, please contact Professor John O'Neill, Chair, Massey University Human Ethics Committee: Southern A, telephone 06 350 5799 x 8771, email: humanethicsoutha@massey.ac.nz.

APPENDIX 4: Consent Form

PARTICIPANT CONSENT FORM

This consent form will be held for a period of five (5) years

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree/do not agree to the interview being audio taped.

I wish/do not wish to have my tapes returned to me.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signature: .... **Date:** ....

Full Name - printed ....

APPENDIX 5: Authority for the Release of Transcripts Form

AUTHORITY FOR THE RELEASE OF TRANSCRIPTS

This form will be held for a period of five (5) years

I confirm that I have had the opportunity to read and amend the transcript of the interview/s conducted with me.

I agree that the edited transcript and extracts from this may be used by the researcher, Guy Burns, in reports and publications arising from the research.

Signature: .... **Date:** ....

Full Name - printed ....

APPENDIX 6: Interview Guide

Personal Biography

- Age
- Gender
- Family history
- Work background
- Interests
- Factors leading to institutional experience

Introduction

Maybe leave these details for the end

What led up to you going to ......?"

Provider/Institutional Experience

- Details of provider/institution/s
- Time spent
- Positive experiences
- Negative experiences
- Socialisation experience of the provider
- Social networks outside of provider
- Feelings towards provider/institution/s
- Understanding of why you were in the provider/institution
- Perceptions of support needs
- Feelings towards peers
- Feelings of staff
- Feelings towards yourself
- Acceptance of your situation
- Awareness towards changing situation

You were at...
Why were you there?
What did it feel like living there?
What did you like?
What did you dislike?
How did the others seem?

Did you make friends?
How did you accept/feel about living there?

Transition from provider/institution

- Details how transition occurred
- Reasons for transition
- Support for transition by staff
- Support for transition by external professionals
- Support for transition by friends
- Support for transition by family
- Details of inner drive towards transition
- Positive feelings regarding transition
- Negative feelings regarding transition

You were at...
How did you leave?
What happened?
How did it happen?
What did it feel like?
What did you experience?
Why do you think you left?
What enabled you to

Experience of new environment after transition

- Details of new environment
- Feelings towards new environment
- Support given at new environment by staff

You went to...
What did that feel like?
Were you getting help or support – from whom?
How did it compare with ...?
What were the factors that helped you move?

- Support given at new environment by friends
- Support given at new environment by professionals
- Support given at new environment by family
- Negative experiences regarding new environment
- Positive experiences regarding new environment
- Perceptions of support needs
- Comparisons of the new environment and former provider/institution
- What are the factors that enabled the transition?

Current situation

- Details of different environments since from transition
- Details of current environment
- Feelings towards current environment
- Perceptions of support needs
- Support given at current environment by staff
- Support given at current environment by friends
- Support given at current environment by professionals
- Support given at current environment by family
- Negative experiences regarding new environment
- Positive experiences regarding new environment
- Comparisons of the current environment and former provider/institution

Have you had other homes since you left ...?
Are you getting help/support – from whom?
How does it feel looking back at when you were at?
What's different to ....?
What would you do differently if you could?

General

- Thoughts regarding disability
- Thoughts regarding impairment
- What made you respond to the research

What are your thoughts regarding disability/impairment?
What made you respond to the research?

Final

That covers the things I wanted to ask. Is there anything you would care to add? Or:

I have no further questions. Do you have anything more you want to bring up, or ask about, before we finish the interview?

Types of Questions

- Introducing
- Follow-up
- Probing
- Specifying
- Direct
- Indirect
- Structuring
- Silence
- Interpreting