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DAYS OF OUR LIVES

People with intellectual disabilities describe their
experiences and viewpoints of services

A thesis presented in partial fulfilment of the requirements
for the degree
of Master of Social Work
at Massey University

Jan Perkins
1996

*There are many more stories to be told
and voices yet to be heard*

(Atkinson and Williams, 1990:244)

ABSTRACT

This thesis is drawn from the experiences and viewpoints expressed by five individuals with intellectual disabilities. The objectives of the research in this thesis were to establish a view from below of disability services, and to identify an agenda for change. The main research question is; how can we improve the quality of daily lived experience in disability services for people with intellectual disabilities?

In this research I developed a set of emancipatory principles on which the process was based. The participants voices were heard through individual interviews and group meetings. On analysis their viewpoints combined into ten themes that described their past and current experiences and gave clear direction as to how services should change.

I set out to provide an opportunity for people with intellectual disabilities to speak safely outside of the service structure and create the agenda as to what was important for them to share.

The issues raised by the participants revealed the power and control exercised by service providers and the lack of opportunity service users have to exercise choice over fundamental aspects of their lives; who they live with, where they live, how they are supported and how their daily environments are structured. The messages they give are simple and clear. They ask that people listen to them and include them in decisions made about their lives.

The viewpoints that are reflected here place the participants as part of an oppressed group, within a service structure dominated by the principle of normalisation and an ideology of disability based upon personal tragedy. Through gaining an understanding of their oppression and also of their achievements, we can create a new set of goals based on emancipatory principles: namely reciprocity and empowerment. It is argued that we can move beyond the binary division of service provider and service user to services based on partnership.

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"DAYS OF OUR LIVES"

People with intellectual disabilities describe their experiences and viewpoints of services

Introduction

I am writing from the perspective of a Pakeha, non-disabled feminist, who has worked as a professional in the area of disability services over two decades. This study is for me, part of a personal as well as a professional journey, which started 25 years ago, when, as a student, I worked in a hospital for people labelled mentally subnormal. At that time I had no analysis of disability and simply felt uncomfortable that people should live in a building called a hospital for the mentally subnormal. I wore a nurse's uniform and carried keys to get in and out of the wards. I wondered why disabled people had to live in a world so different from mine. I got to know many of them well, not just as patients but as people, and enjoyed their company. I was horrified by the oppressive practices we were expected to carry out in the name of care, and my stay in that hospital was short; theirs was not.

I have spent the years since then working in the field of disability. I have attempted to play a part in improving the services provided for disabled people and I am concerned at how little has been achieved. I have come to realise that I have not really been listening to the right people, so I am returning to where I started, spending some time hearing the realities of the lives of service users and using my skills and knowledge in response to what they have to say.

I share a common experience with the people telling their stories, in that I have spent time in the same services. Although I have worked in the area of disability, I have not experienced disability. We shared the same space and time, but the inequality within service structures created a difference in how these things were experienced, by me as a provider, and by them as recipients. In the process of listening and reflecting our experiences became woven together, thus the days referred to became not mine or theirs, but 'ours'.

My thinking as a feminist has enabled me to base this research on emancipatory principles. This research project is about finding a way to provide an opportunity for individuals who have spent significant periods of their lives within residential and day services for people with intellectual disabilities, to tell their stories, and to express their views for change. The ultimate goal of this process is to improve the quality of their lives, by improving the services they receive. It is argued that the emancipatory goal will be achieved if services can move beyond provider and receiver, to become a joint venture in which we strive together to improve the quality of the days of our lives.

I approached the research process with the following key objectives: to establish a view from below of disability services, and to identify an agenda for change. Having documented the service users' experiences and recommendations, I then focused on the main research question, how can we improve the quality of daily lived experience in disability services for people with intellectual disabilities?

In order to accomplish these objectives I took the following steps: first, I examined the research process to find a methodology that would allow the participants' voices to emerge. Second, I provided an opportunity for each individual to tell their story in their own way, to make their own decisions as to what was important to them and how they wanted to share that. I set out to ensure that the process was accessible and safe; that their participation did not place them as a vulnerable group at risk for having spoken. Third, I identified common themes in their daily lived experiences as people with intellectual impairments in services.

My purpose was to draw together the themes from their stories to present a "view from below" of disability services which illuminated their daily lived experiences. It is argued this is a viewpoint that is missing in service descriptions, and is glimpsed only occasionally in the current literature (Ballard, 1994; Horner, 1994; Keith, 1994). I believe that in order to bring about positive change within services, the recommendations of the recipients of services must be documented and acted upon. We need to understand the power relations between service users and service workers and the part that services play in the social construction of disability (Barnes, 1990; Bach, 1994; Brown and Smith, 1992).

The primary focus of the research is the experience of disability and societal and service responses. It is beyond the scope of this project to analyse issues of gender and ethnicity,

although the participants are a mixed gender and ethnic group. There may be issues that are particular to women with intellectual disabilities as opposed to men. Likewise, there may be issues that are specific to Maori with intellectual disabilities. However, within this research project the focus is on the experience of intellectual impairment which the participants have in common.

The Importance of Language

It is important that I clarify at this point, my use of language throughout this thesis. Where I am expressing my own ideas and analyses, I will use the term “disabled people”. This is used in the sense that it has been used by Oliver (1990) to express the disabling process which people experience. Likewise I will use the term “people with intellectual impairments”, to signify that the impairment belongs to the individual, but is not necessarily the disabling factor.

Where I have used terminology such as “mentally retarded” or “developmental disability”; this is the terminology of the writers to whom I am making reference. I have not altered their language as it expresses their underlying perspectives of disability and impairment.

The Format and Outline of the Thesis

The first chapter has two sections. In section one I set out the prevailing beliefs and ideologies of disability. I argue that without an analysis of disability, we can not make sense of the experiences of disabled people. First, I examine personal tragedy theory and the medicalisation, exclusion, segregation and dependency of disabled people. Second, I examine the theory of social oppression and the power relations that operate within disability services; the violence and abuse to which disabled people have been subjected and the issue of compliance which has led to their increased vulnerability. Third, I examine the concept of intellectual impairment and the impact of this label on people’s lives. This leads to an exploration of the principle of normalisation, which has been a dominant theme in service delivery for people with intellectual impairment over the last two decades, and the emergence of the People First movement.

In section two I focus on social policy and service provision. First, I describe the social policies that have had an impact on the lives of disabled people, and in particular, I

examine the policies of deinstitutionalisation and community care. I give examples from current documents outlining policy for service provision in this area. This leads on to an examination of the structure and functions of services for people with intellectual impairments and the influence of the hegemony of normalisation. Finally, I consider the different facets that exist within the caregiving process. I give examples of the themes that have currently emerged within the literature from the perspectives of the caregivers, and identify the need to gain an understanding of the daily lived experiences of the recipients of care.

The second chapter describes the methodology of the research project. I examine the approaches taken by other researchers in the disability field and identify the need to adopt a research paradigm which approaches disability as a political problem; to make research more relevant to the lives of disabled people by creating a history which includes their experiences; and to document the voices of disabled people to present an alternative viewpoint of disability services. The links are established between disability research based on emancipatory principles and feminist principles as the basis for my approach. I describe how I incorporated the principles into my research process; the techniques I adopted from other researchers and the pitfalls I identified within other research projects that I strove to avoid. The practicalities of making contact and collecting and analysing the data are explained; as are the processes used by other researchers that I found useful, and the barriers and difficulties that I encountered.

The third and fourth chapters are the core of the research project. In these chapters the voices of the participants are heard and the dialogue that occurred between us is outlined. The experiences and reflections are divided into ten themes that emerged from the data. The third chapter contains the first four themes which reflect the experience of living with a disability. The fourth chapter contains six themes which focus on significant others in their lives and how they help or hinder. Within each theme examples from other literature are used to compare and contrast with this analysis. Reflections from my own experience are included throughout, but my main purpose in this chapter is to allow the participants to be heard in their own words in a format that acknowledges the reality of their perspectives and at the same time maintains their anonymity within the process.

The fifth chapter summarises the essence of the themes, the key points from the literature, and brings together the recommendations for change. From each theme issues arose which are addressed in terms of creating a new way forward. Examples are identified for

the development of practices within service delivery which are based on partnership. My own personal commitment to this process is stated, together with my recommendations to others who would like to be part of this journey through the days of our lives. The conclusion reflects back over the usefulness of the literature, the appropriateness of the methodology, and the degree to which the research question has been addressed.

Chapter One

The Mountain of Oppression

The title and framework for this chapter originated from Bronfenbrenner's (1979) concept of the ecological environment as a set of nested structures, in which the innermost nest is the developing person. Although this is a useful model to investigate the power relations between the different areas, it did not fit accurately with my concept of the oppression of disabled people, gained from personal experience as a service provider. I have, therefore, inverted the nest concept and have placed the disabled individual at the core of a mountain of oppression (Appendix 5), which I argue more accurately represents their experiences. The focus of the study was people's experiences of services and, therefore, what has emerged is a description of a hidden world, a different way of living, a unique community that has been constructed by ideologies of disability, social policies, service systems, service workers and service users themselves.

In this chapter I will identify the prevailing beliefs and ideologies of disability; how social systems perceive disability and consequently, construct service responses. I will begin with the ideology of personal tragedy; the medicalisation of disability; exclusion from productivity; segregation, and dependency and destruction that have been experienced by disabled people as described by writers such as Oliver (1990) and Sullivan (1995). I argue that it is this ideology of disability which underpins service delivery and which led to the construction of the institutions in which I first began working.

I will then examine the concept of social oppression which is now emerging (Oliver, 1990), which I will argue reflects the experience of service users. I will draw on the work of Freire (1972) to further explore the concept of oppression, as he provides an understanding of the relationship between oppressors and oppressed. It is my experience that compliance has been a major goal of service provision. I will give examples of the violence and compliance to which disabled people have been subjected (Sobsey, 1994; Lovett, 1996) and their consequent responses of submission, or challenging behaviour.

Next I will explore the concept of intellectual impairment; the labelling which results from IQ testing and the particular experience of being so labelled (Ballard, 1994). This

concept has had a major impact on the lives of the research participants in this project and is key to making sense of the direction their lives have followed; why their world has been different to mine. This leads on to an analysis of the principle of normalisation (Wolfensberger, 1972) which has been a dominant influence in service provision for people with intellectual disabilities over the last two decades. This principle had a key influence on my own work practice in the 1970s and 1980s and it is important to examine its relevance to the nineties (Brown and Smith, 1992) and the impact it still has on service users' lives. Finally, in this section I will outline the emergence of the People First movement and the challenges people with intellectual impairments are raising.

In the next section I will focus on social policy; in particular the policies of deinstitutionalisation and community care and the impact of these policies on service provision. I will give some examples of how the ideologies and policies influence the way services are delivered, both in New Zealand and in other Western settings.

Finally, I will focus on the construction of the caregiving process for people with intellectual impairments, with particular reference to Munford (1992, 1995) who writes from a New Zealand perspective and Brown and Smith (1992), who introduce the similarities and differences between the oppression of women and people with intellectual disabilities. I will refer to Foucault's ideas (1977, 1982) which have been developed by Munford (1992, 1994) and Kerr (1994), concerning the technologies of power and the ways in which power relations operate, as a useful framework in understanding the interactions between disabled people and their support workers within the service system. Throughout this chapter I will also include other references which support the key arguments and themes identified by the research participants.

Section One

IDEOLOGIES OF DISABILITY

Disability as Personal Tragedy

My current thinking about disability has been stimulated by the work of Michael Oliver, who is a disabled professional writing in this field. Oliver (1990) has done much to help us understand the hidden ideologies of disability that have become embedded in social consciousness. The major characteristic of these ideologies is personal tragedy theory. This theory locates the problem within the impaired individual, named as the invalid. Disabled people, having been invalidated, then become excluded from the mainstream of society. They are excluded in many cases from the workforce, education, ordinary houses and buildings. Instead they are admitted to segregated settings designed specifically for them. Around this excluded group of problems, professional specialisation develops and systems are organised where disabled people can be examined and fixed, or if they are unable to be fixed, maintained. One of the responses to disability has, therefore, been a medical model of service. Sullivan describes this:

Thus the paralytic, the cripple and the deformed were increasingly subjected to the medical gaze, diagnosed with greater precision into various medical 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.

(Sullivan, 1995:17)

Another key response to disability, has been exclusion from productivity. Oliver argues that anyone unable to work is going to have additional difficulties in both sustaining themselves physically, and establishing social relationships (Oliver, 1990). I agree with McGee (1987) that society's posture towards individuals is based on their capacity to produce, and not on their inherent value as human beings. This has been evident for me in my experience in supporting people in segregated vocational settings and the difficulties experienced by them in gaining entry into the workforce.

In the early part of this century, people with intellectual impairments became noticeable as a group who were seen as unable to cope with the expectation of the industrialised social systems (Tyne, 1992). The societal response was, in general, the development of segregated services. Having separated people out as unproductive and, therefore, a burden on society, it then became possible to view them differently in terms of human rights. At one extreme the service can then become a mechanism for the destruction of the disabled as a group. An example of this is the Hadamar Psychiatric Hospital (Sobsey, 1991) which in 1941 exterminated their 10,000th patient. Gregor Wolbring (1996) describes the current debates on euthanasia in Germany and the belief that mercy killing of some disabled people is preferable to what is viewed as continued suffering. He also states the refusal of euthanasia proponents to equate their policy to that carried out by the Nazis.

In all, more than 100,000 people with mental, physical, or emotional disabilities were starved, sent to the gas chambers, or given lethal injections in Nazi Germany.

(Sobsey, 1991:5)

Although such extreme responses are easy to identify and deplore, the consequence of viewing disability as a personal tragedy (Oliver, 1990) has in general, resulted in an anxiety that has led to the exclusion of people from mainstream society and the development of segregated services. Even where community services have now been established, the ideology of personal tragedy has fostered the notion of dependency, so that things are done for and to disabled people, not with them (Boyles, 1994; Georgeson, 1994; Morris, 1991). In earlier centuries people lived within their own communities without being subjected to intrusive and controlling services. Before the transition from the age of faith the disabled person was approached with a religiously based moral commitment. As Downer (1988) states, the age of enlightenment brought with its scientific values a new fear of censure and the ideology of disability as personal tragedy, which helped to maintain the medicalisation, exclusion, destruction and dependency of disabled people. It is the disabled person who is seen as deficient, as opposed to the person who is doing the measuring. I argue that as Lovett suggests, we have an obligation as non-disabled people to examine our own deficiencies.

Segregation always points to a deficiency in the wisdom and the capacity to love on the part of those who segregate. Unfortunately,

when exclusionists are at work, the victims of their ignorance or indifference are made to feel what victims ordinarily feel; an irrational responsibility for their abuse, guilt for having "caused" their abuse, and shame simply for existing at all.

(Lovett, 1996:9)

People with intellectual impairments have been segregated not only from mainstream society, but also from people with other impairments, in special institutions such as psychopaedic hospitals which still exist in New Zealand. Many of the patients in these institutions accept this way of life and do not realise there could, or should, be a different way (Worth, 1988).

Disability as Social Oppression

A new ideology of disability is emerging from disabled people themselves. Oliver writes as a disabled person who views disability as social oppression produced by a capitalist society and requiring political solutions. He draws on both Marxist and feminist theories to inform his arguments. It is Oliver's analysis of disability as social oppression, Morris's (1991) perspective as a disabled woman and the work of other disabled writers such as Boyles (1994), Keith (1994) and Zola (1977) that have led me as a researcher to consider the power relations between oppressors and oppressed. These power relations are identified in the work of Freire and are useful in understanding the relationships and behaviours that occur between service workers and service users.

Violence is initiated by those who oppress, who exploit, who fail to recognise others as people - not by those who are oppressed, exploited and unrecognised.

(Freire, 1972:32)

The subtle violence of those who control, of which professionals are only one group, remains hidden behind paternalistic mechanisms which deliver welfare to people who deviate from the configuration of a good society. According to Freire it is the objectification of the oppressed, the reducing of people to things, which limits them to a relationship of dependency. In this sense the disabled are an object society in relation to able-bodied societies. The parallel is seen between third world and metropolitan societies, between Pakeha and Maori society (Walker, 1985).

Within service systems the worker can also become oppressed and feel powerless to operate in the way they would wish, against the weight of the organisation.

Just as people with disabilities in controlling service structures are hurt, so too, though to a lesser extent, the people hired to work in them are limited and put to hurtful work when what they would rather do is help.

(Lovett, 1996:xvi)

The oppression and hidden violence received by disabled people is illustrated by Sobsey (1994). He portrays the contrast between the rights accorded to criminals and those denied to disabled people. Outrageous responses to disabled people have been regarded by society as examples of caregiving practices. People have been sterilised, denied the right to sexual expression, passively allowed to die, or purposefully killed by individuals who have judged the lives of disabled people to have no potential quality or value. They have been compelled to provide labour with little or no compensation. They have been punished and subjected to unpleasant and dangerous treatments. All of these things have been done in the name of care (Sobsey, 1994:112). None of these practices could have occurred if the caregiver, the oppressor, had regard for the disabled person as a human being, an equal, rather than as a member of a devalued minority.

Many disabled people have an increased vulnerability as a result of the training they receive. Compliance has been the dominant theme of special education and disability services. It is taught explicitly and implicitly through curricula that present a command as a stimulus condition for every objective (Sobsey, 1994:180). Compliance is considered by many to be a functional skill for disabled people, primarily because it is useful for service providers who manage them, not because it is useful for the individuals themselves. This is evident in the following example, where Ann has overturned a chair and bed in the villa. She is made to straighten all the furniture and remake all the beds, whenever she does this. If she does not do this on verbal instruction, she is physically assisted to do so. This is called a domestic guidance programme.

Less obviously it would seem that Ann had been taught the Stoic virtue of compliance. Foxx has said that one prerequisite for overcorrection is that it takes a trainer who is physically more powerful than the trainee. This makes the procedure clearly one whose purpose is to teach uncritical submission.

(Lovett, 1996:86)

Whereas non-disabled people in many western societies are encouraged to attend assertiveness training programmes for themselves, disabled people continue to be forced into compliance. Generalisation is also a goal of training, that is the ability of the individual to repeat the same behaviour in a variety of settings. Generalisation of compliance leaves people more open to abuse. Sobsey (1994) gives the example of children who are taught to comply with adult directions, then become unable to defy a person who is abusive. He also identifies the failure of some disabled people to develop a sense of personal space, due to the excessive physical support needs they require. These support needs are often met by a range of people some of whom are almost strangers. This also increases the danger that disabled people will be chosen as victims of abuse.

From my own experience in services, I know that abuse has occurred frequently to people with intellectual impairments, particularly in large institution settings, but also in residential settings where individuals work in isolation and are not subject to team monitoring. Unfortunately, when incidents of abuse have been reported it is my experience that disabled people are often not believed, or the matter is dealt with "in house" and does not come to the notice of the legal system. I argue that disabled people are oppressed and subjected to violence and abuse and that instead of training disabled people to be compliant in their subservient place in society, our goal should become one of liberation. As Lovett states:

The goal of liberation movements is not rehabilitation but freedom. The work of liberation is not to train and shape the oppressed to be more accepting of or more acceptable to oppressing systems but to impart the vision, means and power to contradict oppression and to disrupt and destroy the dynamics that support it. People with intellectual disabilities are in the early stages of a liberation movement - they are beginning to recognise that their lowly status in society is due not to their disabilities but to an unjust society. Until this awareness gains wider currency, however, most people - of all kinds - will see the status quo of oppression as "right."

(Lovett, 1996:10)

In order for effective change to occur in services for people with intellectual disabilities, service providers need to rethink the purpose of their services. People with intellectual

disabilities can only be liberated if the oppression of the service system is acknowledged and service workers are prepared to give up their control.

The Concept of Intellectual Disability

In this section I will examine the concept of intellectual disability. Morris (1991), Oliver (1992), Zola (1977) and many others have given voice to the disabling experience. However, it is only recently that thought has been given to the particular experiences of people with intellectual impairments. Ballard (1994) is one of the few writers to bring together the voices of people labelled as intellectually disabled in New Zealand. Through his work they say that they experience disability as discrimination, which keeps them out of the mainstream of schools, work and community. They also say that being labelled is offensive and hurts.

They call us names. They tease us. They say 'Hey, you're from IHC. You come from IHC. You live in an IHC house'. And I turn around and go "Yeah! I do. I do live in an IHC house. So what? At least I'm from the community". There's no need for them to say all those things.

(Ballard, 1994:145)

Ballard states that for him particular themes stand out, the oppressive effects of segregation and the liberating experience of inclusion. Ballard, along with other New Zealand writers (Boyles, 1994; Sullivan, 1995; Hunt, 1995), also gives a clear definition of disability as a social creation.

The experience of disability is in large part a product of the institutional practices of society expressed in education, health, employment and other aspects of community life.

(Ballard, 1994:12)

The concept of intellectual disability is part of this creation of disability (Lea, 1988), although a specific collection of categories has been created in order to partition people with intellectual impairments as different from people with other impairments. Patrick Worth, a Canadian activist, who has been labelled in this category, has this to say:

I did, however, have access to a label. That label was “mentally retarded”. This was not very useful in terms of access. In society today, other labels are used to promote the same kind of limitation to access. Examples of these are developmentally handicapped, mentally handicapped, developmentally delayed etc. These are all labels that take away the identity of a human being.

The labels that are commonly applied in New Zealand are intellectual handicap and intellectual disability. An ongoing dominant theme in this area has been intelligence quotient testing. Individuals have been labelled, and are still labelled, intellectually disabled on the basis of intelligence quotient tests.

General intellectual functioning is defined by the intelligence quotient obtained by assessment with one or more of the standardised, individually administered intelligence tests (eg., Wechsler Intelligence Scales for Children - Revised, Stanford-Binet, Kaufman Assessment Battery for Children). Significantly subaverage intellectual functioning is defined as an IQ of about 70 or below (approximately 2 standard deviations below the mean).

(American Psychiatric Association, 1994:39)

Ballard states that both research and commonsense clearly show that these tests do not in fact measure intelligence, nor can they be used to predict a person's future potential. However, having measured and found individuals to be deficient, societal systems have then responded by deciding that these individuals did not need the education and life experiences offered most children. The Stanford-Binet test resulted from a concern by the French Minister of Education as to how to determine which children should be put in special classes (Santrock and Bartlett, 1986:204). IQ testing has been shown to have cultural and socio-economic bias (Santrock and Bartlett, 1986:235), but as an ostensibly objective system of measurement has been used as a political tool to discriminate against minority groups.

Objective external assessment criteria, such as IQ, aptitude and national achievement tests, are tools traditionally used to maintain distance and control over people.

(Lovett, 1996:42)

I argue that if we are to learn more about the particular experiences of people labelled intellectually impaired, we must move beyond processes of categorisation which do nothing to illuminate peoples lives. The experience of intellectual disability isn't just about what's going on in your brain, it's about what happens to you during the rest of your life as a result of someone 'measuring' your intellectual functioning and defining you as impaired. These are the stories that need to be heard. It is my contention that there are similarities and differences between the experiences of people with intellectual impairments and people with other impairments. One of the key differences is the specialised services they receive.

The Principle of Normalisation

Before exploring the practices within disability services it is important to examine the principle of normalisation as defined by Wolfensberger (1972). This concept has had a significant influence on services for people with intellectual impairments. Much of the writing produced in this field has been based on Wolfensberger's principle. The King's Fund Centre (1980) published a document entitled "An Ordinary Life" which was used extensively in designing services based on normalisation. Many other writers have developed approaches to service delivery from the same principle (Emerson and McGill, 1989; Knoll and Ford, 1987; O'Brien, 1981, 1989; Taylor, Biklen and Knoll, 1987;). Wolfensberger's principle is influenced by Goffman's work on stigma and deviance (Goffman 1963). People have been defined as deviant if they are seen as significantly different from others in a way that is considered negative. The negative observable differences become the stigma. In order to remove the stigma of deviance, services are instructed to apply the principle of normalisation.

The normalisation principle is based on a supposition that there is a culturally normative lifestyle into which we all aspire to fit, that there are behaviours, appearances and experiences that are characteristic of normality. It has been argued by people like Brown and Smith et al (1992), that this is to deny the true diversity that exists within any community and instead prescribe what is seen as valuable from the perspective of the dominant cultural group. It is in effect a principle of assimilation (Brown and Smith, 1989). The objective is to enhance the behaviour, appearance and experience and therefore the status of the devalued person. Chappell (1992) suggests that this denies the value that their difference may be granted and the realities of their situation. For example,

it is not enough to teach work skills to an individual, if we do not address their exclusion from the workforce.

The majority of researchers in the area of intellectual impairment will be familiar with this principle which has dominated service provision for the last two decades. The normalisation principle can be placed within the context of the social construction of disability (Chappell 1992). This brings together the hegemony that has dominated service provision and the emerging materialist analysis of disability, which originates from the experiences and perspectives of people with disabilities (Morris, 1991; Oliver, 1990). A comprehensive theory of disability must include both ideological forces and material constraints.

I argue that normalisation is inadequate as a theory of disability, as it fails to recognise the material constraints in people's lives (Chappell, 1992). It is a professionally dominated functionalist theory, in that it provides a direction for service workers to structure goals for individuals and define a process for the person with a disability to reach those goals. An example of this from my own experience is the sessions I devised to teach money handling skills to individuals, who in reality did not have access to their own money, and had very little money which was not already managed by the system. It also uses interactionist approaches; that is the service worker has a technology to be applied, for example task analysis. Again from my own experience, having learnt how to analyse tasks, this then became the way to teach all tasks to all individuals, regardless of the importance, or the appropriateness of the task, or the method to any one individual's life. As a consequence, people with disabilities end up learning and performing tasks in which they have very little interest and which do nothing to fulfill their hopes and dreams. Normalisation in fact offers service professionals a mandate for improving service provision, with an assumption that this will naturally equate with the service user's requirements. The presumption is that services are about changing disabled people so that they are more like "us" and that disabled people need services that will organise and improve their lives. It is a functionalist theory with no analysis of the power relationship between provider and user. The possibility of conflict of interest is not addressed and the question of who controls the lives of people with disabilities is never asked. The service provider is deemed as naturally in charge of the process as they are representative of normality, they direct the process and define the standards to be achieved.

It can be argued that the normalisation principle is idealist, in that it focuses on changing attitudes and ideas in order to eliminate discrimination (Chappell, 1992; Brown and Smith, 1992). It fails to evaluate the inadequacies of a social system which systematically discriminates against anyone who is considered not fast enough, smart enough, skilled enough or competent enough. Normalisation provides a mechanism for assimilation without questioning the arbitrariness of the boundaries that have been drawn the processes that were used to set them and who holds authority over those processes (Brown and Smith, 1992). I argue that it is a mechanism by which we assist people to fit into the existing social system and in doing so ignore the daily realities of poverty and marginalisation, which continue to be part of the individual's existence.

The dominance of the normalisation principle within the British system has been raised and the debates about its implications for services exposed by Brown and Smith et al (1992). It has been argued that there are similarities and differences between the oppression and discrimination faced by women and by people with disabilities.

The group that women needed to confront first were their protector oppressors - men. The group that people with disabilities have had to confront first are their helpers - the professional community and those who fund services.

(Lovett, 1996:11)

The earlier Scandinavian definitions of normalisation were based on individual human and civil rights (Emerson, 1992). From this perspective there is an expectation that we assist people with disabilities to operate fully as citizens, on the basis that they are entitled to the same rights as non-disabled people. In contrast, Wolfensberger's approach has been to specify standards for conformity. Wolfensberger identifies the values of society as he perceives them and these then become the standards to which we should assist people to conform, in order that they will become valued by society (Bleasdale, 1996). The competing definitions of normalisation led to the term social role valorisation adopted by Wolfensberger in 1983 (Szivos, 1992:126). Although it appears the intention of this term is to establish a positive concept of disability, nowhere in his work is disability described as something to be valued in its own right. The aim is still to bring people into line with existing valued social norms. There is a need to move beyond normalisation, to a climate in which account can be taken of people's needs and desires for affiliation (Szivos, 1992:112).

The ultimate misuse of the normalisation process is described by Sobsey (1991), when he relays how we have moved from grouping people in large institutions, to finding it unacceptable to see even two disabled people together. This is reminiscent of one of the fundamentals of the theory of oppression. In order to maintain power the oppressed must remain divided (Freire, 1972). This process denies the individual the opportunity to share common experiences, and reinforces the feeling of isolation.

I have identified the inadequacies of the normalisation principle and agree with the issues raised by Chappell, Brown and Smith, Emerson and Szivos, but at the same time I acknowledge that it has been a significant tool in enabling the process of deinstitutionalisation. Services have grown and improved in quality from the service providers' perspective, but people with intellectual impairments are still primarily recipients of services, not participants in the mainstream of society. Normalisation is still the key principle from which many intellectual disability services operate. Service providers need to relinquish their ownership of disability. There is a necessity for further exploration of the theory of interdependence and the way in which new service models could emerge driven by disabled people in partnership with non-disabled.

The Emergence of People First

*We don't want to be recognised by a label. We want to be recognised
as people --- first!*

(Worth, 1996:12)

Although normalisation has been a dominant influence over people's lives for some time, people with intellectual disabilities are now starting to assert their own identity and it is important to recognise this issue as it signals a way forward for change. The late 1980s and 1990s have seen the growth of a new movement driven by people with intellectual impairments which is growing internationally (Worth, 1996). People First in Canada has fought for and brought about significant changes in services. An example of this is the campaign they mounted to change the name of the Canadian Association for the Mentally Retarded. As a result of their action it has now become the Association for Community Living. In New Zealand the People First movement is currently under the umbrella of a major service provider and attempts by people with intellectual impairments to establish an independent group with the support of non-disabled allies have on the whole been

unsuccessful (Gosling and Gerzon, 1994). However, those groups that have functioned independently, have grown in understanding and skills (Ballard, 1994).

I argue that in order to establish an independent organisation of people with intellectual impairments, there is a need not only for non-disabled allies to support this initiative, but also a willingness on the behalf of the service providers to give up control over people's lives (Gosling and Gerzon, 1994:2). An independent organisation could then become a vehicle through which people's voices are heard.

Section Two

THE RELATIONSHIP BETWEEN SOCIAL POLICY AND SERVICE PROVISION

For the people who participated in this research project someone, at some stage in their lives, decided that they had an intellectual impairment. As a result of that decision the paths that their lives took became different. They became the recipients of special services, services created to cope with people who are intellectually different. They have, therefore, spent time in special schools, special institutions, special homes and special training centres.

The services they received in many instances were as a result of social policy initiatives. Social policy dictates how our social systems will respond to people who are perceived as vulnerable, unable to live without additional support and resources. The particular policies that have had an impact are deinstitutionalisation and community care (Sullivan, 1995; Tennant, 1996). These policies, which have shaped service development, need to be understood within the broader context of government reforms.

The Impact of Social Policy

Within social welfare policy, disabled people have become firmly classified as welfare recipients. An example of this in New Zealand was the passing of the Disabled Persons Community Welfare Act, 1975. The principle enshrined in this Act was community care (Tennant, 1996:24). This was viewed by some in the disability community as a positive recognition of the need for community care. However, the outcome for many disabled people was their objectification within a system that is ostensibly created to meet their needs, but in reality has always fallen short, as Kelsey and O'Brien identify:

The welfare state was never the universal panacea that many claimed. Not everyone was well provided for. The experiences of Maori, of women and of many of those with disabilities provide a powerful testament to the inadequacies of the welfare state.

(Kelsey and O'Brien, 1995:2)

The focus on the maintenance of the deficient individual underlying legislation, emphasises the separation from the non-disabled (Oliver, 1992). As Ballard (1994) suggests, the most significant difficulties arise from the medical model of disability, whereby disabled people are viewed in terms of problems, or deficits. The deficiency is frequently seen in terms of the ability of the individual to contribute economically (Wills, 1994:252).

With the election of the Fourth Labour Government in 1984 we saw a sharp change in direction in economic and fiscal policy towards economic liberalism, involving the withdrawal of the state from a wide range of activities (Tennant, 1996:26). This withdrawal is summarised by Kelsey:

Rolling back the state is a fundamental tenet of any structural adjustment programme. In New Zealand the desire to corporatise and privatise central and local government operations spread from overtly commercial enterprises and assets to include previously non-commercial activities of health, housing and government research, and ultimately embraced the policy, regulations and service delivery roles of the state.

(Kelsey, 1995:115)

Along with a reduction in state spending, the relationship with the voluntary and private sector changed as competitive free market dogmas were adopted. Kelsey (1995:294) describes how many well resourced voluntary agencies became accountable to and dependent on centralised funding providers. She also suggests that the Business Roundtable's agenda was to shift government's social responsibilities onto the private charity industry. Social security benefits such as unemployment and domestic purposes were cut in 1991 for the first time in New Zealand history (Kelsey and O'Brien, 1995), on the basis of encouraging people to take greater responsibility for their own needs.

However, invalid benefits were increased, as disabled people fell within the group considered incapable of self-help and, therefore, needing direct assistance (Shannon, 1991). The result of this policy was to emphasise the segregation of disabled people from the workforce and from other welfare beneficiaries and to maintain their dependence as recipients of charity. Disabled people have clearly expressed their opinion of this charity ethos.

We do not want charity or special favours and privileges, only the same basic rights and freedoms as others. We wish to be treated as equal human beings, to be able to participate in the common life to the extent of our capabilities without having to face unnecessary barriers to our involvement. We have the same needs and desires as anyone else, to be self-sufficient, self determining, and to have a measure of dignity and self-respect, to be contributing and responsible members of society - to enjoy the same freedoms, rights, responsibilities as anyone else. (Advisory Council for the Community Welfare of Disabled Persons.1866.)

(R.C.S.P. 1988 vol.III:496)

Disabled people segregated today in New Zealand have inherited and had repeatedly indicated to them that their place is at the bottom of the pile. Their differentness is of such social significance and so starkly negatively valued, that they have in effect become "non-people" (Blaszczk, 1988).

Two of the key social policies that have been evident, which are relevant to people with disabilities over the last two decades, are deinstitutionalisation and community care (Tennant, 1996). Deinstitutionalisation first emerged in the 1970s, but in most areas of social policy community care was a product of the 1980s at a time when the welfare state was contracting and devolving responsibilities. By the 1990s there was valid criticism of the implementation of both normalisation and community care in terms of inadequate funding, lack of resources within the community, and high unemployment making integration into the workforce difficult (Tennant, 1996:28).

A greater emphasis is now being placed back on the family and the individual to provide self-help under the policy of economic liberalism. The New Right vision is one of the

disabled person "shopping" for their service provision. This model aims to improve consumer choice and increase consumer power. However, there has been no major structural or process changes within services, to enable people to exercise this choice (State Services Commission, 1990). This change of status the individual now has in relation to services is described by Kelsey and O'Brien:

The citizen has become a customer, buying from a public or private provider a range of services which were once their right under a social contract with the state.

(Kelsey and O'Brien, 1995:52)

The policies of deinstitutionalisation and community care have the appearance of liberation, but are in effect a repositioning, under a different terminology. The nurses and patients, become service providers and clients, but the power relationship does not change. The disabled person is still disempowered. As Georgeson, a disabled woman writer, states:

The reality for disabled people and their families cannot be adequately reflected in the way services are provided until they are incorporated in management and policy development levels.

(Georgeson, 1994:71)

I argue that the New Right assumption that individuals are able to meet their needs by purchasing commodities in the market place, presumes that the commodities contain the necessary essential qualities. How can qualities which cannot be quantified such as dignity, privacy and respect be purchased as commodities? Kerr (1994) describes the new system as one that is captured by professionals and is based on assumptions about both the homogenous nature of community's values and priorities and the improved options that the environment of choice will provide. Funding to purchase is provided on the basis of defined individual need. Individuals are assessed by professionals who will determine this need. The *Central Regional Health Authority Draft Strategic Plan (1996-1997)* for people with intellectual disabilities describes needs assessment as:

the process of determining the current abilities, resources, goals and needs of a person with a disability and prioritising which of those needs are most important

(CRHA,1996:3)

It can be argued that it is the professional not the individual who determines the needs and as funding is limited so that not all needs can be met, it is highly possible that something that is seen as high priority by the individual will not in reality be funded, or may not exist in a product that can be purchased. The above strategic plan also talks about 'maximising independence' (p5) and 'achieve an appropriate level of independence' (p7). The use of the term independence, presupposes the dichotomy of dependence and independence and does not move us towards accepting the reality of all human relationships, that of interdependence as argued by Oliver (1990) and Georgeson (1994). If an individual was truly independent, the concept of support could not be part of the equation.

In 1983 the Disabled Persons Assembly was formed (Tennant, 1996) and has fought for the removal of discrimination of disabled people. It is significant that despite consistent lobbying by the disability movement in New Zealand, it was not until 1993 that the Human Rights Commission Act 1976 was replaced by the Human Rights Act 1993 to include disability as a ground on which it is illegal to discriminate. This demonstrates the difficulty in putting disability on the social policy agenda as a human rights issue.

It is only in very recent documents such as *CRHA Guidelines on Personal Safety and People with Intellectual Disability (1995)*, that we find reference to concepts such as powerlessness and poverty. "Many people with intellectual disability experience poverty and therefore have few choices about which services they use" (1995:5).

I argue that in order to improve the quality of daily lived experience in disability services for people with intellectual impairments, we need to develop social policies based on these current realities. Disability should be accepted as a human rights issue. Deinstitutionalisation needs to continue and the concept of community care needs to be expanded to one of community living (Lovett, 1996; Smull and Harrison, 1992; Van Dam and Cameron-McGill, 1995).

The Impact of Service Provision

Individuals who are moving from institutions to community settings are the most vulnerable. They desperately want to leave. They will agree to anything to escape.

(Smull and Harrison, 1992:53)

In this section I will describe the nature of the services that have been provided and are currently provided to people with intellectual disabilities and the impact services have on people's lives. I will begin by examining institutionalisation. One of the key problems of institutionalisation was the separating of citizens from their communities. Institutional practices compounded the process of depersonalisation by ignoring individual differences and preferences. All the residents are seen to be the same idealised resident (Lovett, 1996). This loss of individual difference has impacted on the process of leaving the institution. Unfortunately, the process has become one of 'deinstitutionalisation' the getting out of the institution, with the community becoming the goal, rather than a positive framework of building community support systems. The result has often been the development of little institutions, group homes within community settings, and day programmes which often resemble the occupational therapy programmes of institutions.

These are the services in which the participants in this research project have spent their lives. Entry into a service in New Zealand depends on the label you are given. The primary label attached to each individual in this research is 'intellectual disability'. They can therefore receive services from those providers who are funded for this category of disability. I have been involved in these services over the last two decades and I have my own experiences as a service worker to recall and explore. I have tried in this project to listen to the inside story, to the experiences of those who live in services. I argue that in order to bring about change with the people who are the recipients, we as professionals must incorporate their view with our own. Horner (1994) is a New Zealand writer who has described the process of deinstitutionalisation in terms of the changes in the quality of people's lives and Ballard (1994) has provided a forum for the voices of service users. However, so far many of the descriptions of services have been written from the viewpoints of the providers. McKnight (1977) described the myth of the benevolent service provider acting out of love for their fellow human beings. Gerber (1990) describes the professionals as follows:

Generally, these experts have been well meaning people, who have often urged compassion and responsibility on societies guilty of cruelty and indifference. But their conceptions of disability give rise to the development of social policy that imposed, in the name of benign paternalism, bureaucratic manipulation and socio-economic dependence, and ultimately dead-end lives, on people with disabilities.

(Gerber, 1990:4)

This apolitical mask is one which disguises the realities of service provision; professionals are not benevolent benefactors but they are earning an income and the services they work within are an economic system that requires growth to survive. If we are to move forward, we must acknowledge these realities. It is my experience that many services for people with intellectual impairments are still operating on a charity model (Perkins, 1994). The service system is indeed growing (Wolfensberger, 1989) based on its capacity to manufacture needs. As more categories of need are devised and defined so new services develop in response. Georgeson (1994) suggests that caregiving and support services have developed that do not always meet disabled people's needs, and in fact they can be in conflict with their needs. This very process of manufacturing need can become a disabling process; as services capture people, and the needs of the service provider and user become inextricably linked, neither can exist without the other. Service providers are now contracted to provide a service and they must compete with other providers for these contracts. It is not surprising, therefore, that service providers are reluctant to allow a person to choose to use another service, as it may mean their job is on the line. As Smull and Harrison (1992:1) state: "most human services develop programmes and put people into them". The reality for many people with intellectual impairments is that they cannot simply exit a service which is not meeting their needs (O'Brien 1996), they require support to do this. Many people are in fact prevented from leaving a service such as a large institution, which is certainly not meeting their needs, by legislation and policy decisions. If people with intellectual impairments do have the same rights as other citizens, then why can not they simply get up and walk out?

In order to understand why they can not, it is important to consider the power relations which operate within the services. The principle of normalisation still underpins most service provision and has given specific impetus to service providers to structure settings which duplicate the rhythms of a culturally normative lifestyle (Wolfensberger, 1972). Individuals are timetabled to go out to vocational settings, to take part in recreation, to follow different procedures on weekend and weekdays, to take holidays and develop relationships with non-disabled peers. This programming of the individual denies the humanity of the person. There is little opportunity to exercise real choice. The impact on the person is that they are forced into situations and with people they do not want to be with and their unhappiness is reflected in their behaviour (Van Dam and Cameron-McGill, 1995). This programming through planning meetings and goal setting is monitored and recorded. It can be argued that people's lives become case histories, files to follow them through the services, recording their likes, dislikes, successes and

failures as described by the service provider, not in their own words. Bach describes this same process as occurring in Britain:

In some quality of life research in the field, the point has been made that capacities, needs and behaviours of persons and their past and future hopes, can be seen in very different ways depending on who is producing the "story" about the person: professional care-givers; government social workers; family members; or the person him or herself.

(Bach,
1994:143)

Edgerton (1967:214) argued that normalisation programmes should be used with institutionalised disabled people to increase their self-confidence to - "help them act as if they were normal after release". From my experience this has been the process adopted in New Zealand. The change from institutional to community based services has in fact done little to change the dynamics of control, as is evident in the following example:

When I was at one home talking to someone who lives there, a staff person just came barging in. At some of the houses the staff don't knock on the door. They just go in. They don't respect people's privacy.

(Ballard, 1994:151)

Oliver (1989) and Morris (1991) describe situations in Britain where services still operate on a basis of "doing for" rather than "planning with" people. As Georgeson points out, as a woman with a disability, she is often presented with a restricted range of options from which to choose (Munford, Georgeson and Gordon, 1994). "Her 'difference' was used to narrow the options of lifestyle choices she could choose to adopt" (1994:268).

Wolfensberger (1989), in his description of human service policies, writes how organisations are influenced by their past. The ways of thinking and doing initiated by the founders continue often at an unconscious level. Past contingencies that are no longer relevant influence current functioning. This was evident for me in an institution for people with intellectual disabilities in which I worked in 1972 in England. It had been a former workhouse and there were still bars on the windows. Many of the work practices still had a custodial perspective. The manifest and latent functions within a service can be

totally opposed. Georgeson (1994) has described how this happens in home support services in New Zealand. Wolfensberger (1989) gives an example of this within a service for the elderly. The manifest function was to keep the people healthy and independent, yet the layout of the building was confusing. All the clocks showed different times, the calendars displayed different dates, the doors were exceedingly heavy and the decorations were childish (p28). It is not surprising that the people were disorientated and confused and felt less healthy and independent than when they entered the service. Another example of a service system's failure to meet an individual's need is given by Rioux (1988). Barry was a 40-year-old man who lived in an institution. Over the years he developed behaviours which became labelled as self abusive. These included vomiting and prolapsing and tearing at his bowel. The service response was to place him in restraint and time out. When the institution closed Barry was transferred to a community service organisation. As part of his transfer he was seen by a GP for a physical examination. It was discovered he had a severe ulcer which was then treated. His behaviour "problems" disappeared. The assumption that his problem was behavioural because of his disability label, had serious physical consequences for this man.

I return again to Zola's assertion (1977) that if we keep focusing on the problem as being located in the individual, we will be blinded to the truth. An example of this is the development of new specialist services based on the classification of the individual's behaviour. It is interesting to note that the visit to New Zealand by McGee in 1985 introducing his non-aversive approaches to challenging behaviour, was followed by the setting up of specialised behavioural services, teams of itinerant behavioural specialists, a proliferation of new training programmes and an increase in the incidences of challenging behaviour. I write as a professional who was involved in the training and delivery of those behavioural services. Prior to McGee's visit, the term challenging behaviour was not used within services, now it is a core element in the national training for support workers in the field of disability. In a research project by Bennie (1995), a total of 950 people living in the Midland and Central RHA¹ region were identified as having an intellectual disability and challenging behaviour.

¹The Midland and Central Regional Health Authorities cover a geographical area from Waikato in the North Island to Nelson / Marlborough in the South Island.

Logan (1988) an administrator of services in Canada, puts forward his view of challenging behaviour. First, he suggests that we should be changing our service structures to suit individuals, rather than fitting people into our systems and second, that we should re-examine for ourselves and society our definition of equality. We should remember Rioux's (1988) definition that challenging behaviour must be seen in relation to the controlling environment. As Bennie (1995:8) states: it is becoming apparent in New Zealand that there are aspects of community living and services that lead to the onset of challenging behaviour. Likewise Barnes (1990) gives examples of control within day programmes in England. He writes of how lip service was paid to the inclusion of users in any planning, although communication was essentially one-way and the primary loyalty was to the employer not the service user. The activities organised within these programmes were not compulsory, but no alternatives were offered and on Fridays there was a deliberate policy of limiting user numbers so that routine paper work could be completed.

The above practices are examples of how service systems primarily train people to be compliant clients (Lovett, 1996), or to use Foucault's (1977) terminology "docile bodies". Those who resist compliance are labelled challenging. Compliant clients are trapped, they can not leave unless someone supports them to do so. This leads me to examine further the dynamics inherent in the giving and receiving of support within services.

THE RELATIONSHIPS WITHIN THE CAREGIVING PROCESS

The dynamics between the person with a disability and their direct support workers are key to the experience of their daily quality of life. Having examined the ideologies and policies that underpin service delivery and the resulting service practices, in this section I will examine the relationships between disabled people who receive services and their direct support people and the impact they have on the quality of life experienced. The caregiving process has been viewed traditionally from the perspective of the caregiver. In order to expose the power relations pervasive in the construction of the process of caregiving, we must first gain an understanding of the daily lived experiences of the participants. This means both those who give assistance and those who require assistance. Although some feminist researchers have focused on the role of women as caregivers, we have still to hear from the disabled people who require assistance. Munford (1992), a

feminist researcher, states: there is a need to re-think feminist frameworks to include the complexities of the lives of disabled people.

As Munford (1992, 1995) and Kerr (1996) have identified, Foucault (1978) offers a means of unmasking the multiple subject positions of individuals with disabilities. Non-disabled writers have tended towards binary divisions which have categorised 'the disabled' as an amorphous group. The caregiving relationship may be oppressive to one or both parties. Often the way in which we organise the work within services, serves to protect the worker from the pain of individual lives (Brown and Smith, 1992). In the nursing profession staff are protected from the anxieties of individual relationships by a focus on tasks. Within a small residential home, where caregivers are working in isolation, this structuring of work is not possible. Brown and Smith (1992) describe four powerful needs which lead carers to create defensive practices. First, the need to avoid painful feelings, second, the need to diffuse responsibility for difficult decisions, third, the need to shield themselves from the intensity of demands on their time and energy and lastly, the need to evoke a familiar framework which glosses over the lack of reciprocity in the caring relationship. As Brown and Smith (1992) identified, there is a need for carers to let go of these defensive practices and to develop practices where they interact with the whole person, at the same time avoiding over-identification. The disabled person's needs must remain paramount, but a balance must be achieved (Georgeson, 1994).

In my experience as a non-disabled professional, the processes of identifying need and delivering care have often been intrusive. The assessment processes used can be seen as an example of Foucault's technologies of power (1977), being operated by professionals to maintain the subjugation of disabled people. This theme is identified by Munford:

Foucault's (1977) articulation of 'the technologies of power' provides a framework for understanding how the 'bodies' of people with disabilities have been observed, examined, assessed, classified and ranked, in order to determine their position in society.

(Munford, 1995:35)

Likewise Kerr (1994:82) uses Foucault's analysis of power to describe how individuals are made subjects, subject to someone else by control and dependence.

The disabled person's status within the caregiving relationship is often one of passivity. Munford (1992:18) describes this as 'waiting' to have their needs met, both on a personal and physical level and on a socio-economic and political level. As noted earlier in the section on social policy, disabled people had a lengthy wait before their inclusion in the Human Rights Act 1993. The experience of waiting is also identified by Keith (1994), a disabled writer living in Britain: "We were always waiting. Frustrated" (35). The disabled person's status is also defined by the terminology used, it is, therefore, important to examine this.

Language plays a role in reinforcing the social construction of disability. Stockholder (1994) states that we must always consider the belief system behind the word. As Munford (1992) states, the words used within the caregiving process imply a 'giving' from the 'carer' to the 'other'. If the other then becomes synonymous with 'recipient' and 'burden', then the policies of community care can be perceived and portrayed as repositioning the 'burden'. Language and labels are discussed further on by the research participants and contribute to the dynamics that occur between those giving and those receiving support within services.

I argue that the world of disability services is often a hidden world, known only to those who live and work within it. The concept of "private and public worlds" was identified by Munford (1992:19). In my own experience of services, it seems apparent that professionals use technologies of power to maintain control and domination of the private world of service organisations. In allowing disabled people to define their own lives and services, professionals must relinquish their control. Professionals are resistant to this change in power relations as they fear they will no longer have a role to play. The goal for disabled people should be re-examined and the necessity for interdependence between all individuals acknowledged (Munford, 1992:20). In this way all participants in the caregiving process can enter the public world together. Transformation of the caregiving process requires change at an individual, political, theoretical and research level.

A key requirement of interdependence is partnership. Smull and Harrison (1992) describe the need for partnership not just between the disabled person and their support person, but also between service providers, families, funding and regulatory bodies. In the current competitive climate this is certainly a challenge. As Smull and Harrison state; "we do not have to like each other as partners, but we do need to respect each other" (1992:38).

Feminist principles can be used to explore and redefine the caregiving process, however, the feminist framework needs to change to be cognisant of the experiences of people who require assistance on an ongoing basis. Morris (1991), a disabled woman writer, sees it as important to make the personal political, a lesson that is derived from feminism. Georgeson (1994) supports Morris's view that feminism has tended to ignore the issues and needs relating to disability. However, in recent years feminist writers have begun to address these issues. Brown and Smith (1992) suggest that feminist theory can provide a clear analysis of power and powerlessness to deepen our understanding of the position of disabled people. I will further explore these points in chapter two.

In this chapter I have explored the prevailing ideologies of disability. I have discussed the subsequent development of social policies based on the notion of charity, creating dependence rather than giving support, so that the lives of disabled people become dominated by welfare systems and service providers. I have described the services influenced by the hegemony of normalisation and considered the power relations that operate within these services and the focus on compliance. I have given thought to the different facets which exist within the caregiving process and the need for the development of the concept of interdependence. In order to make sense of the viewpoints expressed by the research participants, I argue we must have a clear understanding of not only the dynamics of the services they are describing, but also of the ideologies and policies which have led to their construction. It is my belief that people can become trapped within the service system and their voices may be rarely heard. They are buried under a mountain of oppression. In the next chapter I will describe my methodological approach to establish a forum in which the participants' experiences and viewpoints could emerge.

Chapter Two

Methodology - A View from Below

When people are labelled retarded, their motives, wishes and needs are not taken seriously, which can heap frustration onto a lifetime of frustration. In the midst of wealth (we spend billions of dollars on services), they often live in poverty. Surrounded by people (staff, therapists and administrators), they are often lonely. Forced to live in close quarters, they are usually expected not only to remain chaste but in some programmes, not even to touch one another except to shake hands. I have heard too many people labelled retarded told without irony: Adults don't hug. Instead of attending to the basic needs we all take quite seriously in our own lives, we focus on people's behaviour as the primary object of our concern. This shift has robbed people's lives of life. Instead of stories, we focus on incident reports. Instead of a person's history and personality, we give data.

(Lovett, 1996:52)

Everyone enters the research process with a set of beliefs and assumptions based on the knowledge they have at that point in time. In the previous chapter I have described the theoretical influences which informed my thinking about disability. In this chapter I will explain how I responded to issues raised in my review of the literature which are: first, the need to make research more relevant to the lives of disabled people and to create a history which includes their experiences; second, the need to conduct research which listens to the voices of disabled people and presents a view from below and finally, the need to adopt a research paradigm which approaches disability as a social construction. Ballard (1994) endorses the use of stories as research. He sees stories as providing a critical analysis of current issues undertaken by people who have experience of disability in New Zealand. How then to proceed in a way that addresses these issues?

In developing the research process I began with Oliver's (1992) argument, that we must change the social relations of research production if we are to influence policy, so that it improves the lives of disabled people. Oliver uses the Marxist term of 'alienation' to describe the way in which social research has taken from the individual research subject

in order to meet the needs of the researcher. Parallels can be drawn between the experiences of other groups, such as women and Maori in the research process. An example of this is the amount of research done on Maori people in relation to a myriad of social problems, including unemployment, criminal activity, glue ear, mental illness, teenage pregnancy, glue sniffing and truancy. This focus on deficits and problems, as with disabled people, presents a negative image and does nothing to present the real needs of Maori as seen from their perspective. Stokes (1985) identifies an increasing awareness in the Maori world that Maori have been used as guinea pigs for academic research, but that Maori have not gained a great deal by this process.

It is important to consider the history of research in the disability field. Positivist approaches to disability research, based on a premise that scientific knowledge must be definable, measurable and testable, have tended to focus on disability as a problem located within the individual, a deficiency that can be scientifically examined. It has been assumed that research is value-neutral and that appropriate policy about disability will be the outcome of objective, factual research findings. The outcomes from this approach are more likely to focus on the impairment rather than changing the social environment. In contrast, interpretive approaches have tended to view disability as a social problem and sought to enlighten policy makers by providing an account of the experience of disability. However, in both paradigms, positivist and interpretive, disabled people are usually subjects of, not participants in the research process. Their views have not been heard. In order to make research more relevant to the lives of disabled people, Oliver (1992) and Boyles (1995) promote a paradigm of emancipatory research. Within this paradigm disability is viewed as a political problem, which requires policy solutions that will confront oppression on all levels.

Feminist research has made a contribution by identifying three key fundamentals within an emancipatory approach, which are useful to consider in disability research; these are reciprocity, gain and empowerment. Oliver questions however, the ability of the researcher to achieve reciprocity within the existing social relations of research production. Researchers are still in a position of power and can decide what they will or will not give. He argues that research subjects cannot be empowered by their researchers they can only empower themselves. However, I believe you can create a climate where the research participant can also decide what they will give or not give. An example of this is by actively seeking their participation in defining the topics they wish to cover in their interviews.

Researchers have to put their skills at the disposal of the research subjects in Oliver's emancipatory model, and it was with this intention that I entered this research project. Emancipatory research is a process of dialogue between myself, the research worker and disabled people, in order to discover and realise the needs of the people. It is a process of gain for the participants. The research agenda is disabilism. In this project disabilism is defined as the process by which services disable people with intellectual impairments. In recognising this we can work together to change a disablist society. It is important in emancipatory research that individuals are viewed in concrete social reality and the right of each individual to dignity, autonomy, valued activities, private space and developing potentialities is acknowledged.

If we look at the research carried out in the area of intellectual disability we find that the history of people with intellectual impairments is full of the names and faces of the researchers, but not the names and faces of the people whose history is described (Sobsey, 1994). As Ballard (1990) identifies, although ecological research, as defined by Bronfenbrenner (1979), may take longer and could be more expensive, it is necessary if we are to listen to the voices of the participants in the research process and identify the researcher as a part of the ecology of disability. The ecology in this sense is comprised from all the components that contribute to the discourse of disability, including the disabling experience of the individual. Even when research has set out to listen to people with intellectual impairments, the validity of their voices has been discounted on the grounds of their inability to learn and to reason (Gerber, 1990).

Research has acknowledged the need to recognise the intersection of gender, class and race in understanding the structures of power and dominance, but has yet to incorporate an understanding of ability, or perceived ability as Jones (1992:347) points out in her research exploring the stories of adults with learning difficulties who have been deinstitutionalised. The concept of disabilism is only recently emerging within feminist literature and needs to be explored along with other sites of difference such as race, class and age (Munford, 1992, 1995). There are however, a number of common principles underpinning a feminist perspective, which I argue provide a sound basis for research in the area of disability and which I will explore further in this section.

Boyles (1994) challenges non-disabled researchers in the field of disability to identify ways to provide opportunities for disabled people to participate in all levels of decision

making and the development of research criteria. I have developed the following principles for my research. These are based on feminist principles.

1 Disability research should be premised on the oppression of disabled people and be committed to changing it

It is this emancipatory principle, the commitment to change in disabled people's oppression, which pushed me as a researcher not only to find ways of documenting the experience of oppression, but to develop a research process that could lead to action and empowerment. "The libraries are full of research data which have never seen the light of action" (Smith and Noble-Spruell, 1986). The concept of oppression of disabled people has been clearly identified by Oliver (1990) and Sobsey (1991, 1994). As a non-disabled researcher I need to ensure I am part of a process of empowerment. This, therefore, became a consideration in the way in which I established the research dialogue.

2 Disability research should be based on a theory of anti-disabilism

Theories of disabilism (Morris, 1991; Oliver, 1992) are still emerging. Until disabilism is acknowledged it is difficult for people to develop a counter perspective of anti-disabilism. A parallel is the development of anti-racism, which could only be understood once racism was acknowledged. The views of people with intellectual impairments have begun to emerge (Ballard, 1994) and there is a need for more research in this area. Disability theory must be continuously reflexive, accessible to everyone and open to revision, based on the new analyses of enquiries. It should, therefore, provide an appropriate basis from which to develop alternative ways for understanding the world that include the experiences of people with intellectual impairments. Disability research based on anti-disabilism focuses on changing disabilist social systems as opposed to deficient individuals.

3 Disability research should be based on a principle of improving daily lives

The challenge for my research is that it should be for disabled people, to improve the quality of their daily lives. In order to do this we must understand the experience of the participants in this research project; the outcomes of any

research may have relevance only for some people. It was, therefore, important to be involved in discussions with the group for whom my study is focused in order to identify research questions which are relevant to their lives. As Munford (1994) suggests, the role of the researcher is to illuminate the complexity, the richness and diversity of people's lives, rather than categorising the experiences of people with intellectual impairments. This principle incorporates a moral aim of improving lives within the act of research (Oakley, 1987), in contrast to the positivist assertion that empirical knowledge and moral aims must remain separate (Bryson, 1979).

4 Disability research should emphasise a non-exploitative relationship between researcher and researched, based on collaboration, co-operation and mutual respect

The implication of this principle is that the researcher can not be an objective observer, distanced from and measuring the researched, but should be an enquiring partner. Therefore, it was important that I understood the concept of reciprocity, and applied it in the research process. As identified earlier, Oliver (1992) questions the ability of the researcher to achieve reciprocity, within the existing social relations of research production but Oakley (1987:49) is clear about the need for a different role for the researcher, which she describes as 'no intimacy without reciprocity'. As Boyles (1994) states, in the disability context particularly, the concept of partnership is crucial in that reciprocity involves sharing skills and energy and varying abilities. I was careful to make full use of the data from the group participants so that their voices were truly included. I was aware that the information was all there in their stories; it was my job to find and illuminate the themes, rather than to select what fitted with a personal agenda of my own. At all times, the power dynamics between researcher and researched must be carefully examined (McRobbie, 1978).

5 Disability research must recognise the open presence of the researcher as intrinsic to the process

This principle clearly rejects the notion of value-neutral enquiry. It requires instead that as a researcher I make explicit my own value base and the influences I bring to bear on the interactive process of research. As a researcher I must

therefore be aware of any class, status, cultural and value differences or similarities that may inhibit or enhance the research process. It is important to state clearly that my status in the field of disability is that of a non-disabled professional. As Lather (1986) suggests, the researcher's role is that of a privileged expert who must act as a catalyst working with the participants to understand and solve problems. In an emancipatory model there is a need for researchers to put their skills at the disposal of the research subjects (Oliver, 1992). In this process I bring not only my research skills but also my knowledge and experience of services in which people with intellectual impairments live and work.

6 Disability research should question the ownership of the research outcome

Traditionally, it has been accepted that research outcomes are the property of the researcher and/or the body which authorised the research. To be truly emancipatory it can be argued that the research outcome should be owned by the research participants (Boyles, 1995). However, the scope of this research project is defined to some extent by the fact that it is part of a university programme of study. In order to meet its emancipatory goals of improving daily lives, changing oppression and non-exploitation inherent in the other principles outlined, the research outcomes must be accessible to the research participants and to other service workers. This principle raised challenges to be addressed in the research design in terms of language and methods of recording.

7 Disability research should attempt to develop methodologies that are congruent with the ideology of anti-disabilism

This principle links to the second principle. Having established the ideology of disabilism, it is important to develop an appropriate methodology. As Boyles (1994) suggests: there is a need to seek a methodology whereby the personal experience of disability is made political. The question of how such methodology can avoid appropriation and exploitation while supporting political empowerment also needs to be addressed.

This raises the question of overt partiality. The need for overt partiality and the view that women researchers should recognise that their inner view of oppression

equips them with a methodological and political opportunity to make a comprehensive study of exploited groups is emphasised by Mies (1983). Her guidelines call for a replacement of value-free inequity with conscious partiality; of the view from above with the view from below, and of spectator knowledge with active participation. These are important factors that I have attempted to incorporate in my own research approach. Like Mies, I believe you have to interact with a situation in order to be able to understand it, and that the research process should be one of conscientisation for both the researcher and the researched and that methodology should be problem solving, or should include problem solving aspects. The methodology should develop through dialogue in the research process and the research outcomes should be shared.

As Boyles, a disabled researcher, states:

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, 1994:39)

The recognition of disability as a site of difference has occurred only recently. The concept of double oppressions was utilised for discussion by Stanley and Wise (1990). They identified that there is a need for further research to illuminate this perspective. As a non-disabled researcher I am in a difficult situation in terms of 'conscious partiality'. I cannot claim to share the same experience. I can only make a commitment to journey with the participants in an arena where my daily lived experience meets theirs. At this stage people with intellectual impairments need non-disabled allies to work along side them to develop and change services (Hurst, 1995). My approach however, is not always shared by my professional colleagues and can, therefore, at times be a lonely position to maintain. I believe however, that by making my position overt I can signal how change can occur.

The need for new techniques and methodologies is supported by Lather (1986) who urges researchers to experiment, document and share their efforts towards emancipatory

research. Lather is also concerned with the methodological implications of critical theory. She raises a number of the same key issues, one of which is how to involve the research participants in a democratic process of inquiry. My key concerns are with the issues of reciprocity, gain and empowerment. These issues are also raised by Oliver (1992) as mentioned earlier, in his emancipatory approach to disability research.

Having worked through the above issues I have attempted in my research approach to ensure that the methods I used combined the personal and the political in a way that valued disabled people and their perspectives, and identified an agenda for change.

Defining the Research Techniques and Approaches

I have identified how disability research can be developed using the distinctive features of feminist research which provide a valuable set of ideals against which research practice can be checked. In terms of my own research with people with intellectual impairments it was important that I used methods which were consistent with empowerment principles. I was therefore particularly drawn to the use of narratives as explored by Graham (1984) and found Lather's work on research as praxis (1986) particularly valuable in exploring ways of working with disabled people in a democratic, an equitable process of enquiry. I will now discuss some research techniques which have informed my own research approach.

As identified earlier, the history from the perspective of people with intellectual impairments themselves has yet to be explored in depth (Sobsey, 1991). It is evident that the absence of accounts of women's contributions in the past has made it more difficult for their contributions now to be acknowledged. Similarly in the field of disability research has focused on the experiences of caregivers (Munford, 1994; Georgeson, 1994). This research is part of a change of focus to more fully document the experiences of people with disabilities, a process demonstrated by Atkinson and Williams (1990). It has been argued that in order to understand how the caregiving process is experienced, we must listen to the stories of the people involved in the process. Triangulation can then be achieved by comparing the stories and the themes with those raised by similar participants in other research projects.

In research with disabled people there is a tension between portraying them as passive victims of events, in order to highlight oppression and active participants in responding

positively to events, in order to highlight their strengths. This tension is fundamental to any study in women's history (Lewis, 1981) and I see a clear parallel with any study in the history of disabled people. As Jones (1992) in studying the effects of institutional living on people with learning difficulties found, their experiences were situated within a social/cultural framework which showed a fluid process of understanding, resisting and compliance, rather than a polarity of absolute acceptance and absolute domination.

In the first chapter I identified a need to conduct research which listens to the voices of disabled people and presents a view from below. Stories told in the first person are a useful technique in the construction of knowledge about the social world (Graham 1984). The narrative is a popular tradition with no literary demands, "it presumes only that the speaker has a story which she is prepared to share with others" (Graham 1984:107). The story sets limits on the possibilities of manipulation and exploitation as the teller decides what it is they want to share. The storyteller is aware of the information they are providing and has choice and control over the limits of that information. It is the elements of choice and control which are empowering. The disabled people I worked with decided what was important to share, the agenda was set by them, not me. A crucial factor in this telling of stories was that the opportunity was provided outside of the formal structures of the service system. The system was not approached to give permission for their participation and, therefore, their contributions could remain confidential.

Narratives are part of the naturalistic mode of enquiry (Denzin, 1978) and demand receptivity on the part of the researcher. They provide a way of presenting histories from below, a vehicle through which everyday struggles can be conveyed to sceptical outsiders and self-knowledge validated. By sharing stories, individuals can gain an understanding of their situation and, therefore, transform their situation (Ballard, 1994; Munford, 1994).

Storytelling allows for complexity, illuminating the quality of experiences and providing a means of weaving personal experience into social fabric.

Stories convey knowledge within the complexity of human affairs,
expanding our understanding of other people and our sense of
community with them.

(Ballard,1994:302)

The self-structuring of stories can provide a means of dealing with the power inequities in other research processes and therefore counteract exploitation. Stories also provide a mechanism whereby data and interpretation are fused. I decided that storytelling had great potential as a means by which the disabled people I worked with could be actively involved in the research process without adding further to their oppression, in that they could share their experiences without being named and maintain some control over what they shared. It is, therefore, a method which is consistent with empowerment principles.

My research was informed by the above principles covered earlier. I set out to use my skills as a researcher to provide an opportunity for individuals with intellectual impairments to tell their stories; to draw together the themes from their stories in order to present "a view from below" of disability services and to identify an agenda for change in response to the issues raised. By relating their stories in the way they wished, I argue that the daily lived experiences of people with intellectual impairments became visible and the process of telling their story was validating on a personal level in that they found they had commonalities with other participants in the group.

Incorporating the Principles into the Research

There is a general preconception that people with intellectual difficulties have little to contribute or learn from research. Only slowly are people with intellectual disabilities being considered as anything other than "subjects" of research.

(Bashford *et al*; 1995: 213)

I chose to approach only individuals that I knew well. This was important in that I would be able to make contact directly on a personal basis and they would already have a knowledge of who I was. Other disability researchers have experienced difficulty with explaining what they are. Atkinson 1993 reflects on this process:

I introduced myself to the group as someone from the Open University, who was interested in history and was thinking of writing a book on historical events.

(Atkinson, 1993: 62)

By making a direct approach to people I already knew, I could offer people the opportunity as to whether they wanted to participate or not. The process for Atkinson involved getting to know the group and although her original intention was to complete the project in a few weeks, it actually took two years. Atkinson also had to go through another party, in this case a social worker, to make contact.

The fact that I knew the group and tended to come into contact with them at various times, meant that I was also likely to continue to be in contact from time to time once the research was completed and this has certainly been what has happened in practice so far. This addressed another concern expressed by Atkinson and also by Finch (1984), the sense of loss that can be experienced at the end of the research process when the researcher moves on.

For people with intellectual disabilities the use of specific points of reference can be useful in prompting or expanding dialogue. "Communication was enormously helped as we built a shared set of reference points using examples that were meaningful within the group." (Brechin, 1993:79). Having a previous shared set of experiences with the participants in this project was certainly a key advantage in this respect. Not only was I receptive to hearing their experiences I was able to acknowledge their validity against my own self knowledge (Graham, 1984). Although there was potential for the participants to feel obliged to talk to me because they knew me, I am confident that this did not happen. I clearly offered them opportunities to say no, at several points in the contacting process.

An important aspect of the research project is validity. Researchers who hold an objective, positivist world view may see stories as subjective, biased and unrepresentative (Ballard, 1994). Ballard however believes, "that the stories are truthful and that they describe significant experiences, views and calls for justice." (Ballard, 1994:299). This is a belief that I hold regarding my research. The legitimacy of subjectivity in research has been well established within feminist methodology (Stanley and Wise, 1993). It is important that researchers reflect critically on their assumptions and on their relationships with those researched (Ballard, 1994).

I kept a diary of my own experiences, thoughts and emotions, in moving through the project, which I used for reflection on my research. This was in response to Lather's caution (1986) of the dangers of being carried away with our passions as researchers and the need to introduce procedures to protect ourselves. Another concern to address was the

potential for textual appropriation which may have resulted from my ideological positioning. The researcher's values and beliefs can influence the adoption of themes and structures. This appropriation can be reduced by acknowledging the constraints of ideological imposition on data, by indirect empowerment of participants, by writing from a variety of perspectives and by collaborative interpretation of the research data (Opie, 1992).

I set out to make visible their experiences through semi-structured interviews and storytelling which I will describe fully later in this chapter. I then used a process by which themes were extracted; this is also described later in detail. The validity of the themes was checked through a process where summaries were shared at a meeting which was held following the interviews. A similar approach was used by Munford (1989) in her work with women caregivers. This interactive approach invites reciprocal reflexivity and critique (Lather, 1986). As Ballard (1994:301) states;

Change does not involve a prescription to be followed but is a dynamic process in which researchers and community engage in joint learning and problem solving.

The process for me was one of interacting in a dialogue that created its own momentum. As Ballard suggests, researchers should interpret, reinterpret and adjust information as new perceptions and circumstances are introduced (Ballard, 1994:302)

Establishing the Process

In this section I will outline how I responded to the previous points in the way I structured my research. As stated earlier, I wanted to be able to explain clearly what my research was about and to be able to enter a dialogue directly on the topic without having to go through a process of explaining who I was as an individual. From my previous experiences with the individuals I knew they were able to make an informed decision. Another aspect of ensuring informed consent was to allow time for consideration. In this respect I did not ask people to sign consent forms until the first group meeting, which is described later in this chapter.

It was important to structure the design of the research so that individuals could have a support person if they chose. I, therefore, prepared an additional consent form for support

people (Appendix 3). If support people were involved the other people in the group would need to feel comfortable with that person, or separate arrangements would need to be made to work with the individual and their support person outside of the group situation. This process was checked with the group.

As stated earlier, the issue of moving on and creating a sense of loss was avoided by working with people who already knew me and who could continue to have contact with me after the research was completed if they wished to do so. At the same time I acknowledged that I was only spending short amounts of time with them and I should not presume that their participation in the research was of particular significance in proportion to the rest of their activities.

The issues of confidentiality of tapes and documents were addressed in the information form (Appendix 1) and were discussed. The use of tape recording for interviews provides a medium whereby individuals who do not read can receive a record of their story. It was my intention that if any of the initial group approached did not wish to participate, further individuals would be approached until a group of six were identified.

At the start of each interview the issue of confidentiality and safety of data collection and analysis was again discussed. Upon agreement, each individual's story was tape recorded for full transcription. After transcription actual names and identifying details were changed to preserve confidentiality. It was important to be aware that the telling of stories is often a painful process (Finch, 1984) and that support may be required. In this project as I knew the people well, I was able to take time when they showed a need to stop for a while and I also acknowledged their difficulty in discussing some topics.

This study generated qualitative data; "descriptive data, people's own written or spoken words and observable behaviour" (Taylor, 1988:175) which was analysed for underlying patterns and themes. Dominant themes were extracted from the multiple stories and woven into the objectives of the research, documenting past experiences, current situations and hopes and dreams for the future.

The individuals who were invited to participate in the research have from time to time lived or worked with others in the group in a variety of places. It was, therefore, anticipated that clusters of information might emerge around common elements of places, times and people and that the contradictions and commonalties would be made visible.

Each individual was invited to a group meeting at which the themes were presented, discussed and checked against each person's understanding. Issues of confidentiality were addressed for the group meeting and an agreement made to keep within the group any information shared at the meeting. The group could change, add to or delete the information presented at this stage. The meeting was also an opportunity to share a sense of solidarity and to validate experiences.

Individuals were asked if they would like a transcript or tape of their personal story (Fisher, 1991). This was part of the reciprocity within the research process (Oakley, 1981). The responses of the group were also recorded, transcribed and incorporated in the final research outcome. Sharing the results with each participant was an important element. Each individual's unique experiences or perceptions were included and represented an important reality for the participant.

Upon completion of the research project all personalised tapes and transcripts, other than those returned by request to the participants, were destroyed. Participants received a summary of the research and have access to the final document. In the next section I will describe in detail the process of making contact with the participants.

Making Contact

We have also learnt that disabled people must take a leading role in their own empowerment process. That is not to say that professionals and friends cannot participate too - no individual can operate alone - but support must be the support of solidarity, not oppression.

(Hurst, 1995: 529)

I began the data collection process by approaching individuals whom I have known over a period of between ten and 20 years. All of the individuals had been given a label of intellectual impairment and had spent considerable amounts of their lives in a range of day and residential services for people with disabilities. My previous relationship with the individuals had been as a service provider; including the roles of hands-on support worker, advisor on services, and co-ordinator with responsibilities for the running and development of services. I am no longer involved in service delivery in this area but have

maintained contact with a number of individuals with whom I developed over the years a relationship of trust, as identified by the participants.

I began with the intention of approaching six individuals. This intention however changed as soon as the process of dialogue began, and will be described later, as the agenda became not just mine but also theirs. During the process the individuals who became involved chose a pseudonym to maintain their anonymity, for the purpose of clarity I use the pseudonyms in describing my initial approaches.

As explained previously in the methodology section, it was of importance that the participants knew me and I had knowledge of their whereabouts so that I could approach them directly without having to gain "permission" from service providers. This concept of "ownership" which exists in services, ostensibly to safeguard individuals who are vulnerable to exploitation (Sobsey, 1994) is an interesting theme which will be explored. As soon as you divulge to the provider the purpose of your dialogue, anonymity for the research participant is compromised. Other researchers (Brechin, 1993) have used social workers to make initial contact. The participants then become those chosen by the social worker who may have their own agenda as to whom they approach, and again the research participants become identifiable to someone outside of the research process.

Selecting the Participants

MADONNA

The first person I approached chose the pseudonym of "Madonna". I phoned Madonna and set up a time to visit with her to explain the project. At this initial meeting which took place over lunch at Kentucky Fried Chicken, I read over the information sheet (Appendix 1) with her and answered questions as to why I was carrying out the research and left the information with her so that she could think about it.

Madonna phoned me to say she had decided to participate. It was obvious from her comments that she saw her involvement as "helping me", something she was willing to do, but she was cynical that any change would occur in services for her as a result of the research! She agreed to attend a group meeting (as described in the information sheet), at my house but reminded me of her access needs. Would she in fact be able to get into my house? I assured her I would be able to put in place a temporary ramp as I had on another occasion for a friend with a wheelchair. I had to confess however that my toilet

facilities are inaccessible and that she needed to be prepared for that. Madonna raised the question of my proposed use of a tape recorder to tape her individual interview. Her concern was that when she listened to herself on tape she couldn't always understand herself so how would I? I had not thought about this. It was a good point and I agreed to work on finding an alternative method. I also identified that Madonna would need to use a total mobility van to get to my house and that I would pay for this.

ROCKY AND JACK

I then phoned "Rocky" who shares a house with "Jack" and set up a time to visit with them. I was introduced by Rocky as an old friend, to the support worker who was working at that time, and my visit was accepted as a social call. We were able to use the lounge to talk before other residents returned home. This issue of privacy is one that arose constantly throughout the process and will be explored further. Rocky and Jack both expressed interest in being involved in the research after they had read the information sheet. The suggested title, 'Days of our Lives', was greeted with laughter and linked with the television show, but was seen as a good idea. Rocky and Jack were in fact ready to start their storytelling there and then and I explained we needed to establish who else was to be involved first. I told them I had approached Madonna whom they both knew but had not had contact with for some time. They expressed interest at seeing her again. The network which exists around services between people with disabilities is complex and was evident in the discussion we had about possible other participants, some of whom they had maintained contact with over many years and many moves around facilities. Rocky and Jack were both concerned that one person I was considering approaching would not keep confidentiality and said "she'll tell everyone".

It also became obvious that another individual I had considered did not get on with them and they would not feel comfortable being involved in a group with him. They suggested two other people who they thought would be interested, both were people I knew well and I agreed to contact them.

Some of the people we discussed as possible participants were living in residences where it would be impossible to contact them without the service workers being involved, as all phone calls are taken by the service workers, the individuals do not read and there are no private areas in which to talk confidentially. It was more important that the group established should be one where people felt comfortable and safe than to meet my original target of six people. It is interesting to note that the more people you attempt to

bring into contact who live in services, the harder it is to maintain confidentiality, as their movements are known to their support people. I set a tentative date for an initial group meeting with Rocky and Jack for lunch at my house on a Saturday and agreed that I would arrange transport. The venue would therefore be outside of services and the occasion would "pass" as a social gathering. This was important, as people living in services are always required to explain where they are going.

TINA

I tried on several occasions to make phone contact with Tina. Each time she was not at home. I did not want to leave a message as this would raise questions. I attempted contact through her work setting, but she was out in the van. Eventually I gave a letter to a person she boards with during the week, whom I knew I could trust to deliver. The letter contained the information sheet and a request for her to ring me at home.

Tina phoned and we discussed the project and she decided to participate. She agreed to check her availability for the Saturday meeting and get back to me. When she rang to confirm she said she could get dropped off at my house by a friend and asked her support person to take down my address. The support person said "you can do it you don't need me". Tina agreed and took down the address. This issue of unnecessary dependency that is so easily created by services and support workers, in this case was corrected, but is a theme that emerges throughout and will be discussed further.

ELVIS

The final participant I approached chose the pseudonym of "Elvis". I was visiting his workplace for another purpose and hoped to see him, but he was out. I phoned later when he was on reception duty so we were able to talk. I explained the project and he gave me his residential address to post the information sheet and I said I would phone at a later date for his response. "Elvis" has difficulty with reading so I contacted "Rocky" and asked her if she would go over the sheet with him when she next saw him. This she agreed to do and Elvis rang to say he would participate and would come on the Saturday. He had chosen a support person who would bring him and I gave him the address. However the next morning Elvis rang to say that the support person couldn't come and that he had forgotten the time of the meeting. I therefore arranged that I would pick him up, as the issue was one of needing transport, not a support worker.

I have presented in depth information on this process of "contacting" participants as it is a crucial element in ensuring individuals with disabilities who live in services are allowed the opportunity to participate without the knowledge of their service providers. Traditionally in research involving people with intellectual impairments the participants have been chosen by the service provider and the researcher has sought permission from the service provider to carry out their project. Walmsley gives an example of this:

What it tells us about the status of Eileen an adult woman, is that she is surrounded by people, all of whom, it seems, could veto her participation. I became subject to some of the constraints to which Eileen is subject. I felt I could barely move without asking the permission of numerous people. It gave me an insight into how 'caring' operated as benevolent control for Eileen.

(Walmsley, 1993: 39)

As this research is essentially about the voice of the service user being heard, it is important that they have the freedom to speak in whatever way they choose without having to seek "permission". To presume that there is no conflict of interest between service workers and service users, is to deny the reality of services.

It was equally important for the group that they had a say in the composition of the group and that their voice was heard on this issue. In responding to their requests I ensured that the group felt safe with each other. The process of contacting therefore had to be carried out in a way that did not divulge the nature of the contact to other residents and service users.

As a researcher I felt the need to proceed cautiously through this process, in a manner that was covert to the service providers. It would have been a much speedier process if I had taken a traditional approach through the service provider. The process of contacting is also much simpler for research participants who do not live in services as they can be contacted privately without the knowledge of others. The other compounding factor was the need to speak with people and explain the information to individuals who need support with interpreting the written word. The process of communication becomes more complex as in order to ensure the individual is giving informed consent it is necessary to use verbal check-backs to confirm understanding. As Walmsley emphasises: she did not

think participants always understood what she meant when she said she wanted to know about their experiences of care (Walmsley, 1993: 41).

The final point in this contacting process is that it would have been impossible for me as a researcher to have used this method with individuals that I did not already know. The fact that I was already known to them and that we had a positive relationship built over many years, enabled me to communicate effectively with each individual. My knowledge of the service system enabled me to access the individuals without having to ask permission of the system. This required patience and persistence. It would not have been legitimate to approach individuals who were unknown to me using this method. Other researchers in this field have struggled with these issues. Walmsley (1993), describes the mistakes she has made, and the difficulties she had in explaining her purpose to her research participants. She also explains her belief in the value of articulating mistakes so that others can build on your work.

I have tried to build on the work of other researchers and avoid some of the pitfalls they identify. I do not presume to say how they could have done their research better. I only state that as I was in a unique position of knowledge and experience of services, I have used that to the advantage of the participants I worked with.

For me it was significant to understand the barriers that services construct, which isolate service users from the rest of the community, and the inordinate difficulty individuals have in maintaining any privacy in their daily lives.

The First Meeting

One of the principles underlining the research process is that of reciprocity. Part of the bargain therefore for the first meeting was that I would provide lunch. This meant organising food in advance bearing in mind the needs of the group one of whom needs assistance to eat. I therefore chose fare that was suitable for assisting someone to eat, whilst eating my own meal. There are many extra considerations in planning a meeting for people with disabilities in comparison to a group of non-disabled people.

The furniture had to be rearranged in the lounge and the hall cleared of obstacles so that people would have room to manoeuvre. The temporary ramp, a large sheet of steel, was

dragged into place up to the front doorstep and I prayed that the door would be wide enough.

Next came the transport. I rang Jack to say I was on my way and told him to phone Elvis who was the next pick up. This process ensures they are ready and waiting without having to rely on support workers to prompt them as to the time. The process went smoothly and I arrived back with Jack, Rocky and Elvis just as Tina was being dropped off by her friend. In the meantime my partner had taken a message from Madonna that her taxi had not arrived. John, my partner, rang the taxi for her and it was on its way.

Whilst we waited for Madonna there was a general sharing of information about mutual acquaintances. I shared photos of people in times past which established common ground amongst the group. Tina also had some photos to share. Madonna arrived and her wheelchair just made it through the door (with the help of the taxi driver). Everyone was organised with their specific needs for lunch. Tina had brought her own herbal drink as she is on a caffeine free diet. Jack had his saccharin for his sugar free diet and Madonna had her jumbo straws to drink through independently. I was impressed with their personal organisation skills; there is often an assumption that people with intellectual disabilities should have difficulty in this area! The advantage of the research participants knowing each other and feeling comfortable with the group's composition was obvious in the conversation over lunch; evidenced by the way that they supported each other and the ease with which we were able to move into the business of the meeting.

We went over the information sheet again and I asked for questions. There was comment and laughter over "Days of our Lives", the television programme, and general agreement that they thought it a title with which they could connect. I explained again my reason for doing this project; to record their viewpoints and experiences of services; and they agreed that they would like to talk about what was good and not so good and how things should change.

People then signed their consent forms. I had to explain 'signature' as "what you put on your bank forms" something they were all familiar with, as opposed to printing one's name. Our next task was to set times and places for individual interviews. Each person chose a time and setting that suited them, where they would feel comfortable and be alone, for example, before other people came home and before support workers came on duty. Again, the difficulties of privacy were a key issue in this sense.

I explained confidentiality again and the need to choose another name for them to use for their interviews. Each person was to think of a name before their interview. One person still had concerns that people would know what she had said. I explained that I would be careful how I wrote it up, so that people did not know who said what as individuals. I would also avoid naming any particular services they used. This was an important aspect that has been identified in the development of the methodology. Sobsey (1994) urges us to take care that we do not add to the exploitation of vulnerable groups.

We then talked about the idea of making a list of topics that people thought it was important to talk about. This list could then become a guide for the interviews. The topics suggested by the group were:

Staff - social workers; staff training

Jobs - things to do in the day

Places - (facilities) people have been at

School

Where you have lived

Choices about who you live with

Who do you get on with

Who does what jobs around the home.

At the close of this first meeting I assisted Madonna and Elvis to write down the times of their interviews and we set a date for the next group meeting. The transport home was then organised. My partner John, who was known to all the participants, had at their invitation eaten lunch with us. He then left for the meeting part, but by mutual agreement took Tina in his van, as my car only takes three passengers. Transport is an issue for people with disabilities. One of the only ways that people can travel in an electric chair is by total mobility van, the restriction then being the availability at the time it is required. Other members of the group can use public transport, but the costs are high

in relation to their income, which consists of the Invalid Benefit. As reciprocity was important in the research process, the provision of transport by me was not only a financial factor but also an opportunity for the group to enjoy a trip out. After the meeting we detoured around some old haunts that they had not seen for a while.

The Interviews

In this section I will describe the complexities that arose in carrying out the interviews. Again, the issue of lack of privacy arose, partly due to the assumed rights of support people over the lives of those with whom they are interdependent.

ELVIS

The first interview was to be with Elvis. We had agreed to meet mid-afternoon at the house where he lives. This would be a time when no other residents or support people were there. I rang him at his vocational centre that morning to remind him of the time. At the agreed time he did not appear and after waiting a while I decided to go to his vocational centre. Elvis was still there and when he saw me he asked me to come in as his manager wanted to speak to me. Elvis had asked the manager if he could leave early as he was meeting me. The manager has known me for some time. The manager wanted to know where we were going. I responded that Elvis was helping me with a project and that we would be at his house where we could talk without interruptions.

The assumption of the support workers in this instance was that being responsible for an individual means knowing where the person is going and what they are doing, as of right. The other assumption was that the individual themselves can not be relied upon for this information, and that it has to be verified by the non-disabled person, in this case myself. Elvis had already given the information required, was capable of going home independently as he did so every day, the issue, therefore, became one of power over the individual rather than support for the individual. People to an extent are captured by their vocational services, where the ethics of the workplace are applied in terms of authority and rules. Although the individual is not paid to be there, they in fact have no choice over their attendance. This is the place where support is provided, therefore, this is where they must be, whether they require the support or not. The funding to any programme is delivered per person attending, therefore, lack of attendance can mean a reduction in funding, which could result in a deficit for that particular facility.

As a result of my being seen at the vocational centre another resident returned home shortly after our interview had begun, obviously curious to know what was happening. This individual had no doubt exercised his right, and left without asking permission. We explained that we wished to talk in private; and as the other person showed no signs of leaving, switched to another room. We were then able to complete the interview just as the other residents and support people came in. The justification often made for the intensity of supervision for people with intellectual disabilities is their vulnerability to exploitation. However this "surveillance" in Foucault's (1977) sense seems to have become a way of relating to this section of the population as an identified group in order to demonstrate accountability rather than to respond to actual individual need. To be intellectually disabled has come to mean being constantly visible.

In many ways Elvis appears able to live with this level of intrusion and has no doubt developed compliance, doing what others require of him, as a survival skill during the years spent in institutions. For myself the process of carrying out this interview left me with a heightened awareness of the subtlety of power within services. This is something that I feel I was certainly blind to when I was directly involved in hands-on support work. The practices are insidious, and I had no critical analysis of the situation.

MADONNA

The second interview which was to have been with Tina was postponed as she was ill. The next interview therefore was with Madonna. This took place in her own home after her caregiver had left in the morning and we, therefore, had no difficulty with privacy. As I mentioned earlier in the section on making contact, Madonna was concerned that the tape recorder might not be successful as a means of recording the interview as she has a speech impairment. Her concern was that I would not understand her responses and she would not necessarily understand them herself. As I usually use a method of repeating her phrases when I am unsure what she has said in order to check my understanding, the pace of our conversation tends to be reasonably slow. I, therefore, suggested that I try writing her responses as I check them verbally and use the recorder for my questions. This system worked well and did not interfere with the usual pace of our dialogue.

After the interview Madonna asked if I would like a cup of tea. I made one for both of us, following her instructions in the kitchen. As we sat and drank our tea Madonna explained this was a treat as on that day of the week she did not usually have someone there to make a drink. She asked me to assist her to the toilet before I left as otherwise

she would have to wait until the end of the afternoon when home support arrived. I said I was happy to do so. Madonna said it was the worst thing about being disabled, having to ask other people to take you to the toilet. Sometimes you don't have a drink because there will be no-one you can ask. This concept of "waiting" is one that is noted by Munford (1994) and expanded by Georgeson (1994) in terms of the dependence within the caregiving relationship whereby your bodily functions must be regulated to match another person's timetable.

Madonna had a taxi booked to take her to the town centre for the afternoon and I helped her with a coat as it had turned cold. If I hadn't been there at that point she would have had to make do with the clothes she had chosen to wear earlier in the day when temperatures were warmer. As I left I felt really upset at how little Madonna expected of anyone and how appreciative she was that someone was willing to meet her basic needs without making a fuss. I really felt humbled by her ability to cope with such patience and stamina with the situations that arise for her. I turned on the heater in my car and drove home thinking I was hungry and it was lunchtime, what did that mean for Madonna?

JACK AND ROCKY

The third interview was not as straightforward as I expected. I had arranged to go to Jack's home. However, when I arrived there was no-one there. When I tried to follow up by phone there was no response. I had similar experiences when I tried to contact Rocky who also was not there at the time arranged. I was concerned that they may have decided not to participate further in the research and I, therefore, wanted to make contact in a way that did not apply pressure to them. I also wanted to find out what was happening without drawing attention to them. In the end I wrote a letter asking if they still wished to do the interviews and for them to contact me if they did. I also reminded them of their right to withdraw and that this was fine with me if they did.

Rocky phoned me to apologise and to say that they both wanted to do the interviews. The problem was where could they do them as they did not want their flatmates to know. I asked them to think of a venue and I would get back to them. I felt that we needed to be on territory that was neutral and, therefore, did not consider my home appropriate. I had friends who lived near Jack and Rocky and I asked them if it would be possible to use their house for an afternoon when they were out. This was agreed to and was acceptable to Jack and Rocky so we were able to meet without them disclosing their involvement. They had the choice of separate interview times but chose to do a joint interview as they

felt comfortable in supporting each other. This experience again reinforced the difficulties people with disabilities have in living private lives. The issue for them was the fact that their flatmates always knew everything that was happening in their lives and talked about them to others. Although this could well apply to other flatting situations, the options available to individuals are different. Rocky and Jack cannot move to another house or change their flatmates unless this can be negotiated with their service provider. All supported residential services have to be economically viable and current funding levels are constructed around group homes. Usually, a minimum of four people is necessary so that the income is sufficient to pay for the support costs where full support is required. Although the current funding for disability services is based on a philosophy of responding to individual need, the maximum amounts payable are insufficient to purchase individual support. The group home therefore has become an institution within disability services (Clements et al., 1995), constructed by economic policy and disguised under the application of the theory of normalisation (Wolfensberger, 1972) as a flatting situation. The right to a private life, therefore, becomes a structural impossibility.

TINA

The final interview was with Tina. This was logistically easier to organise as Tina does not live with a service provider but in a private board situation with a family. We were able to meet at the house and have the lounge to ourselves for the interview. No questions were asked about what we were doing and hospitality (in terms of cups of tea) was offered. The situation was, therefore, a comfortable one which paralleled the expectations I would have under ordinary circumstances of interviewing someone in their home. This stood out in contrast to the previous experiences with Rocky, Jack and Elvis, which held examples of the way services disable people as described by McKnight (1977) and Lovett (1996). The fact that Tina is happy with her current living situation was apparent throughout the interview and I left to return home feeling positive about the possibilities of life for people with disabilities outside of services.

Analysing the Data

One of the key issues that the researcher faces in analysing data is threats to validity. I explored the concept of the validity of stories (Ballard, 1994; Graham, 1984) in the principles I developed earlier. I also discussed in the fourth principle the importance of the relationship between researcher and participant (Oakley, 1987; McRobbie, 1978). In order to achieve a level of intimacy with people with intellectual disabilities I would argue that it is necessary to become familiar with their setting, as it is only possible to understand their experiences as stated earlier, by entering the services in which they live. In going through this process of developing a relationship, the researcher moves from the stranger position. I have identified this as an important principle. Morse (1994) in contrast, argues that for optimal comprehension the researcher must enter the setting as a stranger; previous familiarity will create a bias, an inability to view the setting with sensitivity. At the same time the researcher is instructed to earn the trust of the participants and establish a level of intimacy. If it is accepted that all researchers enter the setting with bias, constructed from their previous knowledge, beliefs and values, then what becomes important is the acknowledgment of that position. Thus the bias is made explicit and is beneficial in illuminating understanding as explored in the fifth principle. It is my explicit position as a non-disabled ally, who is already known to the group, that has enabled this project to be carried out. This principle is echoed by Ward and Flynn:

We recognise that the role of the non-disabled researcher may be an uncomfortable one but that people with disabilities need non-disabled allies - provided they know their place.

(Ward and Flynn, 1994:45)

I accept that to be actively working with participants as both a direct service provider and a researcher would raise ethical difficulties and is not a situation to be recommended. However, this situation does not apply for me as I had not been involved in an official service provision role with the participants for the last six years.

The data was collected by a process of active inquiry as described previously, with an explicit openness to view the setting from a different perspective. An example of this from an interview with one participant, as follows:

J. I know what I remember about (...) but it's important you tell me what it was like from your point of view.

I actively encouraged open dialogue as demonstrated on another occasion:

I'm going to put my foot in it.

J. You can say anything you want.

The data from the interviews was recorded on tape and transcribed. My reflections on the process were recorded in diary form immediately following the interviews and interactions with individuals and the group. This process of reflection was crucial for me in terms of my ability to analyse our dialogue. Atkinson makes a similar point about her research.

How I presented myself and how people saw me, were important factors in determining how we related to one another. These factors were often not obvious at the time. Indeed, it is only now, through a similar process of recall and reflection, that I can begin to make sense of my own experiences.

(Atkinson, 1993:59)

As described previously, a checklist of questions was developed by the participants at the first meeting. This became the first step in establishing themes. The process of coding and clustering the data around themes was a mobile one where headings developed from the data and from the literature explored in Chapter one and were changeable. Morse (1994:28) describes using this process in her research of sorting and clustering. It is by moving and trying different combinations that understanding begins to emerge.

The process of comprehension of the data and synthesising and merging of the stories was intertwined in the analysis, as the similarities and contradictions came together to create the themes. The themes became a mechanism for representing the group's experience in a way that protects the anonymity of the individual and gives control and order to the research and the writing. This process decontextualises (Atkinson, 1993) as data is removed from the individual to the general description. The themes were then taken back to the group to check their validity as being representative of their own experiences, as explained in the next section.

The Group meets again

The delays in carrying out the interviews meant a rescheduling of the original time set for the group to meet. This was organised by phone. The transport was organised in the same way as for our first group meeting. This time there were no hitches. The participants were familiar with what had happened before and helped in setting up the lunch before we moved on to business.

I explained that what we needed to do was check each person's pseudonym, write up a pen portrait for each person, check the themes I had drawn from their interviews, and collect their ideas and advice for the setting up of future services. The concept of pen portraits was explained in two ways; me giving an example as to how I might describe myself and by giving an example of an author's description from a book jacket. Each person in turn then spoke their own portrait which I recorded and read back to them. The portraits, therefore, are an accurate description of how the individuals wish to be described, rather than how I have chosen to describe them, within the constraints of anonymity.

Next I explained to the group that there was a group of people moving out now from an institution and that I was involved in setting up a new service for them. Their advice was sought on what we should do to make sure the service was right for these people. This exercise, as well as being of benefit to me in the role of a new service developer, provided the group with an opportunity to describe what was important from their own experience as service users. This in effect was a concrete way of taking them back over the areas they had talked about in their interviews 'recontextualising' the data (Morse, 1994:34) and clarified one of the objectives of the research project; to identify how services should change. At this point the research objectives of allowing the participant's voices to emerge, enabling each individual to tell their story in their own way, ensuring a safe and accessible process and identifying an agenda for change had been addressed.

This process also provided in a group format, data which could be used to cross check against the themes I had identified and to add new data in order to meet the objective of identifying common themes in their daily lived experiences of services. The themes from the interviews were read out and checked with the group. Individuals were asked if they would like a taped or a written copy of their own interview and I agreed to provide them with a written summary of the main themes they had identified.

Pen Portraits

JACK

I work in an art room, I'm selling paintings. I live in a flat with three other people. I'm about 40. I've lived in three different residential homes. I like music from the sixties, cars and motorbikes.

ELVIS

I live in a residential home. I work on the reception at the workshop. I also work at a supermarket one day a week. I go to aqua fitness and play basketball. I've lived in 5 different residential homes. I'm 45 years old.

MADONNA

On a Friday I go to the town centre and I sell lollies. Most of the people buy them because I'm lovely. I'm over 21 years old. In the afternoon I go to physio and most of the time on Saturday night I go to the pub.

TINA

Two days a week I go to the food bank and I make up food packs for people on benefits. Then I get a taxi into town. I've lived in 3 residential homes. I like to spend time in town and I go to the workshop late in the afternoon. On a Friday I go to the People's Resource Centre.

ROCKY

I went to the workshop when I was 17. One of my first jobs was putting covers on magazines. Then I moved into a residential home with 3 people and we took turns cooking and shopping. In 1983 I moved to another flat in the city. Then I moved to another flat and a different workshop. Then I moved to a house near the workshop and I worked in a childcare centre. I wasn't very happy there in that house so I moved again and I went to work in an office. I lived in 2 more different houses in the city and one house in a different town. Then back to the city and 3 more moves to where I am now. I have been on a polytech course. I work one day a week.

Themes Identified

The following is a list of the themes that were identified and checked at the final group meeting. It is written in the language used and understood by the group. This list is used as the framework to present their stories. In chapter three I will address the first four themes which represent the experience of living with a disability.

CONTROL

Education: institutions: money: work: jobs: clothes: possessions: mobility.

CHOICE

Over who you live with: what support you get: who supports you: about your living environments: moving houses - when and where you go.

SOMEONE TO LISTEN

The need for someone other than support people to talk to: a person you trust: social workers.

RELATIONSHIPS

With support workers: not getting on with them (conflict): who makes decisions: working well together (partnership): when support workers move on.

In chapter four I will address the following themes which consider the support and hindrance of significant others in their lives.

STAFF TRAINING

All staff should be trained: some don't know what to do: we know more than they do: who's supporting who?

SAFETY

Need for a balance between feeling safe and making decisions for yourself (autonomy).

WAITING

For a decision: to see what happens: for support: until people think you are ready.

PEER RELATIONSHIPS

Sense of history: keeping in touch: sense of community: conflict: lack of privacy.

FAMILIES

Keeping contact: relationships.

SELF IMAGE (how you see yourself)

Pride: labels - acceptance of IH for yourself: negative responses from other people.

Chapter Three

Listening to the Stories - The experience of living with a disability

Our commitment to listening springs from our conviction that the process of institutionalising people takes very little time. Once personal freedom of choice has been denied and personal privacy removed the slippery slope towards feeling undervalued and uncared for becomes a fast and furious downward spiral towards despondency, desperation and depression and finally most sadly, acceptance.

(Phelan and Cole 1993:58)

This chapter and the subsequent chapter are the core of the research project in that the voices of the participants are heard and the dialogue that occurred between us is described. The individual participants are not named even by pseudonym, at their request, so that the direct quotes can not be attributed to any one person in a way that would make them identifiable. I will move through each of the themes giving examples from the stories of the participants, comparisons from the literature described in chapter one in relation to the research questions. For purposes of clarity the quotes from the research participants and myself appear in italics and my statements are prefaced by a J. The first theme is about control and how it is exercised in a variety of settings and arose from common experiences that were identified by the group.

Control

We need to acknowledge that the predominant mode of relationship between staff and the users of services is one of control and the exercise of power.

(McGill and Emerson, 1992: 74)

One of the key themes identified was to do with issues of control and lack of control. This theme seemed fundamental to the other themes and was evident in many different aspects of the participants lives. It was expressed as a feeling that other people had authority, made the decisions, and that things just happened but the participants didn't

know why. This element was also recognised by Shoultz (1995:166) in writing Lucy's story. She states: "I came to see that control by others was a major thread running through the other themes". It was also a key factor in the literature in chapter one when describing the practices within services and the relationships between caregivers and receivers (Georgeson, 1994; Keith, 1994; Smull and Harrison, 1992), and in particular the discussions about abuse and compliance (Lovett, 1996; Sobsey, 1994). There were several areas where the lack of control was evident. The first area I will describe is around the experience of education.

EDUCATION

Some of the participants referred to their experiences in special schools.

J. Did you learn much there?

Not that much - not really.

J. Was there anything important about that time?

Not really - I don't know why I went there - but there was no where else to go - to for me I think.

The environment of the special school was based on therapy, in that the focus was on improving their functioning, rather than educational and was not a site of choice. If you had a disability then for most children that is where you went. Mainstreaming, an educational policy which removed an arbitrary boundary segregating disabled people from ordinary schools, was yet to come. The experience of special education did not reflect a parallel to the usual educational curriculum (Ballard, 1994). Students were not exposed to the same variety as their non-disabled peers.

They tried to help me learn to talk then they tried to teach me how to walk. I always dribbled like a baby - they put me on something like medication to stop dribbling.

Sullivan (1994) discusses the focus on the 'body'. It can be argued that the 'disabled body' is one to be controlled in special schools. The control of the body rather than the education of the mind was the key concern. As identified in chapter one, this is

representative of the medicalisation of disability as described by Sullivan (1995). The labelling of a person as having an intellectual impairment puts them outside of the mainstream of education where they are deemed not to need the education and life experiences offered to most children (Ballard, 1994).

I was just doing sewing down there and - and that, that was really good, and weaving.

Although this person enjoyed these activities they were not exposed to other educational curricula which they might have also enjoyed. The choice was not there. Another significant experience that emerged was that people often did not know why they moved from place to place. Decisions were made without their knowledge.

I don't know I don't know whether it's closed or not, and then um I got um pretty s - I got pretty well sick so my mother and father sent me up to (...) hospital.

The concept of being sick and being in hospital is linked here, although the hospital this person referred to was actually an institution for people with intellectual disabilities. Her parents sent her to hospital, therefore, she reasons that she must have been sick. This occurred at a time when institutions were seen as appropriate places for people with intellectual impairments (Brown and Smith, 1989). People in institutions are deemed as “trainable” rather than “educable” (American Psychiatric Association, 1994). This was, therefore, the end of her educational experience.

For another person their experience had been in a residential school.

Yes (..) that's a real nice place because it's real tidy - tidy! No rubbish on the footpath or the side of the road, you'll be in big trouble, but it was getting too hot anyway. Mum put me there anyway.

Again the parent made a decision of removal. The experience of being educated in special places was a common experience for the group and represents an experience shared by many disabled people of their generation. The advice given to parents at this time was often that this was for the best interests of all concerned. A similar experience in a British context, is expressed by Keith (1994):

I was back in special school, hating the isolation, hating being told to try a bit harder otherwise you'll end up in a home. The threat meant the surrender of dignity, surrender of control. (33).

The process of IQ testing as described in chapter one, led to this segregation of disabled people in special places (Santrock and Bartlett, 1986). Having once been labelled, people were excluded from the mainstream.

INSTITUTIONAL LIFE

The participants were born at a time when people were still routinely being sent to institutions if they had an intellectual disability. This was before the policy of deinstitutionalisation.

30 years ago parents of children with disabilities were "told" to put their children in hospital. Now they are "told" that hospitals are closing. It is politically expedient at this particular time to close long-stay hospitals and normalisation posits an approach to providing services for people in the community.

(Brown and Smith 1989:17)

J. Can you remember when you went to (...). Do you know how old you were?

Um well I was about two years um three years of age before I went to (...)

This was the start of a potential lifetime in an institution for this person. Later in the same story:

J. How old would you have been when you left?

Well I was about twenty one, twenty two I think when I left, and I said to (...) I said oh I'm going to miss you and (...) said why are you going to miss me?, and I said well you're the best recreation people and it'll be sad to miss everybody here at (...)

If your formative years are spent in one place it becomes part of your sense of being. In encouraging people to tell their stories Jones (1992) gained an understanding of the peer community and the sense of family within the institution. It can be hard to leave this 'family'. As Brown and Smith identified (1992:97) "Attention is rarely paid to the rites of passage of leaving an institution". However, as Horner (1994) describes in her research with people leaving an institution, some people have no difficulty with leaving.

He was always busting to get out (of Cloverlea). He wanted out, his goal was to get out of Cloverlea the whole time that he was in here.

(Horner,

1994:161)

It should be recognised that some people need to grieve and to be supported through their feelings of loss and distress. Sinson (1993) described the experience of one woman who was sent out for the evening and came back to find all her stuff packed in sacks on her bed. She described her feelings as being shocked and upset. The next morning without knowing where she was going she was taken to a group home.

The kind of training or education that people with intellectual disabilities have received in institutions has largely been that of compliance (Sobsey, 1991) One participant described his experience of this training process.

He used to say "..... do this" and I did it the same way he did, and um (T...H...) he was one of the best people because he was the only one that I trusted really because he was the best out of the lot of them, but he - everyone else stood there and watched everybody - watched everybody else doing the same thing, and (T...H....) Says to them "why don't you do the same things like (...) did."

Compliance can be viewed as a mechanism of control. Sobsey (1994) describes how it is viewed as a functional skill for people with intellectual disabilities to learn. Lovett (1996) also describes how people who do not comply are viewed as having challenging behaviour. Control was evident not only in the provision of segregated services at a policy level, but also permeated day-to-day functioning.

J. In (...) did you have your own things or did you have - you had uniforms in (...)?

Yeah

J. Did you get different things when you came out?

Well we sort of had government clothing, sort of like government clothing like we had trousers given to us and we had shirts and jerseys given to us and we had all kinds- like government clothing and I said to one of the staff "oh how long are we going to wear these for?" and he said "oh you probably have to wear them for weeks yet, until you manage to move out into the community". We had to end up wearing government clothing until we moved out and when we move out we can do what we like, we can sort of wear our own clothing.

Even when people were given individual clothing they could lose control of it. The concept of owning anything as an individual was difficult to maintain. From my own experience as a worker in an institution, I know that wards had very little space for personal possessions and all laundry was done centrally. For this man the memories are still vivid about these instances many years later:

J. That was the first set of clothes that you had that were yours.

Yeah, and she said "here you are (...) that's all your set , and she gave C...his set, and by the time C... got out of (...) he lost track of his trousers, and track of his shirt and jersey and I said to C..."what have you done with your clothes that Mrs... bought you?" and he said "oh one of the guys took them and was wearing them" and part of the jersey was torn down the front and he says "and I lost track of my shirt ,I can't find my shirt" and I said "well what happened to it?" and he told me that one of the guys was wearing it and it was ripped down here, down the neck side.

J. and what about yours, did you keep track of yours, did you manage to hang on to yours?

Yeah, I managed to keep track of my clothes, I said "whatever happens to my clothes, I wouldn't mind wearing them" and when I sort of moved from (...) I couldn't find the shirt, but I found the jersey, and one of the staff said to me "have you found your trousers?" and I said "yes I've still got them" and they said "well have you still got your shirt?" and I said "no I can't find that" and of course one of the staff found it, it was in one of the other people's clothes and I said "oh where did you find it?" and he said "oh I found it in amongst G...'s clothes" and I said "oh what was it doing there?" and he said "oh one of your support people put it there" and I said "oh" and that's how come I lost track of my shirt, but I managed to get it back off him.

J. I guess with so many people living there that kind of thing must have happened a lot eh?

Yeah, because my grandmother gave me a beautiful suitcase which was this big and that wide and it was black and when I went home for Christmas, my grandmother says to me "what happened to your suitcase?" and I said "oh that got pinched" and she said "how, how did it get pinched?" and I said "one of the staff took it to the mending place" and she said "what was it doing there, it's supposed to be in your room?" and I said "well one of the staff grabbed it and told me to take it down to the fire station, because they wanted to put it away in the lock up storage" and she says "well when you get back you go and get that suitcase back", so I asked one of the staff where my suitcase was and they said "oh I don't know, I can't find it", and then I said to them "oh you put it away, you should know where it is" and then they teamed up looking for it.

J. did you ever get it back?

No.

It is evident here that in an institution personal property like clothing easily becomes communal property and staff attach little importance to supporting people to maintain their own individual identity in terms of their possessions. In my experience in

supporting people leaving institutions one of the most notable factors is the lack of personal possessions people have to take with them. I think it is sad that people have so little to represent a significant portion of their lives. Another factor in the above story is the assumption by the grandmother that people in institutions have rooms of their own. All of the institutions I have worked in have had wards with several beds and the only personal space I have seen in any of them, has been where low partitions are in place to form a cubicle around each bed and a locker.

Sustenance

Anyone who has been in hospital knows the lack of control one has over eating and drinking. These functions are governed by institutional practices. These practices dictated uniformity over such basic things as how people took their tea:

They used to put milk in the teapot at the hospital they did and no-one had to go and look for the milk or anything

J. In the hospital people didn't get to do cooking or anything like that?

No, we weren't allowed in the kitchen, it was all done for us, just like the main hospital, everything's done for them

The institution sets the scene, reinforces the belief, that people with intellectual disabilities cannot cope with taking care of themselves as individuals, they need to be supervised and catered for. Consequently, we find examples of institutional practices in community services as people move out (Lovett, 1996). For example, I have often seen food and drink served out by support workers because they believe the people with disabilities cannot do this appropriately. Worth (1988), a self-advocate also described his dissatisfaction with a group home where the staff did the cooking and “put slop on the table” (p175). Obviously, unless people with disabilities have the opportunity to participate in these activities they will not be able to acquire appropriate skills.

J. Life's better now though eh?

Yeah, oh yes, much better, but nobody likes the idea that um having a staff member with them in the kitchen. I said to (...) you make sure

you've got a staff member with you or else you'll get yourself into trouble.

J. But he could manage teapots on his own.

Yeah I know but nobody's allowed to do it by them self because - just in case they get burnt. Because it comes out very fast and sometimes it doesn't go in the right place.

J. This is the water heater?

Yeah and um it can just splash out at you

J. Maybe you just need to change the water heater, get a safer one.

Yeah I reckon.

Timetables

The community residences may be in effect simply smaller institutions and reflect the same controlling practices. One of the limitations of group homes is that the needs of the group are paramount to the needs of the individual (Van Dam and Cameron-McGill), as there is fixed availability of resources in terms of staffing and rosters. This often leads to people doing things in groups and to fixed timetables.

Then when I went around to visit (...) I sort of got locked out of my bedroom, got locked out of the dormitory and one of the staff came to me and she said to me "what are you - what are you doing out at this hour of the night, you know you're supposed to be in bed at nine or whatever time you're supposed to be home" and I sort of got in a bad mood with her because I didn't like the way she was mistreating (...).

J. What did you used to do in the daytime?

Well in the daytime we used to - we used to go for a drive for quite a few times, and the staff used to make us go to church with them. And of course we went to church service and then they says "oh there's a meeting on tonight in the dining room if you guys are interested" and I

sort of said "oh no I'd rather go and visit (...) and she said "oh that's OK you can go and visit him if you want to" so I went to visit him for a while, and then I come home and Mrs... said "oh did you go to the meeting last night?" and I said "no", and then she said "well you should have".

Although this was a community based service it still felt like an institution because of the expectations of the staff that they would set the rules with which people would conform. Horner (1994) gives an example of this happening in a group home where the staff decided that everyone should have a shower between set times, no doubt again to fit with the availability of staff support.

And I said to one of them that I'd sooner get out of (...) as quickly as possible, and they said "why?", and I said "because the staff are sort of ordering us around", they want money out of the people from (...)

Brown and Smith (1992) reflect on the fact that users need services that do not further disempower them and over which they have some control. This is where normalisation, although a useful tool in getting people out of large institutions, has failed to make explicit the tension between giving value and taking control. As support workers focus on teaching people skills and providing opportunities for people to participate in valued activities, they are unable to see that they are controlling what people are doing. If a person does not want to participate in the valued activity, they will probably be viewed as non-compliant, instead of questioning who decided that the activity was valuable and who has control over where and when it happens? It is the issue of control and who holds it that is key to whether or not a situation is an institution.

MONEY

In this sub-theme the discussion is around financial resources, although the term the participants use is 'money'. This is the concrete resource they see and handle to some degree and therefore the one that has the most meaning for them. Money in terms of broader financial resources, was something that people were aware of, but again did not feel in control of.

What's not good well they didn't tell us how much money we're supposed to be getting.

J. So what do you know about your money?

Um well what do I know about it?

J. Does your benefit go into your account or does it go in- ?

I still don't know if they're ripping me off.

In general people in services don't get to see their money, as their invalid benefits, which all people with intellectual disabilities are entitled to if they are non-wage earners, are paid by automatic payments between Income Support and the service provider. They have nothing concrete to refer to, they do not have bank statements to check what money has gone where, and they don't know what they are entitled to.

J. So do you have an automatic payment for that?

Two. I don't know if I'm getting ripped off or not when I was doing the cleaning

J. OK what happened then?

I was getting sixty and then it went down to thirty dollars.

J. and did they tell you why?

Because I'm doing less days, two days less, because they put (...) on for two days and she wasn't very good

J. So did he ask you about that did you have a choice about that or not?

No he said he was going to give me extra pay before (...) came on.

Although there is a limit to how much people can earn before they start to lose their benefit, they do not necessarily know about this. It is not that they could not understand; the information has not been given to them. Horner (1994) identifies similar issues in her British study:

The lack of money available to people with disabilities seems to be due largely to the fact that their income is usually in the form of welfare payments which are then taken up by the agency that provides their residential and related needs. The people with intellectual disabilities who work in sheltered workshops receive a small amount of money, such as five dollars a week for the people in the present study.

(Horner, 1994:179)

The reality of poverty for many people with disabilities is not often acknowledged (Brown and Smith, 1992) and the realities of being a welfare recipient are often misrepresented (Kelsey, 1995).

J. Do you think it's hard to live on the money that you get?

Yeah, it was better when we had those outside jobs, Who stopped my last job? (...) then they kept on getting me jobs and kept on stopping them

J. When you had earned more money did you still get your benefit as well, or did they take some off your benefit?

Oh only when I was doing the scrub cutting I was getting the whole thing because they didn't know about the scrub cutting eh!

J. So you kept quiet about that?

Why should I tell them, because other people are getting benefits too.

There is also a lack of information about how their residential service is paid for. Although the CRHA (1995) states that funding to purchase services will be based on individual need, and the consumer will then go "shopping" for the best service, for individuals already within services, they are (as stated in the section on social policy), a

captured commodity. The service is contracted to provide for them, but they are not informed of this by the provider and the funding does not go through the consumer.

J. and what about the money that goes like into the house do you know about that, about what happens?

No we don't, no one hasn't told us properly about that yet, we haven't been told, but you're supposed to have someone like (...) you're supposed to have a staff in the home, supposed to be telling us what's going on and what we're supposed to be - we don't really know what's going on, anyway I don't know.

When given the opportunity to think about the home finances the group came up with good ideas of how to be more in control.

This is what I think we should have at home, have a card phone.

J. A card phone oh right, why do you think you need a card phone?

So everyone can pay for their own calls

J. Right, how do calls get paid now, do you get bills?

Yeah, how much was the last one, over thirty dollars. Well it was thirty five or thirty dollars something, everybody's not the same one, they're all different. Oh there is only one person uses the telephone every day. Local calls you don't pay for do you? Well we don't know if they're doing it properly or not, because sometimes you'll find that everybody is getting different, and see, because there's one person find out that told (...) that everybody can pay the same one. No, we don't want to do it that way, uh uh.

J. So you want a system so that you know you are paying for your own calls

That's right.

Again the issue is not feeling in control, not having the information and feeling unable to ask. From a legal point of view this does not have to be the case.

Strictly careworkers, caregivers or parents of a person with an intellectual disability have no legal right to deal with money or property of an adult in their charge. Informally, this is often what happens and in practice they should make sure the money is kept safe and spent on the person with the disability, rather than anyone else.

(Bogard, 1995:172)

In practice it appears that more control is exercised over people's financial resources than can be justified, the key issue being the lack of information provided.

Mm, oh yeah we don't know where all the money goes that the organisation gets

J. I don't think the staff get paid a lot

I don't mean them I mean in the office, we don't know what they do with all of that money, because I don't think it goes to any of the workshops

J. So you think they should have to let you guys know what's happening?

Well we haven't been told about the people who - because the people who on their benefit and the people who go to their work experience, we have not been told properly, they don't say nothing to them. I don't know nothing because I'm too lazy to ask, but I don't want to ask stupid questions like that for - drive me up the wall anyway.

People living in residential services may appear to be 'well off' in terms of the quality of their surroundings. Many of the homes I have seen are desirable properties. The reality is that as individuals they are poor. This was also identified by Horner in her New Zealand research.

I think that one of her biggest limitations is her lack of finances. It really limits how much she can get out and about. What it really boils down to is that she hasn't got enough. I mean it's not as though she was asking for the world, like a car or a video. I mean I've got teenage kids and they ask for the world. But Kate wasn't asking for the world. She was asking for a cream cake and a cup of tea, or a trip out to buy something for five or ten dollars. But the money just wasn't there.

(Horner, 1994:168)

Even outside of residential service structures keeping control of money is an issue. Somehow once a support person becomes involved, control is exercised, as this participant states:

When I was at home I had my own bank account. The first account I opened I was stupid, I told my sister-in-law and she told my home help and I was in trouble because she didn't know what I was doing with my money. I wanted to have my own account that nobody else knew about, but they wouldn't let me.

Not being allowed to control your own money impacts on several levels. On a day to day basis it limits opportunities to exercise choice and to participate in the way you wish in the community. It is a disempowering process as without the information about what resources you do or do not have, and what you are entitled to, it is impossible to make informed decisions about the direction your life will follow. In terms of relationships there is potential for distrust of the people who control the money and a feeling of being owned by the service, which without access to your resources you are unable to exit. Finally there is a loss of individual identity, once you enter a service you are one of a group whose resources are combined to fund a service, you become financially co-dependent. Control is exercised in the guise of paternalism and people are not given the necessary skills to deal with their own money

DAY ACTIVITIES

In the 1970s and 80s day programmes were called workshops and sheltered industry was encouraged. Barnes (1990) describes a similar system occurring in Britain. Vocational services was also a term that was used and as this is the area that I worked in at that time,

I am describing personal experience as well as incorporating other research literature. People were encouraged to see themselves as workers and develop good work habits. This was in theory to prepare them for real jobs in the community. The participants talked about 'work' and 'jobs', although what they were referring to was often contract work, or other activities within the vocational centre. The vocational centres developed sewing and woodwork sections where people learnt skills and made items to be sold for fundraising. Although the participants have had work experience placements, they have had little and limited opportunity to participate in the paid workforce. The reality has been that few people have moved on to employment from the workshops but have found themselves going to and fro between work experience, special courses and the workshop, or vocational centre. This theme has therefore been entitled 'day activities' to encompass the variety of experiences described. People reflected on changes that had happened in their day activities that were outside of their control.

I said to (...) "is the sewing room and the woodwork still going?" and then (...) said to me "no it's not", I said "what happened we used to get a lot of money?" a lot of people used to come over and have a look how everybody getting on and making things, and they order, and they take how long it's going to take and people still coming in to have a look, but now it's stopped, but I don't know what happened, because that was getting good that way, because we were getting a lot of money for the (organisation). Well we can't do that again. We would like to.

The circulation between work, training and work experience being decided and planned for people rather than with people, is described by this participant, who attempted to make her own decisions, but it is still unclear what is actually going to happen.

Yeah, I started on the (Date). But because I was working on a full-time job a lot of staff didn't want me to stop, but it's not really up to them, it's up to me what I want to do, they tried to make me stay there, but I don't really want to, so actually what's going to happen next year, so I'll probably be working like one week with the bus, one week working with the old people and one week working with the office, but we don't really know about the old people, so (.....) is going to help me to find out what's going on, because I'm going back to Polytech next year and I'm not going to be at the Polytech all day, but I'm going to be - like one

week the day, but they let me know what's going on, so I go like this, back and forth, so that's what's going to happen.

Some people feel attached to the workshop, they have positive memories of how it was. When it was considered a place of work, good work habits were emphasised and at that time people were expected to act in the same way as the outside workforce.

Yeah we need better jobs at the workshop, we need more jobs there and everyone should be made to stay in the room like what we used to do before, until morning tea or lunch time.

They felt they had a part to play in the running of the workshop. It is this feeling of having a useful role to play that people miss.

But if I would be there helping the staff like what I used to work with (...), well I used to work but I don't know what happened, I don't know who stopped me doing it. I wasn't very happy. I had to go back to the office.

For others the current situation does not provide the same sense of usefulness. It is boring and repetitive work with little choice.

I would think that there should be more interesting things to do, because we get all these things that come in every month every three months and we get eh a thousand of them, maybe we've folded, printed the envelopes and stuck down with water, some of the envelopes have got a sticky part on them and some don't.

The reason why the past experience is seen as better is partly to do with the variety of activities available. It is unclear what the current role of the day centre is.

J. Do you want to say something about why it was good in the old days?

We had lots more to do then like books and jobs and everything like that.

Barnes (1990) describes how the young disabled people in his study saw the day centres as a place to socialise, rather than a site for rehabilitation or training. Although they were not compelled to attend the centres, the reality was that they had very few options of other places to go. The participants in my study had all been involved in centres at the time when they were called workshops and still saw work as a major focus of the centre. They realised however, that some people did not carry out contract work at the centre and from my own experience I know that some people are considered too disabled to 'work'. This group were often given little opportunities for active participation and the focus for them was around personal care and safety.

You need one staff to keep an eye on the people who can't do work, you only need another staff who can do work, but not in the same group, different groups, because then there aren't enough staff at the workshop, they need more staff, but I'm not there all the time but I'd like to be.

Barnes (1990) argues that the level of user involvement in the delivery of services, is considered by most writers concerned with the experience of impairment to be a central issue. The individuals in this study demonstrate their abilities and willingness to play a more active part in what happens in their day services. They have ideas and experiences that are valuable to offer but have no control in the current system. The day programmes they attend were historically places where they learnt skills to enable them to participate in the community.

The following description from Horner's research, is of one person's lifestyle having recently moved out of an institution and is similar to the experiences of the participants in my research.

Living in the community meant that Kate could, with supervision, catch local buses to her day's activities at a sheltered workshop. There she undertook craft work, went out to a community aerobics class and attended segregated cooking and dance classes. She also occasionally went on walks and to the local swimming pool. In the evenings Kate spent most of her time at home watching television.

(Horner, 1994:160)

The policy now is to integrate people into the community and the workforce (Central Region Health Authority, 1995) and more funding is now being directed away from sheltered industry and day activities into supported employment. Supported employment is defined as a process of placement, training and ongoing support with financial remuneration within an integrated setting (ASENZ, 1996). There is an expectation from the Community Funding Agency, the main funding provider for day programmes, that vocational services demonstrate how they are moving people towards employment. This is consistent with the current policy to reduce welfare spending (Fougere, 1994; Kelsey, 1995). The ultimate objective is that disabled people have the opportunity to become wage earners rather than welfare beneficiaries (ASENZ, 1996). As described in chapter one, the funding policy drives the service direction and although the outcomes may be beneficial for the individual, they are left with confused feelings about what is going on. This is because as identified in the literature, people with disabilities are not included in the development of the programme (Smull and Harrison, 1992), they fit into what is developed for them. One individual describes their current daytime activities.

I go to the (-----) Centre in the morning, help look after the kids and maybe tomorrow I could be on reception because I will be paid for that..... and I go to the Salvation Army on a Monday and Thursday.....I make up food packs, I do it for single people, people who live by themselves and a small family, and the extra large family.

I asked if this was better than being in the workshop.

Oh yes, it gets too boring in the workshop. Oh we're doing all those thousand of those sets. Oh god, everybody was doing it at first and then everybody just started getting sick of them and then there was work coming in from the light bulbs and er all this mail coming in had to be stapled and sent off, put in envelopes and sent off in the boxes and um that's the way it went.....
I wish there was a sewing room. I wish we still had sewing and I wish we still had weaving because in the winter time we did the weaving and we did the sewing in the winter time as well which was much better.

Throughout this theme of daily activities there is a tension for individuals between wanting to go back to the good old days and activities within the vocational centres,

which are remembered as enjoyable and appreciating the variety of opportunity that they experience some of the time in the community. The old activities such as sewing gave a sense of achievement and offered an element of choice, and at the same time were predictable in that people knew exactly what they were doing and why. The current experience of community opportunities is enjoyable, but also unpredictable, and outside of their control. People do not move forward in a planned direction by choice, they are dependent on the decisions of the service providers and unaware of the underlying policy changes.

MOBILITY

The defining of independence is different for workers and disabled people. Workers see independence in terms of the ability to perform tasks without assistance, whereas disabled people define it as the ability to exercise control over and make choices about one's life.

(Perkins, 1994:171)

The final aspect of lack of control that is explored here, is the inability to move around the environment when you have a physical impairment, unless the resources or support are there when you want them.

One participant describes her feelings about her electric wheelchair.

J. What about when you got this chair that must have been a big change?

Well the first day I got the electric chair it was neat - it went for 5 minutes then it stopped (laughter)

J. Was it broken?

Yes broken - it stopped - it feel like the wheels going round but wouldn't go up hills - like a brake on. Oh boy! Then one day I was on a course for 8 weeks I was putting my table on and I put it on and it went up in the air like when you're on a horse

J. Reared up?

It was terrible

J. Did you fall out?

No not really

J. So you love it and hate it this chair?

That was the old one before I had this one

J. It must have made a difference

*The first time I took it on the road I was a bit nervous and a bit uptight
- I'm more able now. Yes.*

I call my chair my baby I don't know why, I love it that's all.

Once she is out of her chair this person is reliant on support being there when she needs it.

Before I went in there I thought someone would sleep over but they don't. What if there was a fire in the night we'd be stuck. I have a phone by the bed for emergencies that's all.

Keith (1994) who also has a physical impairment, reflects on the frustration of fitting into the routine of the support people who control when you get to move where: "We were always waiting. Frustrated. Waiting on the toilet. Humiliated" (35). One of the participants who has a physical impairment, echoed the same feelings, when she stated that waiting for assistance to use the toilet was the worst thing about being disabled. Keith also describes how the staff were rarely available to take them out and were too rigid to be there when the person wanted to return (ibid). Georgeson, (1994) in discussing dependence and independence, had this to say.

Any involvement of caregivers therefore, must ensure that the disabled person maintains control over their life, whilst ensuring that the caregiver meets any self care and other support needs appropriately.

(Georgeson, 1994:67)

For one participant the frustration of the control over her movements led to the following action.

One day I ran away got a train to (...), nobody knew, they got the police searching for me. A taxi driver found me. I'd had enough, I wanted to get away. Now they watch where I'm going. I got into big trouble. It always comes back on me.

Although she is an adult in order to leave the house when she wants and go where she wants, she has to "run away". She is under surveillance (Foucault, 1977) and it is this ongoing visibility which maintains subjection. The practices of the institution are transferred to the community. The response of the service to her actions is to intensify the surveillance rather than to understand the desire to be free, to experience autonomy.

As Keith states:

I learned again how those deemed 'different' are divided from those deemed 'normal', how language is distorted to disguise this division.... It made visible to me something which is pernicious, dangerous because it is invisible. It was as if I had been trapped in a bubble, with powers, procedures, professionals pushing me in, keeping me in that bubble.

(1994:36.)

Conclusion

Throughout this section the experiences shared have reflected the controlling aspects of services that permeate peoples lives. This has been evident for the group in terms of institutionalisation, special schools, growing up in isolation from the mainstream and then being shifted into adult services. Lack of control has been expressed in terms of possessions, money, daily activities and mobility. This intensity of control is not experienced by most other people in the community and is a theme that was also

summarised by Wilkinson (1989) in her study of "being there" over a period of nine months in a service.

It seems that everybody experiences lack of control in certain situations, such as waiting for a delayed train or in the work place. The difference for the men from Oaklands was that most settings exerted control over them than vice versa. This would seem to be inevitable to some extent as they depended largely on paid others for their welfare. However, the incipient build up of powerlessness was disturbing and something the researcher found hard to handle. She recorded her actions in the diaries. Statements like "I was bored and furious; people should not have the right to waste other people's time" reflected the strength of her feelings.

(Wilkinson, 1989:59)

In essence this theme underlies all those that follow and in the next theme which examines 'choice' the focus for the group was particularly around living situations and the support received there.

Choice

How often do those who use services exercise any control over something as basic as who they live with?

(Clements *et al.*, 1995: 428)

Choice is one of the areas identified by O'Brien (1989) as part of the Social Role Valorisation approach which influences current service delivery. However the notion of choice making here (and inherent in the principle of normalisation) is about supporting people to develop the ability to choose. For example:

The physical setting offers the widest possible variety of opportunity for choice and individual and collaborative decision making. For instance, controls for water temperature, lights, radios, stereos, television, cooking and snack preparation equipment are accessible. People who do not know how to use them are systematically trained to do so. People have free time with access to a variety of different leisure

and recreational activities and are expected to choose among different activities for themselves. This includes the option to do nothing. A person who apparently expresses no choice is either taught to do so, or effort is made to understand the person's unconventional methods of communicating.

(O'Brien, 1981:13)

The group expressed a desire to make choices about key areas of their lives, not simply to select from a series of daily opportunities created by the service provider. They identified that real choice from an empowerment perspective is about contributing to the creation of the service that supports you or being enabled to move beyond the parameters of the service in order to live in the way you choose.

From my own experience, apart from the first time when I left home to go to college, I have always had a choice about who I live with. That first time I found myself sharing a room with a stranger in a boarding situation, a situation which was uncomfortable. Nevertheless we were able to negotiate an agreement as to use of space, knowing this was a time limited situation and by the end of the first term I had moved into a flat with a group of friends whom I had got to know through college. Although we may not always make the right choices about whom we live with, in Western society we can exercise this right. A key theme for the research group was that this fundamental right to have a say as to whom you live with was not the usual occurrence. As one of them said:

One of my problems was I didn't want to move into the home. It was there or an institution. I was going to have my own home and get money from R.H.A., it was to be a trust. I was this close to it and it all blew up. I didn't know what to do. My brain couldn't think about it.

This person lives with three males, she had only met one of them before she moved in. This experience of being placed in a home with strangers is echoed in a British setting by Keith in "Mustn't Grumble":

A home. A building in an inter-city residential street. I entered. I did not move in. Always listen to the jargon it says more than they want you to know.

(1994:33)

It is hard to imagine coping with a system where a stranger is deposited in your house, yet this happens continually in group homes for people with disabilities. The example of the participant in my research quoted above, parallels closely that of Keith:

When I arrived I was told I would be sharing a flat with three others.
When I arrived the three residents were told I would be moving in. We
had never met before, but it had been decided that our disparate lives
would collide.

(ibid,1994:34)

It should be argued that where people with disabilities are living together it should be on the same basis of choice as anyone else, because they like each other and get along (Taylor *et al.*,1987). Another of my participants described her experiences of group homes:

You can't choose who you want to be with because there's a - they're not all the same. A.... wasn't very friendly and then R.... started getting nasty and F... started up after her and D.... was the only friendly one in the house.

And R... has followed me all the way down to W....., but he ended up in the same flat as me, J..... said to me "oh you've got a new flatmate now" and I went "oh who's that?" and I looked at him and went "oh no not him, I just spent five years with him".

J. So you didn't know he was going to shift in?

I didn't know that he was coming down you see and we had to live together for a while and I did the cooking up there and wrote out all the groceries, what we needed and that and did all the grocery shopping myself because R... wouldn't help me.

J. So do you think that really if someone else is going to shift in, they should ask you about who's going to shift in?

Yes, I think J.... should have come to me first, instead of him instead of her bringing him up to the flats and said to me "oh you've got a new

flatmate now" it would have been better if she had let me know a week - a week before and then everything would have been all right, but he always fought with me in the flat.

J. Mm, so if you'd been asked before you might have said - you would have had the opportunity to say that you didn't really get on very well wouldn't you?

Yes.

Service deliverers seem to believe they can determine who will get on with who, without taking the simple course of asking people their opinion. People don't move; they are moved. In my recent involvement in setting up new services for people being deinstitutionalised I have frequently asked if the people that are being proposed to live together are compatible. I am invariably told that they are, based on various people's opinion. The reality is that the people have never actually met each other, but on paper they are deemed to be compatible. Taylor et al., (1987) suggests that in selecting people to live in group homes we should not group them according to categories. Sinson (1993) describes the following procedure in use in Scotland, when considering community relocation and interpersonal relationships.

We use Gunzburg P-A-C's. We sometimes ask the psychologist for IQ's and I use a development quotient as well. The Deaf/Blind Association produced a developmental booklet which you fill in and I also use Mary Sheridan which works in a similar way. Basically what you get at each age are four different milestones and if you match up the four with the person you get a reasonably accurate estimate of where they are.

(Sinson, 1993:95)

This assessment process is one which maintains distance from and control over the person (Lovett, 1996) and is similar to the use of IQ testing in terms of the resulting categorisation (Ballard, 1994). The use of standardised testing such as the above, to produce a profile of an individual, was the practice when I first began working in New Zealand in 1974. Since that time there has been a move to person-centred planning (O'Brien, 1989; Smull and Harrison, 1992) which involves the individual and those who

are close to them, in a process of mapping out where they are at. I argue that to make decisions on interpersonal relationships based on cross referencing milestones is unacceptable. How can we have become so blinkered that we believe we can make these decisions about others lives? You can not say that anyone will get on together until they get to meet. Taylor *et al.*, (1987) believes that in concentrating on people's special needs we have forgotten their human needs; the need for companionship and friendship, warmth and human dignity. How can we say we are offering people choice if there is only one option?

J. So how much say do you have when you're moving into a new place or something like that, how does that get done, do they ask who you want to live with?

I think that's a good idea because I don't think everyone needs staff to be told what we're supposed to be doing in our flat, because they've got D... in there and he goes bang bang bang all the time putting away the dishes and he doesn't know how to put it away quiet, makes too much noise and we told him not to fill his drinks up the top because he's spilling and spilling it all over the carpet, but he doesn't listen. I already told him this is your last warning and then he said I'm not doing anything for you, you can do it yourself.

J. So when you moved to (.....) did they ask you who you wanted to stay with or not?

No.

In any shared living situation there will be irritations and disagreements. These however remain more in proportion if we like the people we are living with. Alternatively we can choose to move or ask them to move, if things are not working out. This flexibility does not exist in services and consequently, people often only get to move when a vacancy arises or the situation becomes intolerable and the individual demonstrates challenging behaviour.

There is no evidence that those identified as challenging have needs radically different from those not so identified. It is just that they express their needs in ways that force them on our attention. What they illustrate is relevant to all those who use services (all human beings?) This in turn illustrates another important point - get services right for those who challenge and you get them right for a lot of other people too. Get rid of those who challenge and you lose vital perspectives on those services.

(Clements *et al.*, 1995:429)

Unfortunately, when a person has an intellectual disability label, their challenging behaviour is often viewed as part of the aetiology of intellectual impairment (Perkins, 1994) and we fail to consider the possibility that it is a legitimate response to inappropriate service delivery (Lovett, 1996). This is more likely to happen when services are based on the principle of normalisation, as discussed in chapter one. People working from this perspective, tend not to consider the historical or social context within which behaviours occur, or acknowledge that these contexts change, affecting events and behaviour (Perkins, 1994:161).

I will conclude this section on "who you get to live with", with the successful experience of one of the group.

I lived there for about six years and then nothing was - seemed to be going right with me so I ended up at (.....), then I was there for quite a few years and then everything started going wrong A.... sort of fighting with me and that and then F... started fighting with me and it just got on my nerves, so I said "I want to shift" I said "I don't want to live with (organisation) anymore, I want to live in a normal home with no (organisation) people". And I got a - there was a person who was looking - who wanted someone else to be with her. And she had a son, and I said "oh yes I would like to go down there" and that was in (...) Street. I was there for five years, then I found out we had to move and I didn't have nowhere to go K.... said she'll take me, so I ended up down here. It's really good down here. Yeah so we had a nice tea last night and we had steak and it wasn't very nice so we never had it, we put it to the side of the plate and (...) is taking it back to the shop and I had left

over chicken that was in the fridge. Yeah I get around to doing quite a few things now. I can um watch TV. In my bedroom, I've got my own TV. Yeah I can do what I like now.

When I first met the person quoted above, she was living in an institution. After 15 years living in services she has finally made it into the community. She still receives paid support, but she is no longer owned by an organisation. Isn't this what McKnight means when he talks about regenerating communities?

Our institutions are constantly reforming and reorganising themselves in an effort to create or allow relationships that can be characterised as "care". Nonetheless their ministrations consistently commodify themselves and become a service. For many people with uncommon fallibilities, their need is for care rather than service. While a managed system organised as a structure of control can deliver a service, it cannot deliver care. Care is a special relationship characterised by consent rather than control.

(McKnight, 1989 :14)

Another key aspect of choice identified concerned the people who supported them. In residential services the support people become part of the everyday domestic scene. In many cases they also "sleep over" in the house in case their support is required. As one of the group stated:

Make sure the right people get the jobs - that are working there. People have got to be happy with who they are living with. It doesn't matter if people can't do anything as long as they try to do what they can do, it don't matter if they can't do the job as long as they try.

Participants had ideas to offer about the kind of people they wanted to support them and it would therefore be important to include them in staff selection. I asked people to what extent they had been involved in this process.

J. Do you think you get any choice about who you have for staff?

Like um (K.....) s quite good eh, yes she's quite good, she's very good she takes us out.

(.....) is going to bring different people around the house, which the last manager didn't do. To see which one we like best.

J. That's a good idea.

Yeah that's what we did at (.....)

J. OK. so that was all right when it was happening, but it didn't happen last time?

No.

J. So what should we look for in the people?

They need to be patient and not lazy. They need to help others with the jobs, they need to know what they are doing.

J. Is it important the age of people who support you?

Well sometimes, if you have support people, sometimes you ask them but they can't really do the job, because they don't really know - they're not used to it because that's what they need to learn. Like sometimes if he has a seizure I have to show them what to do, because they don't know what to do.

J. If you had a choice how many support people would you have?

You don't need many people there's too many, but you only need people for the people who can't look after themselves properly. You only need the ones that really need help - people like (.....). (.....) always needs help to do things for her. But some people can do things for themselves - but they can't do everything you know.

Have any of you been involved in interviewing for support people?

I haven't.

Yes I have.

J. Is it a good idea?

It is a good idea because they're the people you talk to if you've got a problem - you know and you mightn't understand what they are saying. Then they have to listen to you - what you want to say to them. So if you don't like them you don't have to talk to them - that's what I always do. Cause I always ring up to say hello to the people if they are home and you speak to the support people but sometimes you don't know who you are talking to. There's too many.

Phelan and Cole (1993) describe their philosophy of putting the person first. They therefore believe that the person has a right to be involved in the process of staff selection. In my experience and that of the group, the decisions regarding who supports who, do not often involve the views of the people receiving the support. The ideas that the group had on staff training will be covered in a later section.

J. OK you get a lot of different staff don't you?

Yeah we um - if someone's going to work only for five days you know like (...) did, because sometimes he worked for seven days in a row and (.....) only worked for just two days in a weekend, but I think that something's going on and I think he's going to work for just one weekend and if he is I'm going to get really angry. Because he's good because he always asks me where I would like to go, you know he's really quite good. But I don't want her to work down one day because it sounds like we're going to have (...) really for six days and (...) going to work for one day but we don't know what days she's going to work on, so we have to wait and see.

It appears that we have become locked into formulas of service provision that are based on ratios for group homes rather than individualised support based on what a person needs help with. We need to adopt a person-centred approach to planning (Smull and Harrison, 1992) that identifies what an individual does and does not need and develop the service response from that basis. Our focus would then become one of supported living (Van Dam and Cameron-McGill, 1995) rather than facility management.

I asked the group what other things they wanted choice about. They talked about choosing one's own room and furniture and making everyday choices about shopping and what to eat. However, one person stated that not everybody gets to do this. The immediate living environment is a key area of concern as people are faced with this every day.

We need to choose the colours

J. What paints and that? What colour is your house

White! and we did not ask for that. I think because someone else told them to paint it white, cause when I said do we have to have it that colour - she said no you don't. It looks stupid. They should have learnt to ask us what colour we want for the house. You don't have to worry about the outside, that's nothing - it's the inside that matters.

Ultimately if people are to be given the right to make choices about who they live with, who supports them and how their daily environments are structured; there must be a redistribution of power, a "giving" from the powerful to the powerless (Freire:1972); otherwise choice making will be restricted to that which is allowable within the system. As stated in the theoretical section, we should be changing our service systems to fit individuals, not fitting people into our existing systems (Logan, 1988). The current social policy reflects the perspective of providing consumer choice (Kelsey, 1995) but as identified earlier the individual is often captured by the service provider and can not exercise this choice. However, the mechanism exists within the funding provider's policy (CRHA, 1996) to provide independent needs assessments, but it is important that this is available not only to new clients entering the system but also to people already receiving services who feel their needs are not being met.

It can be argued that if we continue to be influenced by the theory of Social Role Valorisation then we will continue to believe we have the right to direct others lives. This is illustrated in the following example.

Human service workers must work extra hard to assist people with disabilities achieve competence at work, in their homes, at leisure. Choices will have to be made about how best to do this. For example if a person with a disability had an opportunity of doing two jobs, both with the same pay and convenience, one of which was in a nursing home for elderly people, the other job at a hotel with a good reputation, it would be better to choose the job at the hotel thus avoiding past associations of people with disabilities, with sickness and incapacity.

(Wolfensberger,1989)

It is in denying individuals the right to make their own choices that the true devaluing of people lies. Wilkinson (1989) described that she survived her experience of being in a day service simply because she had the choice to leave after four hours. This "choice" was not available to the resident she was accompanying who indicated that he too felt desperate about having to remain there for a whole day. The next theme addresses an important ingredient in choice making and having your voice heard.

Someone to Listen

People who wish to change services need also to foster a far-sighted and open-minded vision of how things might be which, because it is grounded in reality and fairness, inspires people towards action.

(Brown and Smith 1989: 23)

It was the fundamental premise of listening to people that drew me to this research project. As identified in the theoretical section, only a few people are listening (Ballard, 1994) and only a few people have been listening to the voices of people with disabilities who are trapped within services (Gosling and Gerzon, 1994). As stated in chapter one, Sobsey (1991) identified that the history of services for people with intellectual disability has been written from the perspective of the professionals, not the people who use the

services. Even when people have been listened to as in Edgerton's study (1967), what they say is often not believed. As service providers our hearing can be selective. We provide structured opportunities where we expect people to speak, as in Individual Planning Programmes¹. The control in this situation remains of course with the service planner. I argue that as Munford (1992) suggests, we apply technologies of power to ensure that individuals fit within our schema. If, however we are interested in change, if we believe that people with an intellectual disability have an opinion to express, we must stop and listen.

The group expressed the need to have someone to talk to other than their paid hands-on support people. Someone who would listen to them when they had concerns and someone who did not have power over them. One of the group described a conflict they had with a support person and how they had spoken to a key worker outside of the home.

Well I didn't like him very well.

I went to have meeting with (...) and then (...) had a meeting with the manager.

J. Right and they listened to you that time?

Yeah

J. So they got rid of that person?

Yeah, it's like they asked me why I didn't want her, because she just put the food on the stove and then goes and watches TV all the time and not standing out there - she used to give us raw food, the others eat it then I'd go and cook something else when she's gone.

J. So is (...) like a key worker for you, is he like the key person?

Yeah, because he listens when we talk to him.

¹ Individual Programme Planning is a process introduced in the 1980s in intellectual disability services. Each individual has a planning meeting with their key workers on an annual basis from which an agreed plan of goals for their future is devised.

In the 1970s and 1980s, people had access to social workers who they could talk to about problems. In the restructuring of organisations providing services to people with intellectual disabilities, there has been a move to devolve the tasks of the social worker to become part of the role of the direct hands-on support staff. The social workers would be present at planning meetings and had a key role in people moving between houses. The support workers are often involved in 'doing for', rather than 'listening to' people.

Someone you can talk to properly, don't act like you're stupid, making people laugh think it's funny. Well I wouldn't laugh and think it's funny. I think it's better if we have different staff, it doesn't matter if there is one female, we could have a different male if they listen to you, what you would like to do. But sometimes it's really hard because they don't want to do it, like what P... did, he's always in a hurry to go home all the time.

Essentially the need is for someone to turn to when things arise in the daily life of services.

J. Do you think it was a good idea when you had social workers, Because we don't have them now do we?

No we don't have them anymore and I think it was good. I liked it very much. I don't know why we don't have them anymore. Because none of the staff think about anything like that.

One of the group described how one of the staff listened to them and advocated for them.

"I said I'd like to go and visit C..." and she said "mm good on you, you can go and visit him if you want to", so I went and visited him and stayed there for a while and then they came home and blew A... up, and A... says to them "well if he wants to go out and visit C...it's his own choice, because him and C... used to be great friends together those two" and A... says to Mrs... "it should be fair enough for him to go out if he wants to go out and visit a friend of his, it should be good enough for people to sort of stick up for themselves"

Worth (1988) describes the experiences and feelings of his friends living in institutions. For example, he tells of a man in a sheltered workshop who was bored with the same repetitive tasks and one day stopped working. The staff responded with verbal threats and attempts at physical removal. He hit out in self defence and as a consequence lost his place in a group home and was denied further service. Nobody would listen to his side of the story. Worth describes the feelings of hurt when staff ignore you: "you want to talk to that person, but they walk by you like you are dirt or something" (Worth 1988:169). The biggest barrier that disabled people face in communication is that nobody is listening to them. Examples of this were given by members of the group.

Sometimes you can't do things by yourself and you need the staff member to be there, you need to approach the staff member, but they might be busy and you mightn't want to talk to them

Examples also emerged in Horner's study (1994) of life in a community residence in New Zealand.

The staff often appeared to be involved in carrying out their organisational and other duties. There seemed to be little time available for talking with residents. For example, residents wanting to talk to staff when they arrived home often got the response "Go and put your bag in your room" or "Get in the shower now".

(Horner, 1994:168)

Being ignored can be said to be a subtle form of abuse.

*That's what I can't understand, I was there but they just ignored me
(pause) I felt sick boy- you know?*

In the *Central Regional Health Authority Issues and Guidelines for Services* (1995), the difficulty people have in sustaining and accessing personal networks outside of the service is identified and the consequences identified:

This means that when issues of personal safety arise there is often no one to notice and question an incident or circumstance.

(CRHA, 1995:5)

Horner also comments on the fragility of people's networks.

There is evidence that many people with disabilities are lonely. They are often reported to have fragile or non-existent support networks, and it is frequently noted that they desire friendships with others in the community.

(Horner, 1994:171)

These networks are essential if behaviour such as abuse is to be exposed so that it can be challenged and stopped. As Munford states (1995:51) "It is about people having relationships with others which are not determined by a person who has the "authority" to control one's life". Many people living in disability services do not have friends or other people in their lives who are not paid to be there, people to whom they can talk in safety, about what is happening to them.

Some of the group identified the role that family members played in this respect and this will be covered in a later section. Sometimes the relationship with support workers does provide an opportunity to be heard, as occurred in some of the previous examples. However, "Listening requires time and leads to having to take trouble" (Phelan and Cole, 1993:58), therefore support workers need to be prepared to set aside time to listen to people and to see this as an important aspect of their role. The consequences of listening may also mean having to act on what you have heard, at times this could be taking an advocacy role, which support people may consider to be outside of their responsibilities.

In the next section I will move on to explore the theme of relationships between service users and service workers.

Relationships

It is useful at this point to consider who the people are who work in services. Barnes (1990), in his examination of day care centres, identifies that the majority of workers are young, untrained and female. In their initial interactions with service users they operate on a relatively equal footing, the non-disabled helpers relying on the disabled users to

learn the ropes. Later on as they adjust, the workers take on an authority which changes the basis of the interactions.

Allen *et al* (1988) describe the stress placed on young workers who are untrained, who whilst still learning to take responsibility for their own lives, are attempting to support the emotional needs of service users older than themselves. It is not surprising, therefore, if they are unable to work constructively.

As one of the group responded when asked if the age of people who support you was important.

Well sometimes, if you are going to have support people, sometimes you ask them but they can't really do the job, because they don't really know - they're not used to it because that's what they need to learn. Like sometimes if he has a seizure I have to show them what to do, because they don't know what to do.

It is here that the life experience of people with disabilities goes unrecognised. To grow up and live in disability services means you are exposed on an everyday basis to impairments such as epilepsy. You know what to do. One of the group talked about this.

but a lot of people always shout, but I don't know why people always shout, because we're not supposed to be shouting, well I never shout if it happens to (...) you're supposed to come up to see if they're all right, but when I'm not there they have to be told to move the whole table out, the chair, because she'll hurt herself really bad.

J. You've got to know what to do.

Yes, get the ambulance straight away and then the doctor but if it's over eight minutes, that means you have to ring and then I have to call one of the staff, it doesn't matter who as long as they are not too far away, you know, no-one didn't teach me how to do it, you didn't teach me how to do it, I teach myself.

It is only in recognising people have skills and valuable experiences and knowledge that we can work in partnership. One of the group described this process in action.

Now that he's a full-time staff member I was going to congratulate him and thank him very much for his help because he's been good so far to all the people especially to D... and all of them, and he was sort of helping out with tea and all that and he was sort of helping D ... and all of them to sort of get to know the house and get to tidy up and get to do all the tea and get tea prepared for people

J. What do you like doing most around the place?

Well mostly I like doing cleaning and tidying up and helping the staff doing things.

The relationship between support workers and people with disabilities can become one of conflict.

If I find out she's working that one day and you know what the staff are going to do, they're going to get told off by me, I'm going to growl. I don't like having staff working one day it's stupid they should be working two days not one day. They won't get that much pay if they're going to work for one day better to work for two days, we can't have L... working for six days in a row, because that's not fair, that's why I'll probably have a word . Not with her, it's the people who are not letting other people have enough time. I'm not talking about S..., I'm talking about the staff.

The system is imposed and people's involvement is not sought in the process. There are real difficulties in recruiting people to work on weekends and evenings, particularly as the remuneration is often not seen as adequate. Often the people who are available to work weekends are students, whose primary motive is to earn money for their studies and who are only available at certain times of the year. Consequently, there is a high turnover, particularly with part-time workers.

Sometimes you don't know everybody very well, because you have to give them a chance. Why should we have to give them a chance if they're not going to listen?

J. Mm, well it must be hard when you get a strange person coming in new to start.

But it doesn't really work that way. You've got to give the staff a chance. I wouldn't give staff a chance, no way, what I'd do I'd just go for a walk.

As Smith and Brown (1992) identify, there is a tension between the power over people and the often resulting powerlessness to meet one's own needs. This is played out time and time again in services. This can lead to abuse, neglect or depression unless we begin to find ways in which people can combine the functions of support with the disabled person remaining in control.

J. So who decides about what food you're getting?

Usually me

(Flatmate) Yeah, but he does it all the time, because he's good that's why, but I can do it, but I don't like staff telling me what to do, I won't do it.

As I have demonstrated in the theme "lack of control" many of the interactions particularly within institutions were of compliance, sometimes under the guise of training, as the language in the following remembered interaction shows.

J. It must have been hard learning about money.

Yes and plus one of the staff was sort of teaching me a bit about money handling and he says - "I'll show you something", and I said "what is it you want to show me?" and he showed me the ten dollar note, and the twenty dollar note, and he said to me "how much is there, can you guess?" and I said "um is it fifty dollars or twenty dollars?" and then

he said "no you nearly had it right" and I said "is it fifty?" and he says "yes it's fifty dollars a week", that's part of money handling, when people sort of count out all the money that you have got in you purse, they sort of ask us, give them the money so that they can count it all out and I said "can you count this out please sir?" and he went "yeah, I'll count it all out for you" so we ended up counting one two three four five six seven eight nine ten eleven twelve thirteen fourteen fifteen sixteen and he carried on until he got to a hundred dollar.

The above quote reminded me of the many times I had sat training people in money handling. However this was certainly an improvement on the total lack of communication that I have observed within institutions as demonstrated in the following example from a British institution.

Both men were wheeled straight from the bus to their own rooms where their physical needs were attended to. They were then left in their wheelchairs facing the window until the evening meal was ready. The ubiquitous tape recorder was then set in motion, but at the end of the tape nobody came to change it. Both rooms looked out on an unstimulating view but given the angle of their wheelchairs and their lack of muscular control, it is doubtful whether either man could actually see out of the window. Nobody visited, no member of staff called to see they were all right, no other resident looked in to see them.

(Sinson, 1993: 87)

It can be argued that any degree of communication in the relationship between caregiver and recipient would be desirable in comparison to that level of isolation.

Normalisation has been a major influence on service workers who have been through training programmes. As a person who had been frustrated by the medical perspective of caring within institutions I found the implementation of the normalisation process liberating in working in a community day programme. Liberating for me that was, instead of filling in time with no particular goal, I now had a purpose! I became expert at structuring rhythms of the day that involved people in community participation, training programmes that analysed and taught new skills offering choices within carefully synchronised timetables for meaningful activities. We introduced Individual Planning

Programmes that replaced Case Conferences and in which the individual participated in setting new goals to work towards. What did not change with this process was the power relations between myself as a worker and the individual as a recipient. This analysis I have only gained now in hindsight. It is not the role of the service worker to move the person towards independence in terms of the ability to perform tasks without assistance. Disabled people define independence as the ability to exercise control over and make choices about one's life. (Oliver, 1990).

The power relations are obvious in the following example from Horner's study.

Ella also liked to be able to make decisions for herself and did not enjoy the control staff had over her life. My research notes indicated that many of Ella's complaints about staff involved them telling her what to do. For example, she told me: 'I hate Andy, he makes me get out of bed in the morning'. 'I hate Jan, she makes me go for a walk.' In one interview Ella said 'Deb won't let me stay up till ten o'clock and I don't like it.'

(Horner, 1994:175)

What is required is a move towards interdependence, a state of reciprocity, where both the worker and the disabled person contribute to each other. One of the our group reflected on a moment when reciprocity occurred.

And S... was sort of telling us a bit about himself and how he became well trained as a staff member and I thought it was good of S... to sort of talk a bit about himself.

Another group member gave a clear example of the unequal power within a day centre and how abusive this feels.

If anyone's been naughty they tell them off but when - no I'd better not - It's all right for them but not for disabled people - it's all right for the staff you know what I mean?

J. Yes.

How do I put it - every now and then I pop in to see what it's like - but it's still the same - before I left there (pause) sorry - all of the staff was smoking and having fun and all the other ones you know disabled people was going up and down the hallway all day bored you know (sigh) not like the old days - no way.

J. Is there anything you would like to see changed about services?

The whole lot - one thing I really hate is if you are disabled and people make fun of you, like when you are not able to talk properly they copy you

J. Kids or older people?

Staff.

J. Staff?

*Yes, you don't know how bad it is. But people think that I make trouble -
what can I do? - that's what they think.*

J. Have there been more good times or bad times?

Well before you left it was neat you know (sigh) that's what I hate most of all - shut up now.

This feeling of things changing and losing support people who are valued was echoed by another member of the group.

G....'s really quite good but someone told her off, remember on Christmas Day when she was working. J.... told her off when she didn't come back at the right time when she was supposed to be working. But everything has changed, if you look at the workshop that's not the same people we used to have before, because all the good staff gone, because all the staff used to have all the work going in the room, but it's

different now because it's not the same people. See T... has gone and T... didn't want to leave that place in the first place but now he has gone. He's a good staff T...

J. So you reckon you lose the good staff?

Yeah.

Over the last two decades I have seen enormous staff turnover. Few of the existing staff have any knowledge of the history of people and the history of the services. It is the people with disabilities who have been the constant, who know of the changes and who have a sense of grief for what they have lost. It can be argued that they are beginning to see that things could be different. I will finish this theme with an example of what can happen when we move from control to partnership and when conscientisation occurs (Freire, 1972).

We have grown with the residents as they have discovered that hand in hand with choice comes responsibility and we have weathered the eventual disbelief and anger which is inevitable in the emotions of adults who begin to exercise rights and responsibilities previously denied by other adults. "why didn't they tell us we could do all this before? What right had they to treat us all like children? I know it's better late than never but they should never have been allowed to treat us like they did". Now in his late fifties George was making a cup of tea for himself for the first time in his life when his satisfaction with the achievement turned to disbelief and anger as he recognised what he had been denied all his life. Helping George to acquire the practical skills of making a cup of tea had been straightforward, but it had taken weeks of patient listening and gentle persuasion to enable him to consider that "they" might have been wrong when they told him he could not do such a thing.

(Phelan and Cole, 1993 :59)

It is only at this point Freire would say that the struggle can begin: "With men's (sic) recognition that they have been destroyed" (Freire, 1972:44). This is the point that Freire calls 'conscientisation' when people realise what has happened to them, then they can

start to demand change. It is at this point that revolutions can begin. If we want to be a positive part of the revolution of service change, then I would argue that we must learn to listen and start to work with disabled people in developing more equitable ways of providing support and organising services. We must be prepared to give up our power and work in partnership, to become jointly responsible for a process in which we can all grow. (Freire, 1972; 53)

In this chapter I have described four themes which provide an analysis of the experience people have of disabilism within services. They lack control over key issues; their choices are restricted to within prescribed limits; they have difficulty in finding people to listen to them and they are oppressed within the caregiving relationship. Throughout these themes I have identified key points that could improve the quality of these lived experiences. I will return to these points in the final chapter to provide an agenda for change.

Chapter Four

Listening to the Stories - Significant others who support or hinder

In this chapter I continue to tell the stories from the themes identified by the participants. They talk about staff and their views on training; the need to feel safe whilst still retaining autonomy; the difficulties they experience in waiting; the positive and negative aspects of relationships with their peers; contact with their families; their views about labels, the responses they experience from other people and how they see themselves.

Staff Training

The participants expressed opinions on what training they thought staff had and what training they considered important. They identified that at times they felt they knew more than the staff, for example (as covered in chapter three) in their knowledge of epileptic seizures and that they were in effect supporting the support workers.

The background and training people have influences the way they work and there are a number of people working in community services that were trained in institutions. With the establishment of institutions for people with disabilities there was a development of nursing staff specifically for that area. The term 'psychopaedic' was adopted and the training available was as psychopaedic training officers or nurses. With the process of deinstitutionalisation, support workers with this background moved into the community. Many of the staff in this field, however, have had little or no training other than in-service courses within organisations. I asked one of the group if the support person he had was trained.

Yes they are all fully trained. C... was fully trained when she was sort of like a nurse at one of the psychiatric hospitals that's how C... became involved, she was a nurse before she became one of the staff up here.

It is through this process that institutional practices are often translated into the community setting. The relationship between support worker and service user can remain on a basis of carer and receiver with an emphasis on aspects such as personal care and hygiene, or trainer and trainee with an emphasis on skill acquisition.

Rucker (1987) described the support skills considered desirable in the setting up of a new community based support programme in Nebraska.

The staff hired for work training and home living had an average of over 3 years experience in the field of mental retardation. In addition we felt that staff must demonstrate skills in the areas of behaviour management, environmental control such as multiple scheduling, stimulus control, data collection and multiple/individualised programming. Some staff needed to have skills in the area of sign language.

(Rucker, 1987:117)

When asked about staff training the group were clear that they needed the right sort of people to support them. As a group they made the following comments.

Make sure the right people get the jobs,

J. So what should we look for in the people?

They need to be patient

and not lazy

They've got to help others with the jobs

they need to know what they are doing

and not just watch others

J. OK so we need people who work hard?

Take people out where they would like to go. It's not really up to the staff it's up to the people where they want to go. You can't treat them like - oh I can't say their names-it's really up to them what they'd like to do and when they want to.

They shouldn't treat them like babies, not to be treated like kids.

Treat people the same way they treat everyone else

The above statements about what support people should do, could seem at first sight to fit with the goal of residential services articulated by Knoll and Ford (1987), that is people should participate in the community as their neighbours do and that within the home they should be actively involved in the functioning of the house to the maximum extent possible. "After all the life of a home revolves around the people who live there; people's lives are not defined by their houses." (ibid:134)

However nowhere in this goal of participation does it talk about the quality of the relationships or how the goal was arrived at. Doesn't 'not being treated as kids' mean making decisions about the life you lead, rather than being involved in activities? Who decides 'the maximum extent possible' and who defines what it is that 'neighbours do'?

Robert Bogdan reported that when he visited the residence of three people with severe and multiple disabilities who lived with a family, he asked the name of the programme. The response of the family was that there wasn't a name - 'it's a home, not a programme'.

(Horner, 1994:176)

If you live as part of a family it is easier to maintain the perspective of a home. It would appear that with the group home model, the focus can easily become that of a facility from the perspective of the staff who work there, or of a pseudo-family, with the staff taking on the parental role (Clements *et al*, 1995). If the life of the home is truly to revolve around the people, staff need training to sought out the boundaries, follow the directions of the people and to listen and respect what people say. There are some tasks which the group saw as staff jobs and these will be referred to in the section on safety. Phelan and Cole (1993:61), use the following key question to themselves in the process of selecting support people: "Would I feel comfortable with this person reading a private letter to me?"

I feel strongly that support workers need to be trained to work for and with people not organisations. The organisation should be the vehicle that facilitates the support of

people. The following statement demonstrates that in a British setting this is often not the case.

The staff who were supposedly our arms and legs, supposedly at our beck and call, were rarely available to take us out, were too rigid to say 'Be back anytime and we'll be there to give you the necessary hand'

(Keith, 1994:33)

If we were to incorporate the views of disabled people into staff training and facilitate their participation in the delivery of the training, we might achieve a better balance between meeting people's needs without taking over control of people's lives.

Safety

One of the issues that arose when thinking about the support the participants needed from staff and, therefore, training needed for staff, was in the area of feeling safe. For people who had medical conditions like epilepsy this was important and also for people who needed assistance to physically move around.

As previously mentioned in the theme of 'Control' there is the safety issue of being alone in an environment in which you are immobilised, in the event of an emergency. This is a common issue for many people with physical impairments who cannot afford 24 hour support. People with physical impairments given the right aids however, can move autonomously around the community. This requires some 'letting go' by those who support them.

*The first time I went on the road I was a bit nervous and a bit uptight -
I'm more able now. Yes.*

The group home is one way of gathering people together to share support needs with a consequent loss of autonomy. However even in a group situation all needs are not necessarily met.

J. What do you need staff for?

I guess for emergencies yeah, or getting new staff members trained.

Yeah but sometimes it's going to be hard because when L... came over and spoke to us on Thursday she said to us about it on Thursday that we couldn't have anybody on Friday, but I said to her we do need someone to come on Friday to do putting out someone's medicine, because no-one wants to do it and I don't want to do it, because it's dangerous, it's not my problem because I'm not a staff. I don't do the staff job it's not my job, I don't get paid to do it. Yeah so we need someone to stay on Friday to fill up T... 's medicine because she has to have it because she has to have it because she has seizures.

It was in such crucial aspects of safety that people identified a need and this may pose difficulties with high staff turnovers.

What kind of training do you think it is important that staff have?

I think they should know what to do when you have a fire, when someone has a turn and helping people like M... (M. is blind)

J. Like teaching him to do things?

Yeah because it's like he doesn't do any jobs down the house where we are now because we have to do it with him.

J. So there should be someone who helps and teaches him to do it properly?

Yeah

J. Do you think that most of the staff that you have are trained enough?

No, not the one that's just going to leave, I don't think he's really that good.

When we talk about community integration we may view people as capable in terms of the skills and abilities they have and therefore presume that they can function 'independently'. It is this dichotomy we are trapped in between dependence and independence as modes of functioning that raises problems for people. As stated earlier I argue that there is a need to move towards interdependence in order to avoid dumping people without adequate support. The research shows there are things we can do together in partnership with others where our skills and abilities can be complimentary (Boyles, 1995). There are also as Georgeson (1994) identified, some tasks that are essential in terms of meeting the needs of disabled people, such as bathing, dressing and grooming, to enable people to live with dignity. O'Brien (1996) used the analogy that providing assistance is like entering a dance, where we learn the steps together and develop the rhythm as we progress.

J. OK. If you had the choice, do you like having jobs out on your own, or do you prefer to be with a team, scrub cutting or whatever?

With a team.

Just in case I 'go off'. Because the last one I had at the supermarket I had it underneath this seat - you know those seats stuck in the ground, that's why I'm all sore. And this woman got me kicked out because I punched the person when I was having the turn.

J. Oh, so you feel safer if you're with a team?

Yeah, because when I was working with some of those guys scrub cutting they were learning what to do, learning first aid.

Sinson (1993) gives a full description of a programme in Scotland that moves people from institutional settings to community flats. The process is one of moving from dependence through a training flat, to a community flat where the support is gradually faded, to occasional visits by key workers. One key worker describes the outcome for one person.

She's so proud of her home but I wonder if she's just existing there. When she comes home she does the same thing every time. She'll take her coat off and she'll switch on the television and that's time for tea. If

you go in one day and then again the next day, you'll find her sitting in exactly the same place and everything in the same place - as if it hasn't been touched. In an ordinary house there is always something out of place. Like Enid's house - where she has to tidy up - that tells you an awful lot and that's normality. I wonder if Mary just spends her time just standing by the window - she misses company.

(Sinson 1993:112)

There is a balance to be found between safety and autonomy and it can be argued that the only way to identify what this is for each person is to listen to them. People know what they need and what they can do for themselves, as one person described about her time working in a shop.

Yeah. I wish it was still going, that was very good. That was down town.

On a Friday night I worked till about six o'clock at night time, because we had a late night and that was always on a Friday. We always finished about half past six at night and I got myself back home, that wasn't very hard to do anyway. The staff thought that I would find it very difficult to do, no.

J. You used to work the till and that eh?

Yeah. I said "I can do it" I said "you just wait and see, I'll be back here - back in the house at seven o'clock", and I always was on a Friday.

This research reinforces other research in that it shows that we may need to refocus our concept of services away from fitting people into what services want to do (Logan, 1988), towards responding appropriately to each individual's needs (Georgeson, 1994). If we acknowledge that all disabled people have skills and abilities they can utilise given the right support, we can then learn to dance together in partnership (Boyles, 1995; O'Brien, 1996).

Waiting

In the first chapter I identified the passivity of many disabled people within the caregiving relationship, which Munford (1992) describes as 'waiting' to have their needs met on a variety of levels. There have been many points in this study when people have identified 'waiting'. Although many of the examples given have already been included within the other themes, it is important I feel to note that it is part of the everyday acceptance that people in services develop, that things will happen when someone else decides or when people have time. It is insidious to daily living and, therefore, largely invisible, it becomes part of a routine that nobody stops to question. An example of this from my own experience is that I can remember as a support worker assisting someone on to the toilet, rushing away to do something else and getting involved, only to realise the person has been sitting waiting for me to come back. I don't recall the person complaining, just accepting this as the way it was. For myself I think I was enmeshed in the image of "super-carer" (Munford, 1995:17) creatively juggling a myriad of responsibilities. 'Waiting' also becomes part of the experience of caregivers in terms of their interactions with professionals (Munford, 1995; Wills, 1994).

After 15 years of *waiting* to live in the community, not in an institution, not in a group home, this person is now content.

*Um well I just like to live a normal life and not be with the others
because that's the way I said I wanted it and that's the way it turned out
to be and I think I've found it much better
And so I actually have a good time now, last night I did all the
vegetables, for the first time last night.*

In her study, Sinson (1993) describes the lead up to a move into the community. She critiques the continuum model where one is trained in readiness for the next stages of residential placement.

The first to move were the people living in the lodge and the bungalow in the grounds who had been on minimal care training for four and a half years. They had already completed their basic social skills training and it was doubtful how many of them were actually disabled. They resented this length of time. The minute we offered them homes they

couldn't wait. You get people to a certain crescendo point and up to a certain level of development and given these criteria you then have to move them on.

(ibid:93)

The concept of readiness has been a trap in services (O'Brien, 1989) that has been reinforced by the use of standardised assessment tools that chart people's achievements on developmental scales. Dixon (1994), a parent, describes the fact that people learn to do ordinary things in ordinary places. People are able to live in the community with appropriate support as they learn. My research and others have shown the importance of people achieving new skills, rather than waiting until someone decides they are ready. Sometimes, as in the case of one group member who was institutionalised at three, one must wait for a change in government policy such as deinstitutionalisation, before something happens.

and that's when we all decided to leave (name of institution)

J. OK so how did that come about, how old would you have been when you left?

Well I was about twenty one, twenty two I think when I left.

For another person, it was always waiting to be told what is happening.

I think it might be the same thing we are doing in 1995 at the moment, but I don't really - really sure what's going to happen, I have to wait and see,

D... has to talk to C.... because she's my support person, so I have to wait and see.

But I know I'll be getting a job for every Friday but I don't know which, so I have to wait and see.

It can be argued that waiting in effect becomes another subtle form of abuse.

Disabled people mainly live in a world which consists of 'Wait a minute,' and so their lives go by ignored, continually abused by those with power and who exert control.

(Macfarlane, 1994:88)

So far I have focused on the relationships and interactions between service users and service workers, I will now move on in the next theme to describe the peer relationships the group identified.

Peer Relationships

One of the themes that stood out clearly from the start of this research project was a sense of history that exists between people who have spent their time in disability services. Our initial conversations revolved around, 'do you remember so and so?' and 'what happened to so and so?' Reminiscences occurred during the interviews about particular people. These conversations were able to happen because I was also part of their history and knew the people and places they spoke of.

J. So you still keep in touch with some people do you?

Yeah we do yeah

J. Like B.....?

Well actually I'm just waiting for a letter from her.

I haven't seen her for a couple of years. She left because D..., oh she thought I was talking about her, but it was the other way - it was D... and then she left the house.

But I think that she's not living the same place that she was, but I think it's not far away, but she's still living in a flat by herself, you know. I think she's got a job in H....

One of the group stated that he had better friends when he had lived in another area than he did now. A lot of the people had moved to different parts of the country but were still living in disability services so there was a 'grapevine' of information that operated. This

network is part of the culture of people with disabilities (Horner, 1994; Jones, 1992; Perkins, 1994).

Do you remember when we had a wedding for P.... and P....? P... told me they had to go home so I wasn't really happy about it, but I didn't know what to do. I said "P.... this is not your home this is really belonging to your husband, not your place, what are you doing?" and then she told the other two to go home but I was in the kitchen I think making myself a drink, that was a long time ago.

I told him not to live with her. It didn't work out.

She's big now, P....'s big and smoking a lot and drinking.

The person who had lived in an institution for most of his life could remember a long list of names of people who had lived with him. When asked about the people who had left at the same time as him, he knew where most of them were and still had contact with a number who were nearby. He recalls meeting up with some of them.

*Er I think I was at O... and Mrs ... was the one that took me to the workshop to meet some of the people there and I met up with all my old friends, the first guy I met up with was C....
She said this is C... and I said "oh I know C..." and she says "do you?" and I said "yes" because he was one of the guys I knew from (the institution).*

The people who have lived together in an institution have a greater understanding and acceptance of each other based on their shared experience (Jones, 1992). One of them describes his current living situation with another resident who was with him in the institution.

Yeah because I get along with G.... and all of them. I get along with all these people so far, because G....'s really the only one that really needs help at the moment because he's - how shall I put it? He's sort of like A..., but he's sort of helping a bit, he's um coping on the job and that and doing things for the staff like helping with the tea and - yeah he's

good that way, he prepares everything and sometimes people may give him a hard time, but he's OK with people that know him a lot, he's OK that way.

I asked another person who had lived in an institution if they had maintained contact with people from there.

J. Have you got friends that you've had for a long time?

Oh yes, um all of them up there knows me and I went up there one Friday and one of my friends came out and she said "oh T..., long time no see" and then A... saw me and she was so pleased to see me that she wanted my phone number, so I gave her my phone number and I gave my address to her, which she wanted and I said to her "if you're going to come down to my place for the day, you must always ring to make sure we're going to be home" because I said to her sometimes I'm not home.

I reminisced with one person about the day service we had both been at.

J. What about when I was there, you had people who were friends.

Yes

J. But a lot of them aren't there now

Do you mean that when they left?

J. I mean that people, I don't know why they left, but some people moved

I think they left because they were bored, that's what I think, but they were more able people, they could do lots of things not like me.

It is my experience that there is a high turnover of staff and consequently I often find that support workers have very little knowledge of the past lives of the people they

support. However, amongst the people themselves, when you know them and, therefore, know what to ask them about, there is an extensive source of history. The friendships that people have developed are strong and there is a sense of solidarity. This was also noted in Horner's study.

You go anywhere with Chris and he seems to know a lot of people. He remembers people from way back. Like he remembers Cloverlea staff. He has a wide range of acquaintances.

(Horner, 1994 :171)

As Freire (1972) describes the sense of solidarity that emerges among the oppressed in opposition to the oppressors, I would argue that a parallel has emerged for people in disability services. Their sense of solidarity comes from their shared sense of experience in common environments as users of services, who have supported each other in developing strategies to survive against the controlling aspects of service deliverers.

In the field of mental handicap the growth of the self-advocacy movement reflects the ability of the spirit of self-determination to emerge in the face of *and* (paradoxically) with the help of, an oppressive and dependency-inducing style of professional help. Many professionals, of course, struggle to escape from this difficulty. Others fail to recognise its existence.

(Breachin and Swain,1994:48)

The people in the group have moved around a lot and lived in several homes as is seen in Rocky's pen portrait. Often examples emerged of the moves happening because there was conflict between people living together, or people where unhappy with their environments.

(Day Programme) wasn't very good because I didn't like the way it was in that the others there just didn't get on you know. They um - I got sick and I ended up in hospital and I never went back again and I don't know how R... did it, maybe she said something to the staff that she doesn't want to go anymore, she could have I'm not sure, because I said to her - I have asked her, how come you're not at (Day Programme), she said to me she doesn't want to go there anymore.

J. Well it's good she didn't have to stay then isn't it if she didn't want to

Yeah. No they seem to move around - move around a lot

J. Go round in circles and meet up with each other again

Yeah, I'll say.

The hospital the person referred to above was a psychiatric one.

Another example was:

I was sort of staying with them for a while and then S.... says "oh, I've done tea, could you do the dishes?" and I said "S... , you're supposed to be doing the dishes and everybody else was meant to have a rest" and of course S... and C... and all of them started an argument and that's what started the whole performance off and then I said to S.... "well if you don't behave yourself, I'm going to move out and move somewhere else where you can't pick on people."

J. So you didn't get on with her eh.

No

J. So is that when you came back to W....

Yeah and I decided to move up here.

We talked about the difference between learning skills in an institution like cooking and using them in a home.

J. It'd be a bit different when you're in a house like this eh?

Yes, because then you have to do things for yourself and do things for other people as well, as well as doing things for yourself, at the same time.

It seems that we have put effort into teaching people to do tasks, but have not addressed the area of social functioning, team work and reciprocity. We respond to problems by moving people on rather than supporting people to problem solve (Lovett, 1996; Phelan and Cole, 1993).

Then I came home and there was a big argument P.... was shouting at her for nothing and she said "I wasn't to know that J.... was coming" to the house yeah, so I didn't last long at the house anyway.

This research and other research has shown that if we continue to operate residential services on a group home basis we need to ensure that people have choice about who they live with, and that disabled people also learn skills like team building and conflict resolution.

One of the other issues identified in terms of peer relationships was the lack of privacy. This in a sense is another characteristic of a close community; everyone knows what everyone else is doing. The issues of privacy and confidentiality are inter-linked, as without the former it is extremely difficult to have the latter.

Then what happens someone tells someone else before they're not supposed to be telling everybody, you're supposed to keep it to yourself. I don't like telling everybody if someone told me to and that's what I said to A... "no don't tell anybody what happens" but he tells everybody you know what he gets, then she starts crying.

J. It's pretty hard to have any secrets in isn't it?

Well S.... is the same too. There's a problem going on, people tell, you know you've got D..., you've got S.... and you've got K... . There's about three people who tell all the time, you're not supposed to do that, you're supposed to keep it to your self. Well what happens if you say to your husband "oh John, please don't tell anybody", you like to keep it for yourself, because you'll spoil it and when anybody says something to me, I say "don't tell anyone". I already told D.... off, she's a staff and I said to D... "what have you done? Have you told?" and she did. I wasn't very happy with her, but she did get told off from me. It doesn't matter

if you are a staff, I will growl. If people don't like it that's their problem. They've been told lots of times not to say anything. If J... tells me to keep this secret, I'll keep this secret for myself, I don't go and tell anybody about it, because that's stupid. Because the people never forget what you said that's why.

This point about confidentiality was raised in the initial composition of the research group. Some people were not asked to participate as they were viewed by their peers as people who could not keep secrets.

The other aspect of privacy was not being able to spend time on one's own.

Half of them go and hide themselves, they hide themselves in the toilets half the time.

J. And that's where people go to get out of the way, in the toilets?

Yeah it's the only place they can hide, they just lock themselves in the toilet.

The issue of being able to talk to people without others knowing was raised earlier in the section on making contact. It seems that there are few places where people can just be alone or with friends, without others knowing.

You see last time he was coming over my place at for the weekend, but he wasn't really sleeping with me, but he was sleeping - I was sleeping on my double bed, he was sleeping on one side of my bed, I was sleeping on one side. He told and I got angry. Sometimes he's forgetting not to let the staff know that's the problem.

The following quote echos the theme of privacy raised above.

I missed the luxury of private sorrow, the joy of a private tear. What was private had been made public.

(Keith, 1994:35)

It has been demonstrated that within peer relationships there are multiple dynamics. There is solidarity and conflict; a sense of shared history which brings people together and also a loss of individual privacy. These are elements of the culture that exists in disability services. It is difficult to live within this culture and maintain individuality, and this can be where conflict arises. It is not a matter of being together always through choice. The structure is imposed and may actively prevent people who wish to remain together from doing so, at the same time dictating to those who do not wish to be together, that they have no other option. Without the service culture however, some individuals would no doubt continue to view each other as peers and maintain relationships. For example the desire to reconnect with people who were still considered friends, but who no longer lived in the same service area, was expressed by the participants. In this sense the relationships are a creation of both the service structures and the community of intellectually disabled people.

Families

The other area of relationships which was important to the group was that of families. For the two people who had been institutionalised at an early age the sense of family was more one of knowing where you came from and who you were related to, rather than having an ongoing contact at the time.

J. Do you still see any of your family there?

Well I see my sister occasionally and my brother-in-law, I see them quite a bit.

J. Oh right do they live near here?

Well my sister, she lives up in Taupo in (.....)'s Bay, that's mine and my uncle's and my father's surname

J. So that's where your name comes from

Yeah.

For the other person she recalled how she came to be with the service organisation after leaving residential school and the extended family members that she was living with at that time, before she was encouraged to go 'flatting'.

J. Was that the first place?

Yeah, C..... was the first place, C.... when I was sixteen, that's when I was sixteen years old when I came, because that was my uncle Bobby asked my mother and who's the other one and my cousin, that's my uncle Bobby's grandson, so that's when I first started, because I remember you picked me up from my auntie's place when I moved down to

As a service worker I recall that the normalisation principle was behind our thinking regarding the development of residential services, at that time. The group home was portrayed as 'flatting' and the age appropriate norm applied for teenagers and young adults, was to leave home and flat with others of a similar age group. I suppose on a personal level at the time, this seemed to match my own experience of leaving home at 18 to flat whilst I was at college. I certainly did not analyse at the time the cultural or economic differences between our situations. It is only in hindsight that I reflect on the fact that my eldest brother did not leave home until he was 40 despite the fact that he was a wage earner from 18. He certainly did not conform to the age appropriate norm for leaving home. Often if an adult with a disability remained at home this was viewed as a parental difficulty in 'letting go'. One of the group however was quite clear about his desire to leave home.

J. OK so you were living at home then

Yeah

J. and then it was quite a while before you came into residential

Yes I got sick of that crabby guy

J. Your Dad?

Yeah

J. and I suppose most of your brothers had left home by then eh

Yeah they all got a headache from Mum and Dad.

Another member of the group who was still living at home at the start of this study, saw herself as having far more autonomy than the other group members. Certainly her financial situation was better and she had more freedom to move around the community. During this study she moved into a residential service with a consequent loss of control over both her finances and her mobility. This was in spite of her protestation.

They want me to move - I'm not going to move - I've lived here since I was little.

A key person of importance in her life was her brother, as he was her remaining family link, who kept in regular contact. Maintaining some family contact is important to the participants in the group.

J. Do you still have contact with your brothers now?

Yeah, my brother and sister still rings me sometimes

J. And you still go to big family gatherings and things, yes?

Yeah, when was the last big party earlier this year. Auntie and uncle were seventy, they're twins, that's when relations from overseas came too

J. So who organises for you to go to something like that?

My brother rang me up and said he was going to come and pick me up.

As mentioned earlier in the theme 'someone to listen', for some people it is family members who fulfil this role.

Yes, so I used to ring my parents and I told my father I wasn't very happy and so Dad came up to the flats and he had a go with J....

J. Do you see any of your brothers and that now?

Um I see G..... quite a bit. If I don't know - I got this letter from Farmers and I didn't quite understand it and he came up to the house to read it and he said to me "oh that's no good" so he just screwed it up and put it in the rubbish tin

J. So he keeps in touch if you need him?

Yeah, or I ring them. If I need healing on me, my brother does healing and my sister-in-law too

J. Oh really?

Um, if there's anything wrong I ask them whether they'll do healing on me

J. Does it work?

Oh yes it does. It works all right. They take the aches and pains out of me. Yeah It's amazing how things work.

Horner also identified the importance of family and described the family contacts of the people in her study.

His supervisors at the institution and in the community reported that Chris's siblings visited him once or twice a year. During the period of the study one of his brothers visited and Chris reported this to me with great excitement.

(Horner,1994:170)

One of the most important people in Ella's social network was her mother. My research notes indicate that Ella often talked about her mother and regularly telephoned and visited her.

(ibid:171)

It is important as service providers that we recognise the importance of family. Historically the development of institutions severed families, as parents were advised that this was the appropriate place for their children (Brown and Smith, 1989), and it has not been easy for people to rebuild or maintain those connections. Given my experience in working alongside people with disabilities, I would argue that we have no right to step unasked between a person and their family. Unfortunately, this happens, as in the following example.

Ella was sometimes grounded for misbehaviour and this included not being allowed to visit her mother on the designated fortnightly weekends. Ella's mother explained at the end of her interview that she was not sure if she would see Ella in the weekend or not. She said "It depends if she's (Ella') been good or not, if they (staff) will let her". It could be argued that in this case staff undermined this relationship, viewing it as a tool for controlling Ella rather than seeing it contributing to Ella's quality of life.

(Horner, 1994:181)

There is no doubt that the sense of family however distant and tenuous and the ability to keep in contact were important for the members of the group. It is a part of their identity, their self-image. Equally, family members have identified the importance for them in maintaining their roles, unfortunately these roles have often become defined for them by professionals (Wills, 1994). "Many families feel they live in 'no-win' situation" (Munford, Georgeson and Gordon, 1994:273) they are criticised for being over-protective and they are criticised for not continuing in a key role. For the families of the participants in this study it must be remembered that they had their children at a time when parents were encouraged to place their disabled children in institutions.

Such long-stay residential institutions were a response to the understandings of the time. Parents, family and whanau were often advised by professionals to put their child into institutional care and it

is important to recognise the caring work of institutional staff. But society failed then, and sometimes fails today, to provide the level and kind of support that would ensure all children and adults with disabilities could live in family, whanau and community settings.

(Ballard, 1994:16)

Self Image

The final theme identified by the group is that of self image, how people see themselves. This is key to the whole project as it is indicative of how they view their lives, a perspective as to the quality of life that can only be defined from within. People talked about the labels that have been applied to them and how they felt about those labels. The focus of the study was people's experiences of services and therefore what has emerged is a description of a hidden world, a different way of living, a unique community that has been constructed by ideologies of disability; social policies; service systems; service workers and service users themselves. This research has been an attempt to portray the realities of that day-to-day experience within those services for the people who live there. In talking about the responses they get from 'other' people, they place themselves in juxtaposition to the non-disabled community. The complexity of power relations can only be understood by examining not only the forces of the institution, but the subject in relation to the institution (Foucault, 1982).

Far from being simply victims, they formed supportive and emotionally rewarding relationships which provided a foundation for building their own sense of community. They were not simply products of the institution, but active participants in developing their sense of self as social/cultural beings, contextualised within their collective institutional experiences.

(Jones, 1992:340)

The participants in this research project demonstrated clearly throughout the interviews, this sense of dual identity, they are users of services and members of a community.

J. If you were going to change anything about the (organisation) what would you like different?

Well I would like to see a new name put towards the (organisation)

J. Right what kind of name?

Well I can't think of a name at the moment, but I'd -

J. What don't you like about the name?

Well it's because people around the streets, they call you an IH criminal and I said to one of them "that's silly, you don't call people criminals, because how do you expect people to talk to you, how do you expect people to answer you if you're going to call them a criminal?"

J. so you think it's not a good label?

No, because even S.... agrees with me when I say I don't like the name.

J. So what do you think about the word when people say handicapped?

I think it's crude of them that way of calling it the way they put it.

The above comments reflect discomfort and anger at the label IH, intellectual handicap, that has been applied to people and a desire to change this. I asked another person:

J. What about the name, the IH name

Well I want to try and give a new name. We want to have a new name instead of IH, but they can't think of one. If we start with finding the right name, the right one for our workshop.

It is one thing to recognise what is disliked in the current label but there are difficulties in coming up with an alternative. It is interesting that the group accepted the concept of having a collective name; a label with which they identify. Nobody expressed the thought

that they did not need to have a collective name, this may be indicative of their sense of solidarity. In a conversation with two others different opinions were expressed.

So what about the name (...) What do you think about the name?

Who wants to change it? I don't feel embarrassed being the (...)

J. But one time people talked about people using the word handicapped and wanted it changed.

Who wanted to change everything?

Because it's really not a nice name calling it handicapped, because when you look at many of these people they don't look like handicapped, though some of them are normal people, but not everybody, because sometimes a lot of people can't cook by themselves, like P.... because she can't cook by herself because she needs someone to help her and then there's a lot of people who can't write, you think that all what P.... can do is just have a tennis ball in her hand all the time and that's all she can do, but if she wants a cup of tea she'll put her hands on her mouth "cup of tea" but she can't say the words.

Whereas the first person accepts the label, the second person is describing the diversity within the named group and questioning what the word handicapped means. As she points out, people have skills that go unrecognised and as Sobsey stated (1991), what is considered functional communication, is communication that is functional for the non-disabled. People are considered as good communicators if they use verbal language, whereas signs are not recognised as part of the functional language used by non-disabled people.

In the following conversation there are a number of examples of responses people experienced, based on not only where they lived but the background they came from.

J. Do you see (address) as being your house, or being (organisation)'s house?

I just like calling it a home, not the (organisation) home, because that's stupid, but what happens if you have too many kids on the street saying - getting smart all the time oh it just belongs to the (organisation), but it's not really nice. You don't like people getting smart to you all the time, but I don't say nothing

J. But you said before like you didn't mind the name (...) that you think it's OK

Yeah, I don't feel embarrassed

J. I suppose it depends what people say about it doesn't it? It's only if people use it you know for putting you down.

I believe that what is being represented here is the desire to own your own name and for that name to be viewed in a positive light. As Brown and Smith (1992) identify it is part of the process of assertion.

Well what happens when we have a house we have a name called 'open day' and I wasn't very happy about it.

J. Is this at your house?

It's the (organisation) open day see when we have visitors coming around to see what the place looks like and I was the last person at not done my bedroom, I had to hurry up and stuff all my stuff in the drawers and getting in the shower and come out of the shower and hello they're all coming in

J. I wouldn't want an open day at my house.

The one we had at (address) was a laugh, certain people didn't want me there - to stay they, didn't want me and R... there, they talked to us after it's finished one of these goons wearing suits, but we like took them outside and said something to them out the back.

J. So why didn't they want you there?

They said I wasn't good enough for that house.

J. Because you didn't wear a suit, is that why?

Oh, I'm not like B..., but they said I wasn't good enough for the house, me and R.... so I took them out the back door and told them where to go

J. Did they shut up after that?

Yeah, because I told them I don't care who they were at the (organisation) or whatever, they wanted more people like D....because he's from the upper class and that.

From my experience I know that the houses people live in often belong to the organisation and are 'opened' publicly as a way of promoting the profile of the organisation and raising funds. This reinforces for visitors the charity image for the people who live in the house. Again the decisions about who lives where are outside of the control of the service user. Class, in terms of working class, as a site of difference can also be viewed negatively, for example if people live in state housing. This is something that this participant has experienced. However, in the above example this is a point on which he chose to be assertive.

My brother's club used to come out here and do some things at the workshop and exercises and all that, it only stopped because my back was getting too sore. The only other people that used to come where P.... and J..., P.... only came for the free food. You should have seen what those trouble makers that would come up there with, from across the road, like they were getting smart from across the road when I was having a cup of tea in the kitchen and I turned my back to them and said they could come over so they could get a good surprise when they see all the guys doing martial arts, my brother's Tae Kwon Doe.

J. So you think it's important to defend yourself against people who get smart?

No, I wanted them to take notice and most of the guys used to be about five black belts there and who else used to come sometimes, D....'s friend, he's got a blind friend that's a black belt.

This person feels proud of who he is and understands the power of minority groups supporting each other, redefining the image of disabled people. This person also made another insightful comment regarding negative labels when we talked about his first contact with disability services.

J. You were only a teenager then

Is that what they call them and I thought they call them youths now.

J. Oh sorry, you were a youth then.

Oh not really, they call them a youth when they get into trouble eh.

The understanding of stigma comes from experiencing the responses of others. This experience can lead to people wanting to distance themselves from others. This was the case in Horner's study.

He (Chris) doesn't like intellectually handicapped people. That's why he's so possessive of you (the researcher). He's got enough brains to know that there is stigma attached to them as well as him If they go out all together he'll get out of the van or taxi and distance himself from the group. In his determination to become part of the community Chris had learned that by not associating with people who had stigma attached to them, he was more likely to be accepted as an individual in the community.

(Horner,1994:172)

However this was not the case in this study: although one member of the group had expressed her happiness at no longer living with other people with disabilities, we had the following conversation.

J. What did you think of those big camps that we used to have?

Oh they were terrific.

J. Did you like them?

Yeah, they don't seem to have those now

J. No

I don't know why.

J. I think they think it's better for people to go away in small groups.

It is only in recent years that disability has been spoken of as something which could be valued, in the emergence of the Disability Pride movement (Oliver, 1990). Disabled people who are involved in this movement have a different image of themselves. The lessons learnt from the feminist and Black movements are that: "The conviction that one's group is worth fighting for has to come at least partly from within." (Szivos, 1992:128)

In this chapter and the preceding chapter, I have focused on the key research questions and I have explored the themes identified from the data, commented from my own recollections of services and compared the themes with examples from the literature, in order to present a view from below of disability services and to identify an agenda for change. In the final chapter I will give recommendations for future service delivery from each theme, based on the points raised by the group and my own experience, in order to address the main research question: How can we improve the quality of daily lived experience in disability services for people with intellectual disabilities?

Chapter Five

Where to from Here? - Recommendations for Change

I am struggling to find ways of hearing the voices of people with learning difficulties. I am making many mistakes. It could be done better. But by writing about the process honestly, I hope I can help others build on my work, so that those voices can be heard more clearly, more loudly in future. There has been so much injustice done that we need to know about so that we can fight against it. This was not part of the explanations I gave people. At the outset it seemed too ambitious. It is only now on reflection, that I believe it.

(Walmsley, 1993: 45)

I began this research project with a key question: how can we improve the quality of daily lived experience in disability services? In order to address this question I began with some key theoretical perspectives about the experiences of people with disabilities and the ways in which disability has been constructed, based on a summary of the literature. I raised points about the ideologies of disability and the social policies that underpin and impact on service delivery. I explored the literature relating to the dynamics and relationships within service systems and the caregiving process. In the second chapter I developed and described the methodological approach I had undertaken to produce the data in partnership with the participants in the research project. In the third and fourth chapters I presented and analysed the data in a framework of themes that were generated by the research participants and combined key points from the literature. In this chapter I will revisit each of the themes and combine the key points raised by the participants, with the key points from the literature. In doing so I will produce a framework which I argue can be used in the development of services, which will lead to improvements in the daily lived experience of people with intellectual disabilities.

CONTROL

A key question here is:- Are we, as service providers and support workers, prepared to accept our position as one of control and are we prepared to give up that control? The participants identified that being in control, or not, was fundamental to everything that

happened in their lives. This was also identified as a key theme in the literature (Horner, 1994; Lovett, 1996; Shoultz, 1995). When people do not have control their options are either to comply, or resist. I argue from the literature, (Lovett, 1996; Meyer and Evans, 1989) and from this research, that many of the most serious behaviour problems can be attributed to issues of control. Many people resist compliance; it is liberation not compliance that should be our goal in services (Lovett, 1996). We need to be prepared to give up our power to work in partnership, to become jointly responsible for a process in which we can all grow (Freire, 1972:53). From this research I have identified that the ideology underpinning the way in which we view disability should be as social oppression (Ballard, 1994; Boyles, 1995; Georgeson, 1994; Keith, 1994; Morris, 1991; Oliver, 1990), and that the fundamental principle to guide our practice in the way we provide services should be empowerment (Boyles, 1995; Freire, 1972; Sobsey, 1994).

This research revealed that the position that has been structured for people with intellectual impairments, parallels that of other disabled people and is one of oppression (Boyles, 1995; Oliver, 1990; Sobsey, 1994). Disabled people are challenging this position and are struggling to gain power (Boyles, 1995; Georgeson, 1994; Keith, 1994; Morris, 1991; Oliver, 1990; 1992; Sullivan, 1995). People with intellectual disabilities are only recently beginning to realise their powerlessness (Gosling and Gerzon, 1994; Lovett, 1996; Worth, 1988; 1996). In this research several key areas in which the ability to have control were identified by the participants as important. The first of these was education. The group members identified that they spent unproductive time in segregated schools. The current policy in education is now one of mainstreaming, however, it is important that we understand that 'being there', is not enough and that meaningful learning should occur for each student (Ballard, 1994). When a student with a disability is in education, they should acquire knowledge, and as researchers we should find ways of adapting curriculum and providing support to ensure this happens (Boyles, 1995). Given the knowledge we now have, it is clear that professionals need to continue to listen to the aspirations of parents of children with disabilities and to work in partnership with them (Brown, 1994) if the educational experience is to be successful. What happens in education will set the scene for disabled people's future expectations of adult support services. An example of how school can be a positive experience is given by a mother:

Now I feel much more included at my local school. I don't have to constantly explain about Jeff. People see me, see me as a parent, see the hassles, the joys, the achievements. I have a much better measure

of what is okay. My friends at school tell me when they think something unfair happens to Jeff or me. The monitors are there. Jeff's education and development is open like anyone else's.

(Dixon, 1994: 81)

Another key area identified where lack of control was experienced was in living in institutions. The participants in this research who spent time in institutions ask that we remember their history, and that we understand that institutions have a culture and that this is part of their identity (Horner, 1994; Jones, 1992). They may want to revisit the past and remain in contact with old friends. There are still a large number of people living in institutions: for example around 700 people are living in institutional settings in Wellington, Horowhenua and Nelson. (CRHA, 1996:8). We have heard in this project from the participants and from the literature (Sobsey, 1994; Worth, 1989; 1996), about life in institutions. It is clear that institutions are not appropriate places for people with intellectual disabilities to live and as researchers we must continue to plan for deinstitutionalisation. Several key points have been identified in this process. Transition teams need to ensure that as people move out they are able to choose who they live with and who supports them (Smull and Harrison, 1992). Service providers and transition workers need to take time over this process, to ensure people are involved in the setting up of their new environments. They should take the new support people into the institution so that they understand the person's history (Worth, 1989). Staff may need to support people through the grief process and ensure they keep in touch with people who are important to them (Horner, 1994; Jones, 1992). A simple practical strategy I would suggest is to take photographs of the people and their friends before they leave, so that they will have memories to look back on and make sure they have the means of keeping in touch. Staff need to learn about support needs so that the people moving out feel safe. An example of this is where people have epilepsy. This will require adequate funding being allocated to the transition process to carry out person-centred planning (O'Brien, 1989; 1996; Smull and Harrison, 1992) and appropriate people facilitating the process. I would argue that people who have worked all their lives in institutions are often unable to see people's real potential and ability; they are themselves institutionalised.

Currently, the process of consultation around deinstitutionalisation involves parents and whanau (CRHA, 1996). In addition, Individual Needs Assessments are carried out. This is presumably where people have an opportunity to say they would like to live somewhere else. What is missing in this process is the giving of information as to what

alternatives there could be to their current way of living and the facilitation of group discussion as to how they feel about living in the institution and leaving the institution.

There are many people, such as the participants in this research, who could be usefully involved in talking to people in institutions and supporting them to make decisions (Worth, 1996). The presumption is that people in institutions are not capable of doing this and that others need to make decisions for them.

How do we explain to people who have only lived in one world that there is another world? As in Plato's description (Fay, 1987:11), I would argue that it is the person who has emerged from one to the other who is best equipped to go back and lead people through. If we are operating on empowerment principles, we need to work with people before and during the transition process (Smull and Harrison, 1992). It is not a case of providing people with 'normal daily and weekly routines in a community setting'. It is creating with them step by step their future (O'Brien, 1989). We must ensure that institutional practices, such as timetabling and the way food is prepared, are not transferred to the community (Clements *et al*, 1995; Lovett, 1996; Van Dam, 1995).

Another key area of control identified in this research concerned financial resources. The participants needed the meaning of money and funding to be demystified. We should think of simple ways of explaining the benefit system and the funding of services. People have a right to know where the money comes from and where the money goes to. If a person is going to earn money they must know what effect this will have on their benefit. They can then make informed decisions about what they want to do. Knowledge in this area, as in all areas, is power. There is a need for more simple information such as that produced by Bogard (1995). Where people have ideas about systems for handling their finances, they should be listened to. The group wanted to operate their own bank accounts, so that by going through this process they can then understand it and support can be provided as needed. There is a need for freedom to choose how to spend discretionary money. Other ideas they expressed such as phone cards could also be very practical, as they would not incur large phone bills.

This research has also shown that considerable control is exercised around daily activities. It has been identified that we need to talk with people about what they want to do with their days. We should discuss the options, provide information, examine our resources and look at ways to build support around the individual's choices (Barnes,

1990; Phelan and Cole, 1993). Where we have existing programmes, we should begin by involving people in the daily running of the programmes and the decision making. When we are developing new programmes we should do this in partnership, seeking and discussing ideas. In this way the programmes will be built by the people.

This research identified that people are disempowered by the current process. It can be argued that if we are to change this, we need to understand and explain the funding categories used by the main funding body for day programmes, the Community Funding Agency. Currently these are based on continuum models of people working on daily activity programmes through to supported employment, which may necessitate people moving from provider to provider as they progress, fitting into the existing system. It has been identified in this project that the continuum model is not a useful approach (Sinson, 1993), and that we need to build the system around the needs of the person (Logan, 1988; Smull and Harrison, 1992). A more holistic approach would be to fund an individual to pay for their support needs to do whatever they identify they want to do. This again requires a different ideology driving the funding mechanisms, rather than the dichotomy of dependence and independence (Oliver, 1990). I have identified the need for social policy that recognises the individual's support needs as of right, not as recipients of charity (Kelsey, 1995) and we as a society agree to provide for their quality of life as citizens, not as dependents (Boyles, 1994; Georgeson, 1994; Morris, 1991). Once we accept that people are citizens then we have an obligation to remove the barriers to full participation. This does not mean providing funding on the basis of an individual setting goals to become more 'able', with an expectation that as they move through the continuum, their support needs will be less. We need to acknowledge the ongoing need for support, the nature of which may change over time (Boyles, 1995; Georgeson, 1994). Often support has been put in place based on current need, but there is no review process to examine whether this is still appropriate.

A final area where lack of control was experienced was in terms of mobility. I have identified in this research that we must ensure that people have access to equipment to promote their mobility (Keith, 1994). This may mean lobbying for resources and acting as an advocate. It has been argued that the current system of funding resources through accredited assessment (CRHA, 1996) is inadequate and professionally dominated (Georgeson, 1994). This means for example that many people do not meet the criteria for aids such as electric wheelchairs, because they are not working or in full-time education. The fact that they cannot access the above because they do not have the electric

wheelchair puts them in an impossible situation. This project has shown transformation in a person's lifestyle when they have the resource to move independently within the environment, as opposed to waiting to be moved (Keith, 1994) as a key example of empowerment. It has also been highlighted that when people have this mobility they must be free to move around without 'asking permission'. We should be asking people when and where support is needed, not demanding that people fit within our rosters for support (Georgeson, 1994; Keith, 1994). At times compromise may be necessary, but this should be on a basis of mutual agreement through negotiation.

CHOICE

This research has shown that people need to be able to exercise choice about the important areas of their lives, who they live with, where they live, how they are supported and how their daily environments are structured. It has been demonstrated that we have become locked into formulas of service provision that are based on ratios for group homes and day programmes rather than individualised support based on a person's needs and desires (Clements *et al.*, 1995; McGill and Emerson, 1992; Van Dam and Cameron-McGill, 1995; Wilkinson, 1989).

Choice should become the process that drives the system rather than the system being the structure into which the individual fits (Logan, 1988; Lovett, 1996; O'Brien, 1989). We must, therefore, ensure there are mechanisms built into services, where information is given from which decisions can be made by people. We must ensure that the people living in services have as much information about the service as the people delivering the service. We must also ensure there is a mechanism for people with disabilities to exit services if and when they wish to.

On a daily basis we must ask ourselves, why am I doing this? Who is it for? Who decided it should be done this way? We must involve people in the decision making as services develop so that people can choose where and with whom they live (Taylor *et al.*, 1987). People must participate in the selection of support workers (Phelan and Cole, 1993). Our vision must remain open; the ideal service should evolve. It is not a goal we are moving towards but a path we are creating (O'Brien, 1996). What we achieve may well be different from existing models of service. It is in denying individuals the right to make their own choices that the true devaluing of people lies. There will be constraints on resources at times which may present barriers, however, it is important that people are

still able to exercise choice within these restrictions. Constraints on resources should not be used as a justification so as not to consult with people with disabilities.

SOMEONE TO LISTEN

The group identified a need for someone outside of their support system who would listen to them. The key here is to recognise that the support worker will always have more power in the relationship than the service user (Sobsey, 1994). This is a fundamental premise which must be acknowledged. At the end of the day the support people go home, they can exit the service and are paid for their support. They can choose to leave and work elsewhere. It is important that support workers are listening on a daily basis, but it is equally important that someone else is there for each individual, an independent person outside of the service system, who does not have power over them.

In this respect the intended provision of an Independent Service Co-ordination service (CRHA, 1996: Draft Strategic Plan) could be of value, if the service is readily accessible when a person needs it. However there is a further daily ongoing need for people who do not have family to talk to (Horner, 1994). In this respect the need for a local advocacy system that works alongside the service provider, but is separate from them, has been identified in this project, such as People First (Gosling and Gerzon, 1994; Worth, 1988; 1996). This system could provide both group and individual advocacy. This would be in addition to the Health and Disability Commission advocacy system whose function is to deal with major concerns. Individuals need to be supported to develop and maintain personal networks.

There is also a need for more opportunities for people to continue to tell their stories, to be heard and legitimised as a part of society (Ballard, 1994; Boyles, 1995). There are individuals in similar positions to mine, who have long histories as service deliverers and who are no longer working in service support systems, who could provide opportunities for this to happen. There is a need for non-disabled allies to facilitate the process, at this stage (Gosling and Gerzon, 1994; Phelan and Cole, 1993).

RELATIONSHIPS

This research has shown that in order to improve the quality of relationships between service workers and service users, we must consider who the people are who work in

services (Allen *et al*, 1988; Brown and Smith, 1992). It has been demonstrated that people entering this area of work need to have training so that they begin with an understanding of working in partnership (Boyles, 1995; Munford, Georgeson and Gordon, 1994). Likewise, those people who have worked in institutions need to be deinstitutionalised (Phelan and Cole, 1993). It is not enough to have good intentions. People do not want to be 'looked after' or 'controlled', they want to be supported (Georgeson, 1994; Morris, 1991; Munford, 1992; 1994; 1995). Service workers must be recognised as people with skills and valued by the service providers. They in turn must recognise the skills of the people they support and value them as individuals. Support people need skills in problem solving and conflict resolution in order to work in partnership (Phelan and Cole, 1993). The key is to learn how to work *with* people. What is required is a move towards interdependence, a state of reciprocity, where both the worker and the disabled person contribute to each other (Boyles, 1995; Lovett, 1996; O'Brien, 1996). For example, as a support worker I have participated with people with intellectual disabilities in heavy construction work, which, because I am relatively small, would have been impossible if the people I was supporting were not physically more capable than me.

It has been identified in this project that service organisations and funding providers need to examine how to recruit and retain good support workers (Brown and Smith, 1989; Phelan and Cole 1993). This may mean considering pay levels, working conditions and career opportunities in service budgets, so that the loss of good support staff that has been identified by the participants does not continue to occur. Social policies should identify the true costs of quality community service and community services should not be viewed as a cheap option to institutions (Kelsey, 1995; Munford, 1989). As a society we have historically spent large amounts on isolating disabled people from our communities (Sobsey, 1994; Lovett, 1996). It has been identified that the state is cutting back social welfare spending (Kelsey, 1995; Tennant, 1996). There is no mechanism to ensure that as institutions close the funding for supporting people with intellectual disabilities is not diverted into other areas of expenditure. I argue that if funding could be delivered to the individual based on actual identified need for supported living, rather than on traditional formulas for group homes (Van Dam and Cameron-McGill, 1995), which have established the benchmarks; then service providers would need to demonstrate to the individual and their advocates that they were the service which could best meet their needs. This would depend on services being available to fulfil their needs. The individual would then become the purchaser of the service, not the government, and accountability

would be to the individual and their advocates. The power relations within the relationship would be altered and a collaborative approach to service provision, as described by Georgeson (1994), established.

This research has identified that in considering staff training we should begin by asking people what they want from their support people. The group gave clear indications of the standards and qualities they expected from staff. We should therefore consider involving disabled people not just in staff selection but also in ongoing staff training. Support workers above all need to learn to listen to the people they support and respect their wishes; they need to understand issues of power and control. It is not simply a case of ensuring support workers have the necessary practical skills, they must operate not from the principle of normalisation (Brown and Smith, 1992), but from an understanding of the social construction of disability (Oliver, 1990). As Sobsey stated (1992), they must become part of the solution not part of the problem. In order to do so they need to acknowledge the part they have played in the social construction of disability. Staff should view their primary role as working for and with people, not organisations. The organisation is the vehicle that facilitates the support.

SAFETY

Another key issue identified was the need to feel safe. This requires finding a balance between support and autonomy (Georgeson, 1994; Keith, 1994). This will vary from person to person and from place to place. Support workers need to consider when and how their support is required and when it becomes an unnecessary intrusion. Again we can only learn this by listening; when to be there and when to let go (Lovett, 1996). This means service providers reconsider the flexibility of the service systems and look for broader alternatives to community support outside of group homes and day programmes (Van Dam and Cameron-McGill, 1995). Safety also means we must have a level of stability in the support system. The group identified that it was hard to feel safe with people you didn't know and who had not been given the information necessary to meet your needs. We need to ensure good communication systems exist within services, that people work as team members, that staff turnover is reduced and quality induction processes are implemented for new staff. Existing staff also need to be kept up to date with new information and involved with the people they support in service development. For example, support workers and people with disabilities can attend conferences and

consultation workshops together and make changes in their services based on the information they receive.

WAITING

Another key concept identified by the research was that of 'waiting' (Munford, 1995; Keith, 1994). If we include service users as active participants in all that we do, we will address the difficulties people experience in 'waiting' (Macfarlane, 1994). Waiting is the passive state in which disabled people find themselves, whilst others are busy doing. If we are working in partnership (Boyles, 1995), then both disabled people and service workers will be involved in the processes of doing, thinking, deciding, finding out, and the dichotomy between passivity and activity will cease to exist. The participants continually identified the need to be involved, to work interdependently with their peers and their support workers. They demonstrated the skills they have to offer to each other and in educating those who support them. They know what has happened in the past, what was successful and they should participate fully in the planning for the future. When disabled people have participated in planning they have succeeded in bringing about major change, as in the People First successes in Canada (Worth, 1996) and in the New Zealand groups whose members have grown in understanding and skills (Ballard, 1994). Disabled people can also be proactive by participating in selecting and training support staff, as opposed to waiting for support workers to be found for them and to acquire appropriate skills.

PEER RELATIONSHIPS

In carrying out this research project I was involved with a network of people who have a history. This is a history which in some sense I have been part of, yet apart from. I refer here to the culture that exists amongst people of shared experience. There are other people with similar backgrounds to my own who also know the history of people with intellectual disabilities, but we are outside of the relationships that exist between them. They have a common understanding of each other's experience, which has been identified in this research (Horner, 1994; Jones, 1992), which we should learn to listen to and use constructively when problems arise. A parallel which we can learn from in this respect is the culture and community of the Deaf community (Townsend, 1994). This community has a highly developed network and a way of operating that is built on the positive experience of being Deaf and that can not be understood unless we learn to

access their language. A spirit of self-determination is starting to emerge amongst people with intellectual disabilities (Brechtin and Swain, 1994; Lovett, 1996). We should enable people to preserve their history through documenting their stories, and to maintain contact with people from their past. This is a process which can easily be facilitated without additional funding costs.

The tensions that occur within peer relationships were also identified by the group. I would argue that we should apply equal effort to teaching team building and problem solving skills to the people we support as we do to support workers (Phelan and Cole, 1993). We must ensure that people do not have to continue to live with people they dislike (Smull and Harrison, 1992; Lovett, 1996). Another key aspect that emerged from the research within the concept of peer relationships was the issue of lack of privacy. We need to respect people's privacy in the way that environments are structured and provide opportunities for people to be together and to be alone as they wish. The other aspect of lack of privacy that emerged for the participants was the difficulty of maintaining confidentiality in any area of their lives (Keith, 1994). People's lives should have private and public areas and as service workers we need to acknowledge we are in a privileged position and must maintain confidentiality. We should cultivate the art of minding our own business (Bernstein and Halaszyn, 1989) and refrain from gossip.

FAMILIES

This research has shown that historically service delivery has alienated people with disabilities from their families (Brown and Smith, 1989). It is important that we recognise that for some people this has resulted in an unacknowledged sense of bereavement, both for the family and for the individual (Wills, 1994).

It is important to people's sense of self that they know their roots (Jones, 1992). We need to consider the purpose of services in supporting both the individual and their family. The issues of grieving that occur within families who have a disabled child need to be worked through successfully if the family is to remain intact (Lambert, 1994; Wills, 1994; Bogard, 1994). The decision to leave home should occur naturally for the person and their family as part of the person's development. This research has demonstrated that this is rarely been the case, instead it has often been at the instigation of professionals. Leaving home should happen at different ages for different people as it does with non-disabled people.

When people have moved away from their families they need to be supported to maintain contact and to work through processes of letting go. Family members may still play an important role as advocates and we should respect and support their involvement (Horner, 1994). Where conflict arises between people and their family there is a need to facilitate conflict resolution. There is no doubt that the sense of family, however distant and tenuous, is of importance to a person's identity.

SELF IMAGE

Finally, we return to the individuals who participated in this study and their self image. This has been an exploration of their world through their eyes. Their sense of self has been constructed to a large extent by their experiences in services. These experiences are what separate them from other groups in society; in this respect they are unique. This uniqueness has been negatively labelled by the non-disabled community. The individuals have pride in who they are. They have demonstrated an ability to survive and a desire to speak and name for themselves. Whatever label they are known by in future it should be their name. They feel devalued in their contact with the non-disabled community but they also have a sense of pride about their own community.

In this chapter I have presented the recommendations drawn from the themes, from the viewpoint of the people who told their stories, and the literature considered throughout this research project. The messages they give are simple and clear. These are not unreasonable demands nor are they economically non-viable, (that is not to say that there are no funding implications). This research project set out to consult, that is to 'seek advice' from the people who know, the people who live the lives in our services, in order to address the question: How can we improve the quality of daily lived experience in disability services? The agenda grew from the guidelines developed by the participants, based on the principles of emancipatory research developed in chapter two. The emancipatory outcome has been achieved, by the response to these messages, by 'jointly considering', we can do a lot to improve the quality of the 'days of our lives'. It has to be a joint venture, a partnership, because that is what people have asked for. It is not their life and my life as separate entities because we are part of each other's lives. We have to move beyond the us and them and start working together. It is simple but it is not easy.

Final Reflections on the Research and the 'Days of Our Lives'

This research has been about discovering a way to improve the quality of daily lived experience in disability services for people with intellectual disabilities. I began this thesis with an analysis of the literature. This enabled me to explore the competing ideologies of disability and understand the ideology of social construction and the importance of the emergence of disability viewed as social oppression (Boyles, 1995; Oliver, 1990; Morris, 1991; Sullivan, 1995). The literature also revealed the impact of the key changes in social policy: the reduction in welfare spending (Kelsey, 1995) and the move from institutionalisation to community care in the field of disability (Tennant, 1996). This reflected the experiences of some of the research group who have spent part of their lives in institutions and are now living in community settings.

I explored historical perspectives on disability services (McKnight, 1977; Sobsey, 1994), and the impact of normalisation on service delivery (O'Brien, 1981; Wolfensberger, 1972). I also explored the newly emerging challenges to the way we structure services, which have included the perspectives of disabled people and their families (Ballard, 1994; Munford and Nash, 1994; Rioux and Bach, 1994). In this area the critiques of the principle of normalisation assembled by Brown and Smith *et al* were enlightening in terms of naming many of my own experiences as a service worker whose practice had been based on this principle. Certainly many of the current experiences of the participants reflected the underlying influence of normalisation on service delivery.

I discovered that although there is a significant amount of literature covering the views and perspectives of professionals in this field, as identified by Sobsey (1994), there is a scarcity of material which acknowledges and presents the views and experiences of people with intellectual impairments. However, the work of disabled writers such as Boyles (1995), Georgeson (1994), Keith (1994), Morris (1991) and Sullivan (1995) illuminated the personal experience of disability in a way that offered parallels and contrasts, to the experiences of this research group. I found the research conducted by Horner (1994) useful as a comparison within a New Zealand setting and the work of Sinson (1993) interesting as an overseas perspective of deinstitutionalisation. Both of these studies presented the voices of people with intellectual disabilities. The analysis of New Zealand perspectives on disability (Ballard, 1994), from families, whanau and people with disabilities provided a valuable context for comparison, with the experiences of the participants in this research. The work of Sobsey (1994) allowed me to consider

issues of abuse and compliance, and identify that within this study it was the daily systematic exercise of power and expectations of compliance that was abusive, but also that the participants did not view themselves as victims, they were individuals living complex lives with struggles and tensions, joys and sorrows. This perspective has also been presented by other writers such as Jones (1992) and Atkinson (1993).

Many of the challenges to current service delivery presented by writers such as Bach (1994), O'Brien (1989), Lovett (1996), Phelan and Cole (1993), Smull and Harrison (1992) and Van Dam and Cameron-McGill (1995) echoed the viewpoints of the participants in this research. They demonstrated a need to work in partnership with service users, to keep the people at the centre of all our planning and to structure service responses around individual need based on empowerment principles rather than forcing people into existing systems.

The methodological approach that I developed was influenced both by my exploration of feminist principles and the emancipatory paradigms that have been developed by disabled researches and their allies (Ballard, 1994; Boyles, 1995; Munford, 1992; 1994; 1995). This approach enabled me to design the research in a way that allowed the participants to make decisions about what was important for them to share and also to create a process which was safe for them to do so, and, therefore, to achieve the second objective of the research project. In doing so my awareness was raised to openly position myself within the research process, and to use my experience to make sense of their world. The appropriateness of story telling as a research method for people with intellectual disabilities was confirmed. The first objective of this research project: to examine the research process and to find a methodology that would allow the participants voices to emerge, was achieved. I am aware that there is a need for further research from this perspective, which not only describes the viewpoints and ideas of people with intellectual disabilities, but is also written in a way that is accessible to them as a community, through techniques such as parallel writing (Bashford, Townsley and Williams, 1995). This has been beyond the capacity of this project to produce in total; however the research participants have received a summary of the key points, in the form of a charter (Appendix 4). The third objective of the research was to identify common themes in the daily lived experiences of people with intellectual impairments in services. This objective was achieved by the thematic reconstruction of data presented and analysed in chapters three and four.

HOW CAN WE IMPROVE THE QUALITY OF DAILY LIVED EXPERIENCES IN DISABILITY SERVICES?

In summarising the responses to the main research question: How can we improve the quality of daily lived experience in disability services, (to which I responded in detail in chapter five), I have identified with the participants the following key points which I have written in language that was checked and agreed with them. This has been presented to the participants in the form of a charter (Appendix 4) and is an example of the use of parallel writing (Bashford *et al.*, 1995).

People who live in disability services need to have more control over their own lives. They need to handle and understand their finances and to have choices about where they work and what jobs they do. They need to have people around them who listen to them and who, if they have a problem, will assist them to solve it. They need to have choices about who they live with and who supports them. If they are moving from an institution or a community house they need to be involved in the planning and the decision making. It is important that they have support people that they get on with, that support people work with them and ask them what they want. They need to feel safe, to know that the people around them understand their needs and can take care of them when it is necessary. They want to make their own decisions, even if they make mistakes, and not have to wait for other people to decide for them. They do not like the way people use labels about them; they want to name their own identity. They like to be able to get together with their friends and decide what they would like to do. They like to keep in touch with people they knew in the past and have contact with old friends. It is important that they have some privacy, that they are allowed to have secrets and that information is kept confidential. It is also important to keep in touch with their families. They want to be involved in staff selection and staff training, so that they have confidence in people who support them.

FURTHER REFLECTIONS ON THE PAST, PRESENT AND FUTURE RESEARCH

This research project has been a personal journey. It has taken me back in time through territory which I thought would be familiar. The landscape has not changed but my vision has and I can now see the people and the places from a different perspective within it. I am standing in a different place. I have learnt many things from undertaking the journey

and feel a strong commitment to act upon what I have learnt. This is a process which I have already embarked on in my current daily work in new service development. The issues raised by the participants have become my guide book to move forward; I am looking and listening with a new awareness and continually questioning what is it that people really need and how that support can be delivered on their terms. It is exciting and challenging work and I hope that others will join in the challenge.

At the beginning of this project I identified that the majority of literature available in this field is written from the perspectives of the professionals (Sobsey, 1994). There is a need for the further documentation of more stories, both through the facilitation of non-disabled allies and also directly from people with intellectual disabilities. This may necessitate the development of further educational opportunities and a greater openness to presentation styles. I would challenge all researchers in this field to ensure that their future projects openly consult with people with intellectual disabilities and include their perspectives.

THE CHALLENGE FOR PRACTICE

I would recommend that anyone involved in service delivery examines how power and control is currently operating in their service. In order to do this they need to establish a dialogue with the service users. This in itself will start to address the issue of service users having people who listen to them. Establishing a dialogue can begin immediately, just by entering the service with a listening ear rather than an open mouth; although disabled people who have been used to being directed may require some time to adjust to this new approach. From this process of dialogue, opportunities and possibilities will arise for service users and service workers to move forward together. This can be a liberating process for all those involved.

Postscript

In sharing their experiences with me the people in this project have taught me a lot. I am amazed by their strength, their ability to survive the mountain of oppression that has been heaped on them. I am humbled by their willingness to accept the people who support them. Despite all the harm that we have inflicted on them, they are happy to help us change. I hope that their story will enable us to work together to change the days of our lives.

Appendix 1

Information Sheet

My name is Jan Perkins. This research is for a Masters of Social Work degree through Massey University. My supervisor is Dr Robyn Munford.

The title of the research is "Days of our lives: An exploration of the experiences of people with intellectual disabilities as recipients of services".

What is the study about?

This study is about people describing the experiences they have in residential and day time support services. It is an opportunity to tell your own story in a way that will help to change the services provided to better meet your own needs.

What will participants have to do?

If you agree to take part you will be asked to come to a group meeting with five other participants. You will then have an interview on your own or with a support person of your choice. You will decide what you want to share in that interview. You will be asked if you agree to the interview being taped. You will also be asked to a final group meeting to hear what has been written at that stage.

How much time is involved?

The time involved is two individual meetings of two hours and two group meetings of two hours within a period of one year.

What can you expect from the researcher?

I will organise transport for you to the group meetings, provide refreshments and arrange for any other support you need to participate. If you take part in this study you have the right to:

- refuse to have your interview taped;
- request that the audio tape be turned off at any time;

- refuse to answer any particular question and to withdraw from the study at any time;
- ask any questions about the study during your participation;
- provide information on the understanding that it is completely confidential to the researcher. All names will be changed in any reports so that it is not possible to identify you; and
- be given a summary of the study when it is finished.

If you agree to take part you will be asked to sign a consent form.

Appendix 2

Consent Form

"Days of our lives: an exploration of the experiences of people with intellectual disabilities as recipients of services".

I have read/heard the information sheet for this study and have been told what the study is about.

I have had any questions I want to ask answered.

I understand I can pull out of the study at any time.

I understand I can decide what I want to share.

I agree to give information and know it will not be shared with anyone else unless I say it can. If it is shared it will be without my name being used.

I wish to be part of this study in the way set out on the information sheet.

I agree/do not agree to the interviews being taped.

I have the right to request that the audio tape be turned off at any time.

Signed:

Name:

Date:

Appendix 3

Confidentiality Statement for Support People

I agree that any information disclosed in my presence at an individual interview or a group meeting will be entirely confidential.

Signed:

In the presence of

Date:

CHARTER OF PEOPLE WHO USE DISABILITY SERVICES

People who live in disability services need to have more control over their own lives.

WE need to handle and understand our finances and to have choices about where we work and what we do. WE need to have people around us who listen to us and who, if we have a problem, will assist us to solve it. WE need to have choices about who we live with and who supports us. IF we are moving from an institution or a community house we need to be involved in the planning and the decision making. IT is important that we have support people that we get on with, that support people work with us and ask us what we want. WE need to feel safe, to know that the people around us understand our needs and can take care of us when it is necessary.

WE want to make our own decisions, even if we make mistakes, and not to have to wait for other people to decide for us. WE do not like the way people use labels about us; we want to name our own identity. WE like to be able to get together with our friends and decide what we would like to do. WE like to keep in touch with people we knew in the past and have contact with old friends. IT is important that we have some privacy, that we are allowed to have secrets and that information is kept confidential. IT is important to keep in touch with our families. WE want to be involved in staff selection and staff training, so that we have confidence in people who support us.

Appendix 5

Diagram of Mountain of Oppression



Appendix 6

Ethical Statement

The research will meet the requirements of the code of Ethical Conduct for Research and Teaching involving human subjects. (Massey University)

Access to participants

All individuals invited to participate in this research will be people I have known on a personal level over a number of years. I will therefore approach each individual myself and will not be accessing their participation through any organisation of which they are a service consumer. Any prior consent sought from a service organisation would immediately breach processes of confidentiality. I will not approach any individual with whom I do not already have a basis of personal trust.

Informed Consent

The gaining of informed consent from research participants is a crucial issue for research involving adults with intellectual impairments. Time and care will be taken to explain the consent form and the information form. Where participants cannot read, a taped recording of the process of explanation of the research information and the giving of consent will be made, to verify the signed consent.

Confidentiality

Confidentiality will be ensured to all participants. Data checks will be used so that individuals can remove any personal identification and check the accuracy of material recorded. Participants will have access only to the summaries of other peoples stories. All participants will receive a summary of the research findings and will have access to the final reports. Data will be kept in a locked cupboard or room and tapes and transcripts will be destroyed after use, except for tapes requested and returned to individuals of their personal story. All support people participating at individual request will sign a confidentiality statement (see Appendix 3).

Potential Harm to Participants

The responsibility of the researcher in working with people with intellectual impairments is to the people themselves. The rights, interests and sensitivities of the participants must be acknowledged and protected at all times.

Participant's rights to decline

People who participate will sign a consent form at the beginning of the project and will be clearly informed of their right to withdraw at anytime.

Arrangements for participants to receive information

Full information about the aims of the research will be conveyed verbally and in writing. (see appendix 1)

Use of the information

The participants will have control of the information they volunteer. They will have the opportunity to edit or withdraw information which is personal to them. In consultation with participants information provided by individuals will be made available to the group. Participants will have the right to remain anonymous to the rest of the group in the use of the personal information shared. Participants will not however have control over information offered by other participants. The researcher will not exploit participants in any way and will not use any information for personal gain.

Conflicts of interest

The researcher will not include any participants with whom they have a professional relationship.

Legal Issues

The researcher will communicate honestly with the supervisors and academic board of Massey University as to the progress of and commitment to the project. The research document will be held by Massey University.

Bibliography

- Abberley, P. (1989). Disabled people normality and social work. In L. Barton (Ed). *Disability and Dependency*. Basingstoke: Falmer Press.
- Allen, P., Pahl, J., and Quine, L. (1988). *Staff in the mental handicap services: a study of change*. University of Kent, Canterbury: Health Services Research Unit.
- American Psychiatric Association (1994). *Diagnostic and statistical manual of mental health disorders*. Fourth Edition. Washington: A.P.A.
- Armstrong, Patricia; Hamilton, Roberta. (1988). Feminist Scholarship Introduction. In *Canadian Review of Sociology and Anthropology* 25.
- ASENZ, (1996). *Jobs for New Zealanders with Disability: The ASENZ Vision for Employment Policy and Services*. Levin: Omega Publications Limited.
- Atkinson, P. (1993) Relating. In P. Shakespeare (Ed). *Reflecting on Research: practice issues in health and social welfare*. Buckingham, England: Open University Press.
- Atkinson, P. and Williams, F. (1990). *Know me as I am: an anthology of prose, poetry and art by people with learning difficulties*. Sevenoaks: Hodder and Stoughton.
- Bach, M. (1994) Quality and Life: Questioning the Vantage Points for Research. In M, Rioux and M. Bach (Eds). *Disability is not measles: New Research Paradigms in Disability*, York University, Ontario, Canada, The Roeher Institute.
- Ballard, K. (1990). A socio-political perspective on disability: a comment from the New Zealand context. (IEEIR, Monograph, 51). In *Disability and the necessity for a socio-political perspective*.
- Ballard, K. (1994). *Disability, Family, Whanau and Society*. The Dunmore Press Limited, New Zealand.

- Ballard, K., Bray, A., Burrows, L., Watson, M., MacArthur J. (1992). *The Otago Family Network: A Report on the Research Contract to the Research and Statistics Division*, Ministry of Education. A Joint Project of the Donald Beasley Institute and the University of Otago.
- Barnes, C. (1990). *Cabbage syndrome: the social construction of dependence*. Basingstoke: Falmer Press.
- Bashford, L; Townsley, R; and Williams, C. (1995) Parallel Text: Making Research Accessible to People with Intellectual Disabilities. In *International Journal of Disability, Development and Education*, Vol.42, No.3, pp.211-220. University of Queensland Press.
- Bascand, P. J. (1987). *Disabled people in employment: a survey of employers attitudes*. N.Z. Rehabilitation League.
- Bennie, G. (1995). *Needs, Supports and Services. People with intellectual Disability who have Challenging Behaviour*. Central Regional Health Authority.
- Bernstein, G and Halaszyn, J. (1989). *Human Services - that must be so rewarding* Baltimore: P.H. Brookes.
- Biklen, D. (1988). The myth of clinical judgement. In *Journal of Social Issues*, 44 (1), 127-140.
- Blaszczk, M.J (1988). The world we have gained. In Royal Commission on Social Policy, Vol. III *The April Report*. Wellington.
- Bleasdale, M. (1996). Evaluating 'values' - a critique of value theory in social role valorisation. In *Australian Disability Review*, 1:3-22.
- Bogard, M. (1994). Sallie and Mel. In K. Ballard (Ed). *Disability, Family, Whanau and Society*. New Zealand: The Dunmore Press.
- Bogard, M. (1995). *The Legal Rights of People with Intellectual Disabilities*. Wellington: Legal Resources Trust.

- Boyles, P. (1994). Empowerment through the research process: The development of new research paradigms. In R. Munford and M. Sullivan (Eds). *Thinking Critically about Disability*. Massey University.
- Boyles, P. (1995). Enabling participation through partnership. In P. Beatson (Ed) *New Zealand Journal of Disability Studies*. Massey University.
- Brechin, A. (1993). Sharing. In P. Shakespeare (Ed). *Reflecting on research: practice issues in health and Social Welfare*. Buckingham, England: Open University Press.
- Brechin, A. and Swain, J. (1994). Creating a 'working alliance' with people with learning difficulties. In A. Brechin and J. Walmsley (Eds). *Making Connections: Reflecting on the Lives and Experiences of People with Learning Difficulties*. London: Hodder and Stroughton.
- Bronfenbrenner, U. (1979). *The ecology of human development*. New York: Harvard University.
- Brown, C. (1990, April 26). Fight for children left for the crows. *Dominion Sunday Times* p.29.
- Brown, C. (1994). Parents and professionals: future directions. In K. Ballard. (Ed). *Disability, Family, Whanau and Society*. New Zealand: The Dunmore Press.
- Brown, H. and Smith, H. (1989). Whose 'ordinary life' is it anyway? In *Journal of Practical Approaches to Developmental Handicap*. Vol.14, No.2.
- Brown, H. and Smith, H. (1992). Inside-out: a psychodynamic approach to normalisation. In H. Smith and H. Brown (Eds). *Normalisation a reader for the nineties*. London: Routledge.
- Bryson, L. (1979). How do we proceed now we know science is not value free. In W. Green. (Ed). *Focus on Social Responsibility in Science*. Christchurch: New Zealand Association of Scientists.

- Carmen, E. (1981). Inequality and women's mental health: an overview. In *American Journal of Psychiatry*, 138 1319-30.
- Central Regional Health Authority, (1995). *Coming Back: People with Intellectual Disabilities Returning to our Communities*. Wellington.
- Central Regional Health Authority, (1995). *Personal Safety and People with Intellectual Disability Issues and guidelines for services*. Wellington.
- Central Regional Health Authority, (1996). *Options for the future*. Report of the Kimberley Centre Services Redevelopment Working Group. Wellington.
- Central Regional Health Authority, (1996). *Intellectual Disability Services Draft Strategic Plan*. 1996-1999. Wellington.
- Chappell, A. L. (1992). Towards a sociological critique of the normalisation principle. In *Disability, Handicap and Society*, 7 (1).
- Clements, J; Clare, I; and Ezelle, L. (1995). Real Men, Real Women, Real Lives? Gender issues in learning disabilities and challenging behaviour. In *Disability and Society*, Vol.10, No.4.
- Cole, S.S. (1986). Facing the challenges of sexual abuse in persons with disabilities. In *Sexuality and Disability*, 7. (3-4). 71-87.
- Dalley, E. (1992). Social welfare ideologies and normalisation: links and conflicts. In H. Brown and H. Smith (Eds). *Normalisation a reader for the nineties*. London: Routledge.
- Denzin, N.K. (1978) *The Research Act*. New York. McGraw Hill.
- Dixon, J. (1994). Doing ordinary things - is it possible? In K. Ballard. (Ed). *Disability, Family, Whanau and Society*. New Zealand: The Dunmore Press.
- Downer, B. (1988). The efficacy of behaviour modification techniques: In M. Rioux (Ed). *The language of pain*. Ontario: G. Allan Roeher Institute.

- Edgerton, R.B. (1967). *The cloak of competence: stigma in the lives of the mentally retarded*. Berkeley and Los Angeles: University of California Press.
- Emerson, E. and McGill, P.C. (1989). Normalisation and applied behaviour analysis: values and technology in services for people with learning difficulties. In *Behavioural Psychotherapy*, 17: 101-117.
- Emerson, E. (1992). What is normalisation? In H. Brown and H. Smith (Eds). *Normalisation a reader for the nineties*. London: Routledge.
- Fay, B. (1987). *Critical Social Science*. Cambridge: Polity Press.
- Ferguson, P. M., Ferguson, D. L. and Taylor, S. J. (1992). *Interpreting Disability: A Qualitative Reader*, New York: Teachers College Press.
- Finch, Janet (1984). "'It's great to have someone to talk to"; the Ethics and Politics of Interviewing Women' in Colin Bell and Helen Roberts (Eds). *Social Researching: Politics, Problems, Practice*, London, Routledge and Kegan Press.
- Fisher, B.J. (1991). The essence of life: life histories as a method for generating images of successful ageing, In *Teaching Sociology*, 19 (January): 21-27.
- Foucault, M. (1977). *Discipline and punish*. Harmondsworth: Penguin.
- Foucault, M. (1982). The subject of power. In *Critical Enquiry*, 8783-794.
- Fougere, G. (1994). The state and health reform. In A. Sharp (Ed). *Leap Into the Dark: The Changing Role of the State in New Zealand since 1984*. Auckland: Auckland University Press.
- Freire, P. (1972). *Pedagogy of the oppressed*. Harmondsworth: Penguin.
- Frye, Marilyn (1983). *The Politics of Reality: Essays in Feminist Theory*, New York: Crossing Press.

- Georgeson, S. (1994). Caregiving - an alternative view. In R. Munford and M. Sullivan (Eds). *Thinking Critically about Disability*. Massey University.
- Gerber, D.A. (1990). Listening to disabled people: the problem of voice and authority in Robert B. Edgerton's the cloak of competence. In *Disability, handicap and society*, 5(1).
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Englewood N. (Ed) Prentice-Hall.
- Goodnow, Jacqueline; Pateman, Carole (Eds). (1985). *Women, Social Science and Public Policy*. Sydney, Allen and Unwin.
- Gosling, D. and Gerzon, R. (1994). *Barriers to a Dream*. The Report of the People First National Committee. September 1993-August 1994. New Zealand: November 1994.
- Graham, Hilary (1984). Surveying Through Stores. In: Colin Bell and Helen Roberts (Eds). *Social Researching: Politics, Problems, Practice*. London; Routledge and Kegan Paul.
- Groce, N. (1985). *Everyone here spoke sign language: Hereditary deafness on Martha's vineyard*. London: Harvard University Press.
- Hanmer, Jalna; Leonard, Diana (1984). Negotiating the Problem: The DHSS and Research on Violence in Marriage. In Colin Bell and Helen Roberts (Eds). *Social Researching: Politics, Problems, Practice*. London, Routledge and Kegan Paul.
- Hard, S. (1986, October 22). *Sexual abuse of the developmentally disabled: a case study*. Paper presented at the National Conference of Executives of Associations for Regarded Citizens Omaha, Nebraska.
- Harding, Sandra (1986). *The Science Question in Feminism*. Ithaca, Cornell University Press.

- Horner, A. (1994). Leaving the Institution. In K. Ballard (Ed). *Disability, Whanau and Society*. New Zealand: The Dunmore Press Limited.
- Horsefield, Anne (1988). *Women in the Economy*. Wellington, Ministry of Women's Affairs.
- Hunt, R. (1995). An economic empowerment approach to disability. In P. Beatson (Ed). *New Zealand Journal of Disability Studies*. No.1. Massey University.
- Hurst, R. (1995). Choice and Empowerment - lessons from Europe. In *Disability and Society*, Vol.10. No.4.
- Hutchison, P., Beechey, L., Forster, C., and Fowke, B. (1992). Double jeopardy: women with disabilities speak out about community and relationships, In *Entourage*, 7(2).
- Illich, I. (1977). *Disabling professions*. London: Marion Boyers.
- Jones, K. (1992). Listening to hidden voices: power domination, resistance and pleasure within Hunoria regional centre. In *Disability, Handicap and Society*, 7(4).
- Keith, L. (1994) *Mustn't Grumble Writing by Disabled Women*, London, The Women's Press.
- Kelsey, J. (1995). *The New Zealand Experiment. A World Model for Structural Adjustment?* Auckland University Press, Bridget Williams Books.
- Kelsey, J. and O'Brien, M. (1995). *Setting the record straight. Social Development in Aotearoa/New Zealand*. Wellington: Association of Non Government Organisations of Aotearoa.
- Kerr, A. (1994). Parents, professionals, power, politics and children with disabilities. In R. Munford and M. Sullivan. (Eds). *Thinking Critically about Disability*. Massey University.

- King's Fund Centre. (1980). *An Ordinary Life. Comprehensive locally based services for mentally handicapped people*. London.
- Knoll, J and Ford, A. (1987). Beyond Caregiving: A Reconceptualization of the Role of the Residential Service Provider. In Taylor, Biklen and Knoll (Eds). *Community Integration for People with Severe Disabilities* Columbia University: Teachers College Press.
- Lambert, T. (1994). Marie and Murray. In K. Ballard (Ed). *Disability, Family, Whanau and Society*. New Zealand: The Dunmore Press Limited.
- Lather, Patti (1986). *Research as Praxis*. HER56.3 Copyright by the President and Fellows of Hansard College.
- Lea, S. (1988). Mental retardation: social construction or clinical reality? In *Disability, Handicap and Society*, 3.
- Lewis, Jane (1981). Women Lost and Found: The Impact of Feminism on History. In Dale Spender (Ed). *Men's Studies Modified: The Impact of Feminism on the Social Sciences* Oxford, Pergamon Press.
- Lipsky, M. (1989). Street level bureaucracy. In L. Barton (Ed). *Disability and Dependency*. Basingstoke: Falmer Press.
- Logan, D. (1988). Redefining the problem: an alternative view of difficult behaviour. In M. Rioux (Ed). *The language of pain*. Ontario: G. Allan Roeher Institute.
- Lovett, H. (1996) *Learning to listen: Positive approaches and people with difficult behaviour*. Baltimore: P.H. Brookes.
- Macfarlane, A. (1994). Subtle Forms of Abuse and their Long Term Effects. In *Disability and Society*, Vol.9, No.1.
- McGee, J. J., Menolascino, F. J., Hobbs, D. C. and Menasek, P. E. (1987). *Gentle teaching: a non-aversive approach to helping persons with mental retardation*. New York: Human Science Press.

- McGill, P. and Emerson, E. (1992). Normalisation and applied behaviour analysis: values and technology in human services. In H. Brown and H. Smith (Eds). *Normalisation a reader for the nineties*. London: Routledge.
- McKnight, J. (1977). Professionalised service and disabling help. In I. Illich (Ed). *Disabling Professions*. London: Marion Boyers.
- McKnight, J. (1989). Regenerating Community. In Allan G. Roher Institute (Ed). *The Pursuit of Leisure: Enriching the Lives of People who have a Disability*. York University: Ontario.
- McRobbie, Angela (1978). 'Working Class Girls and the Culture of Feminism. In Women's Studies Group Centre for Contemporary Culture and Studies, University of Birmingham. *Woman Take Issue*. London, Hutchinson.
- McRobbie, Angela (1982). The Politics of Feminist Research: Between Talk, Text and Action. *Feminist Review*.
- Meyer, L. H. and Evans I. M. (1989). *Non-aversive interventions for behaviour problems*. Baltimore: P. H. Brookes.
- Mies, Maria (1983). Towards a Methodology for Feminist Research. In Gloria Bowles and Renata D. Klein (Eds). *Theories of Women's Studies*. London, Routledge and Kegan Paul.
- Minister of Health, (1995). "A new Deal - Delivered" Address to Disability Support Services Group. 28 February.
- Morris, J. (1991). *Pride against Prejudice: Transforming attitudes to disability*. London: The Women's Press.
- Morris, P. (1969). *Put away: a sociological study of institutions for the mentally retarded*. London: Routledge and Kegan Paul.
- Morse, J. (1994). *Critical Issues in Qualitative Research Methods*. California, Thousand Oaks: Sage Publications.

- Munford, R., (1989) *The Hidden Costs of Caring: Women who Care for People with Intellectual Disabilities*. Unpublished PHD Thesis Massey University.
- Munford, R. (1992). *The politics of caregiving*. Paper presented at the IASSMD 1992, Queensland, Australia.
- Munford, R. (1994). Caregiving: A shared commitment. In K. Ballard (Ed). *Disability, Family, Whanau and Society*. The Dunmore Press Limited, New Zealand.
- Munford, R. (1995). A Position of Marginalisation or Inclusion? The experiences of women with disabilities. In P. Beatson (Ed). *New Zealand Journal of Disability Studies*. No.1 Massey University.
- Munford, R., Georgeson, S. and Gordon, J. (1994). Social work with people with disabilities and their families. In R. Munford and M. Nash (Eds). *Social Work in Action*. New Zealand: The Dunmore Press Limited.
- Oakley, Anne (1987). Interviewing Women: A Contradiction In Terms. In Helen Roberts (Ed). *Doing Feminist Research*. London: Routledge and Kegan Paul.
- O'Brien, J. (1981). *The principle of normalisation: A foundation for effective services*. Toronto: National Institute on Mental Retardation.
- O'Brien, J. (1989). What's worth working for? Developing high quality services for people with severe disabilities. In V.J. Bradley and M.A. Bersani (Eds). *Quality assurance for individuals with developmental disabilities. It's everybody's business*. Baltimore: P.H. Brookes.
- O'Brien, J. (1996). *Assistance with Integrity: The Use and Abuse of Power in Human Services*. Workshop presentation. Auckland College of Education: 15th. August, 1996.
- Oliver, M. (1989). Disability and dependency: a creation of industrial societies. In L. Barton (Ed). *Disability and Dependency*. Basingstoke: Falmer Press.
- Oliver, M. (1990). *The politics of disablement*. London: Macmillan.

- Oliver, M. (1992). Challenging the social relations of research production. In *Disability and Handicap and Society*, 1 (2).
- Opie, Anne. (1992). Qualitative Research: Appropriation of the Other and Empowerment, *Feminist Review*, No. 50.
- Oswin, M. (1984). *They keep going away: a critical study of short-term residential care services for children who are mentally handicapped*. London: King's Fund.
- Perkins, J. (1994). Challenging behaviour and disability. In R. Munford and M. Sullivan (Eds). *Thinking Critically about Disability*. Massey University.
- Phelan, P. and Coles, S. (1993). Social Work in a Traditional Setting. In M. Oliver (Ed). *Social work Disabled People and Disabling Environments*. London: Jessica Kingsley Publishers.
- Price, M. (1988). Speaking as a parent. In M. Rioux (Ed). *The language of pain*. Ontario: G. Allan Roeher Institute.
- Rioux, M. (1988). *The language of pain*. Ontario: G. Allan Roeher Institute.
- Royal Commission on Social Policy (1988). *The April Report*. Vol.111. Wellington.
- Rucker, L. (1987). A Difference You Can See: One Example of Services to Persons with Severe Mental Retardation in the Community. In Taylor, Biklen and Knoll (Eds). *Community Integration for People with Severe Disabilities*. Columbia University: Teachers College Press.
- Santrock, W. and Bartlett, J. (1986). *Developmental Psychology: A life cycle perspective*. U.S.A: Wm. C. Brown Publishers.
- Shannon, P. (1991). *Social policy: critical issues in New Zealand society*. Auckland: Oxford University Press.

- Shipley, J. and Upton, S. (1992). *Support for independence: a discussion paper on the funding and delivery of disability support services*. A policy document presented by the Minister of Social Welfare and the Minister of Health. Parliament Buildings, Wellington, New Zealand.
- Shoultz, B. (1995). "My Heart Chose Freedom". The story of Lucy Rider's Second Life. In Taylor, Bogdan, Lutfiyya (Eds). *The Variety of Community Experience. Qualitative Studies of Family and Community Life*. Baltimore: P.H. Brookes.
- Sinson, J. (1993). *Group Homes and Community Integration of Developmentally Disabled People. Micro-institutionalisation?* London: Jessica Kingsley Publishers Ltd.
- Smith, Brenda; Noble-Spruell, Carolyn (1986). An overview of Feminist Research Perspectives. In Helen Marchant and Betsy Wearing (Eds). *Gender Reclaimed: Women in Social Work*. Sydney: Hall and Iremenga.
- Smith, Dorothy (1987). *The Everyday World as Problematic: A Feminist Sociology*, Boston, Mass: Northeastern University Press, Milton Keynes: Open University Press.
- Smull, M. and Harrison, S. (1992). *Supporting people with severe reputations in the community*. Baltimore, Maryland.
- Sobsey, Dick (1991). *Liberty, Equality, Community*. Keynote address: Empowerment Conference. November 11th, Auckland, New Zealand.
- Sobsey, D. (1994). *Violence and Abuse in the Lives of People with Disabilities: The End of Silent Acceptance?* Baltimore: P. H. Brookes.
- Spender, Dale (1981). *The Gatekeepers: A Feminist Critique of Academic Publishing*. In Helen Roberts (Ed). *Doing Feminist Research*. London: Routledge and Kegan Paul.
- Stanley, Liz., Wise, Sue. (1990). *Feminist Praxis: Research Theory and Epistemology in Feminist Sociology*. London: Routledge and Kegan Paul.

- Stanley, Liz; Wise, Sue (1993). *Breaking Out: Feminist Consciousness and Feminist Research*. London, Routledge and Kegan Paul.
- State Services Commission (1990). *The invisible minority: a report of the policy development working group on the employment of people with disabilities*. Wellington, New Zealand: Government Print.
- Stockholder, F. (1994). Naming and Renaming Persons with Intellectual Disabilities. In M. Roux and M. Bach (Eds). *Disability is not measles: New Research Paradigms in Disability*, York University, Ontario, Canada: The Roeher Institute.
- Stokes, E. (1985). *Maori Research and Development*. Wellington National Research Advisory Council.
- Sullivan, M. (1995). Regulating the Anomalous Body in Aotearoa/New Zealand. In P. Beatson (Ed). *New Zealand Journal of Disability Studies*. No.1. Massey University.
- Szivos, S. (1992). The limits to integration? In H. Smith and H. Brown (Eds.), *Normalisation a reader for the nineties*. London: Routledge.
- Taylor, S. J., (1988). Preface to Generations of Hope. In *Journal of the association for Persons with Severe Handicaps*, 13, (3), 177-187.
- Taylor, S. J., Biklen, D., and Knoll, J. (1987). *Community integration for people with severe disabilities*. Columbia University: Teachers College Press.
- Tennant, M. (1996). Disability in N.Z.: an historical survey. In P. Beatson (Ed). *New Zealand Journal of Disability Studies*. No.2. Massey University.
- Thomson, J. (1995). *Indigence to Independence*. Massey University. Unpublished Masters Thesis.
- Townsend, S. (1994). Unheard Voices. In R. Munford and M.Nash (Eds). *Social Work in Action*. New Zealand : The Dunmore Press.

- Tyne, A. (1992). Normalisation from theory to practice. In H. Smith and H. Brown (Eds). *Normalisation a reader for the nineties*. London: Routledge.
- Van Dam, T. and Cameron-McGill, F. (1995). Beyond group homes. In *Interaction*. Vol. 8 / 3: 7-12.
- Walker, R.J. (1985). Cultural domination of Taha Maori: The potential for radical transformation. In Codd, Harker and Nash (Eds). *Political Issues in New Zealand Education*. Palmerston North: The Dunmore Press Limited.
- Walmsley, J. (1993). Contradictions in caring: reciprocity and interdependence. In *Disability, Handicap and Society*, 8, (2).
- Walmsley, J. (1993). Explaining. In P. Shakespeare (Ed). *Reflecting on Research: practice issues in health and social welfare*. Buckingham, England: Open University Press.
- Ward, L. and Flynn, M. (1994). What Matters Most: Disability, Research and Empowerment. In M. Rioux and M. Bach (Eds). *Disability is not measles: New Research Paradigms in Disability*, York University, Ontario, Canada: The Roeher Institute.
- Whitehead, S. (1992). The social origins of normalisation. In H. Smith and H. Brown (Eds). *Normalisation a reader for the nineties*. London: Routledge.
- Wilkinson, J. (1989). Being There: Evaluating life quality from feelings and daily experience. In A. Brechin and J. Walmsley (Eds). *Making Connections: Reflecting on the Lives and Experiences of People with learning Difficulties*. London: Hodder and Stroughton.
- Wills, R. (1994). It is time to stop. In K. Ballard (Ed). *Disability, family, Whanau and Society*. New Zealand: The Dunmore Press Limited.
- Wollbring, G. (1996). *Who should live and who should die? Questions of eugenics and euthanasia*. Seminar Presentation. Department of Social Policy and Social Work. Massey University. 15th November.

- Wolfensberger, W. (1972). *Normalisation: the principle of normalisation in human services*. Toronto: National Institute on Mental Retardation.
- Wolfensberger, W. (1989). Human service policies: the rhetoric versus the reality. In L. Barton (Ed). *Disability and Dependency*. Basingstoke: Falmer Press.
- Worth, P. (1988). A self advocate's perspective. In M. Rioux (Ed). *The language of pain*. Ontario: G. Allan Roeher Institute.
- Worth, P. (1996). *Access Means Empowering the Powerless*. Address to the 18th World Conference of Rehabilitation. 19th. September, Auckland. New Zealand.
- Zola, I. K. (1977). Healthism and disability medicalisation. In I. Illich (Ed). *Disabling Professions*. London: Marion Boyers.